

MCFT-007

Counselling and Family Therapy: Applications and Interventions

Block

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WORKING WITH PHYSICAL ILLNESS AND SELF ABUSE

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BLOCK 3 WORKING WITH PHYSICAL ILLNESS AND SELF ABUSE

Block 3 of Course MCFT-007 is “Working with Physical Illness and Self Abuse”. The Block will acquaint you with the knowledge of application of counselling and family therapy with individuals suffering from physical illnesses and its effect and coping by their family members. We will learn about dealing with chronic illness, HIV/AIDS, substance abuse, and deliberate self harm. The Block consists of the following five Units.

Unit 10 is entitled “*Working with Chronic Illness*”. The Unit acquaints you with the knowledge of family systems illness model in detail. It outlines family’s adaptation to illness. Challenges faced by an adult patient, patient who is a child, families depending on who is ill and families coping with terminal illness have been discussed. Further, the Unit outlines the role of therapy and therapist in the process. Assessment and goal setting for therapy has been described. Medical family therapy technique has been explained at length. The family therapist’s role in helping couples coping with chronic illness, families coping with childhood chronic illness, families coping with terminal illness has been discussed. At the end of this Unit, you will acquire skills necessary for working with chronic illness which have been explained quite well.

Unit 11 is named “*Dealing with HIV/AIDS*”. As the name suggests, the Unit will acquaint you with specific family issues faced by individual having HIV. We will learn about many issues which have an impact on their family life. Issues specific to sero-concordant and discordant couples have been discussed. The Unit focusses on the essential skills required to counsel while dealing with HIV/AIDS patients. Family assessment and intervention are explained in this Unit.

Unit 12 is “*Dealing with Substance Use Disorders*”. The Unit begins with explaining assessment of substance use disorders. We will study treatment of substance use disorders and the psychological approaches used for treatment in this Unit. Motivation enhancement, brief intervention, relapse prevention and specific issues about psychological approaches has been explained at length in the Unit.

Unit 13 is entitled “*Working with Substance Disorder Families*”. The Unit focuses on the need for families to be included in intervention for alcohol related problems. It discusses the affect on families and children in substance disorder families. It outlines the protective factors present in such families. The Unit describes at length counselling for substance disorder families. Intervention and necessary information for families to prevent relapse among patients has been discussed at length in the end of the Unit.

Unit 14 is on “*Dealing with Deliberate Self Harm*”. The Unit begins with the introduction of meaning and definition of self-harm. It outlines the risk factors associated with self harm and suicide. Why someone self-harms?; What are the functions served by self-harm?; Why prevent self-harm?; are few of the questions this Unit will throw light on. After studying this Unit, you will understand the role of a counsellor/ family therapist in helping such patients. You will be able to assess the risks and need of the patient and in the end of the Unit understand how to deal with deliberate self-harm.

UNIT 10 WORKING WITH CHRONIC ILLNESS

Structure

- 10.1 Introduction
- 10.2 Family Systems-Illness Model
 - 10.2.1 Psychosocial Types of Illness
 - 10.2.2 Time Phases of Illness
 - 10.2.3 Interface of Individual, Family and Illness Development
 - 10.2.4 Health Beliefs
- 10.3 Family's Adaptation to Illness
 - 10.3.1 Role Shift
 - 10.3.2 Lifestyle Changes
 - 10.3.3 Communicating and Finding Support
 - 10.3.4 Changing What You Can Control and Accepting What You Cannot
 - 10.3.5 Finding Meaning in the Illness
 - 10.3.6 Grieving for the Losses the Illness Causes
 - 10.3.7 Family Interactions with the Health Care Community
 - 10.3.8 Finances
- 10.4 Challenges Faced by an Adult Patient
- 10.5 Challenges Faced by a Patient Who is a Child
- 10.6 Challenges Faced by Families Depending on Who is Ill
 - 10.6.1 Parent with Chronic Illness
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- 10.7 Families Coping with Terminal Illness
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 - 10.7.2 Untimely Death
 - 10.7.3 Special Stigma of AIDS
- 10.8 Structure of the Therapy Process
- 10.9 Role of the Therapist
- 10.10 Assessment
 - 10.10.1 Timeline of the Illness and Illness Story
 - 10.10.2 Family's History with the Health Care System
 - 10.10.3 Health and Illness-Related Beliefs
 - 10.10.4 Pre-illness Level of Functioning
 - 10.10.5 Dysfunctional Triangles
 - 10.10.6 Family Life Cycle Stage and Issues
 - 10.10.7 Family Social Network
- 10.11 Goal Setting

- 10.12 Techniques of Medical Family Therapy
 - 10.12.1 Recognize the Biological Dimension
 - 10.12.2 Solicit the Illness Story
 - 10.12.3 Provide Psychoeducation and Support
 - 10.12.4 Facilitate Communication with Health Care Professionals
 - 10.12.5 Respect Defenses, Remove Blame and Accept Unacceptable Feelings
 - 10.12.6 Maintain Communication
 - 10.12.7 Attend to Developmental Issues
 - 10.12.8 Increase a Sense of Agency in the Patient and the Family
- 10.13 Couples Coping with Chronic Illness
 - 10.13.1 Facilitate Couple Communication
 - 10.13.2 Increase Intimacy
 - 10.13.3 Rebalance Relationship Skews and Redefine the Illness as “Our” Problem
- 10.14 Families Coping with Parental Chronic Illness
 - 10.14.1 Facilitate Parent-Child Communication
 - 10.14.2 Sensitivity to Issues of Fairness
- 10.15 Families Coping with Childhood Chronic Illness
 - 10.15.1 Work with Issues of Denial and Unresolved Grief
 - 10.15.2 Help the Family Treat the Child as a Child and not an Illness
 - 10.15.3 Help Families Negotiate with Schools
 - 10.15.4 Interventions to Deal with Unhealthy Family Patterns
- 10.16 Families Coping with Terminal Illness
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 - 10.16.3 Utilizing Rituals
 - 10.16.4 Saying Good-Bye
 - 10.16.5 Making the Most of it
- 10.17 Let Us Sum Up
- 10.18 Glossary
- 10.19 Answers to Check Your Progress Exercises
- 10.20 Unit End Questions
- 10.21 Further Readings and References

10.1 INTRODUCTION

Chronic illness is one of the most trying periods in the life of the patient and his family. As it becomes more and more clear that the illness will not disappear anytime very soon, the patient goes through alternation of courage and despair, anger and depression. The immediate family finds it difficult to withdraw support from the patient but may start getting casual, reluctant and unemotional about it, and sometimes even openly hostile to the patient. Illness also generally means additional expenses, and sometimes a reduced income. While all this makes chronic illness look like an unmixed curse and endless misery, for some families such difficult phases turn out to be opportunities for bonding and spiritual growth. How the patient looks at illness affects the way his family responds to the event. On the other hand, the family members have a strong influence on the patient's

adjustment to the illness and adherence to treatment. This highlights the importance of the systems perspective in order to understand how the patient and family adjust to the chronic illness in a member of the family. The patient or the family, do not live in a vacuum. They influence each other and are interdependent. They also interact with other systems outside the family. For example, the patient and the family may interact with physicians, nurses, mental health therapists, physical therapists, dieticians, and other hospital staff as they receive medical care and coordinate services. The interactions among the different care providers in the medical setting as well as their interaction with the patient influence the patient's functioning and recovery. That is why, the family therapist can play an important role in helping the family tide over the difficult period, facilitating the recovery of the patient, and providing that unobtrusive nudge which may guide the family towards putting the opportunity provided by chronic illness to good use.

McDaniel, Hepworth, & Doherty (1992) coined the term 'Medical Family Therapy' to refer to a biopsychosocial treatment of individuals and families dealing with medical problems. Rolland (1994) proposed that with chronic disorders, a biopsychosocial orientation should be conceptualized from a systems perspective, with the family as the interactive focal point. It is important to look at the unfolding of a chronic illness from a developmental perspective focussing on the interface between the illness, the individual and family life cycles. This Unit will help you to do that.

Objectives

After studying this Unit, you will be able to:

- Define medical family therapy;
- Describe the Family Systems-Illness Model;
- Describe the factors affecting the family's adaptation to chronic illness;
- Describe the special challenges faced by patients depending on whether they are adults or children;
- Discuss the special issues faced by families in which a parent, partner or a child is ill;
- Describe the special issues faced by families coping with terminal illness;
- Discuss the structure of therapy in the medical setting;
- Discuss the role of a therapist working with a patient with chronic illness and his/her family;
- Enumerate the steps in the assessment of a patient with chronic illness and his/her family;
- Explain the process of setting goals for therapy with a patient with chronic illness and his/her family;
- Explain the techniques of medical family therapy;
- Explain the specific techniques specially useful with families where the patient is a parent, a child, or the partner; and
- Explain the techniques specially useful with families where the patient has a terminal illness.

10.2 FAMILY SYSTEMS-ILLNESS MODEL

The Family Systems-Illness Model was proposed by Rolland (1994). The model addresses three dimensions: (1) 'psychosocial types' of illness and disability; (2) major developmental phases in their natural history; and (3) key family system variables.

10.2.1 Psychosocial Types of Illness

The implications of different chronic illnesses for the patient and the family can be quite different. The important variables of illness in this respect are its onset, course, outcome, the degree of incapacitation, and the level of uncertainty about its trajectory.

Onset

Chronic illnesses can have either an acute onset, as in stroke, or a gradual onset, as in Huntington's Disease. For an illness with an acute onset, the family needs to utilize its crisis management skills. In order to adapt quickly and effectively to the changes brought about by the illness, the family needs to tolerate emotionally charged situations, exchange roles flexibly, problem solve efficiently and utilize outside resources. On the other hand, for an illness with gradual onset the family would have more time to adjust and adapt to the changes in a planned manner.

Course

The course of a chronic illness can be either progressive and constant or be progressive but characterized by relapses and remissions. With progressive diseases such as multiple sclerosis, Parkinson's disease, or Alzheimer's disease, the disability worsens in a stepwise or gradual fashion. The family's difficulties increase as the patient's disability worsens. The family members are also required to change their roles and caretaking responsibilities as the disease progresses. With an illness with a constant course, an initial event is followed by a stable biological course, as after a single heart attack. The family has to make one-time changes, after which life is stable and predictable over a considerable period of time. With a relapsing/episodic course, such as in asthma and epilepsy, stable low symptom periods alternate with periods of flare-up or exacerbation. This requires the family to cope with uncertainty because it is impossible to predict when a recurrence might occur. It may also require flexibility to keep alternating between two forms of family organization.

Outcome

When an illness can lead to death or shorten the lifespan, it can have a profound psychosocial impact. For example, a terminal illness such as late stage metastatic cancer may force the family to deal with impending loss of a member.

Incapacitation

The extent, kind and timing of incapacitation are likely to affect the family stress. Incapacitation may involve impairment of cognition (e.g. Alzheimer's disease), movement (e.g. paralysis), stamina (e.g. coronary heart disease) or other faculties, depending on the nature of the illness. With some illnesses the incapacitation is most at the beginning of the illness (e.g. stroke), while in others it increases in the later phases (e.g. Alzheimer's disease) allowing the family more time to prepare for anticipated changes.

Predictability of an illness is the degree of certainty about the way and rate at which it unfolds. If the course of an illness is uncertain, the family is in the dark about what is coming and when. The family has no idea about the time it has before the condition worsens.

10.2.2 Time Phases of Illness

Each phase of an illness has its own psychosocial developmental tasks that require unique family strengths, attitudes or changes from the family. A chronic illness has three major time phases: crisis, chronic and terminal.

Crisis phase

The crisis phase includes the pre-diagnosis phase when symptoms emerge as well as the initial adjustment soon after the diagnosis. This phase brings many developmental tasks for the patient and family that include creating a meaning for the illness, grieving the loss of the pre-illness family identity, accepting the permanency of the condition, learning to live with illness related symptoms and treatments, developing family flexibility in the face of change and uncertainty, and forging a relationship with medical professionals.

Chronic phase

The chronic phase of the illness has been referred to as ‘the long haul’ (Rolland, 1994). The salient tasks during this phase include avoiding burnout, rebalancing relationship skews among the family members, redefining individual and family developmental goals within the constraints of the illness and sustaining intimacy in the face of threatened loss.

Terminal phase

During the terminal phase the inevitability of death becomes apparent and dominates family life. During this phase the family must cope with issues of separation, loss, mourning, and family reorganization beyond the loss. The family may deal with unfinished business, spend precious time together, say goodbyes, and begin the process of family reorganization.

10.2.3 Interface of Individual, Family and Illness Development

The individual, family and illness can all be viewed from the developmental lens and they all have different developmental tasks that need to be accomplished at different stages. We have already discussed some of the tasks to be completed at different stages of disease progression. Erikson’s psychosocial stages of development provide a good model for the developmental tasks that individuals need to complete at different stages of the lifespan. In Course 1, you have read in detail about the family life cycle stages, and are aware that each stage has its own developmental tasks. Usually a chronic illness pushes the individual and family developmental processes towards transition. It may be important to look at the fit between the psychosocial demands of the illness and the individual and family developmental tasks at a particular point in the life cycle. This fit is likely to change as the course of the illness unfolds in relation to the family life cycle and the development of each member.

10.2.4 Health Beliefs

It is important to understand illness-related attitudes and beliefs that family members hold in order to help them cope with the illness. Different families have different multigenerational legacies and scripts that shape a family's health beliefs and response to illness. This will be elaborated upon in the sections on assessment and intervention techniques.

Check Your Progress Exercise 1

Note: a) Read the following question carefully and answer in the space provided.

b) Check your answer with that provided at the end of this Unit.

Fill in the blanks:

1. A stroke has a/an _____ onset.
2. If the incapacitation increases in the later phase of the illness, it allows the family _____ time to prepare for anticipated changes.
3. The _____ phase of the illness is referred to as "the long haul".
4. The family may deal with unfinished business during the _____ phase of the illness.

10.3 FAMILY'S ADAPTATION TO ILLNESS

The changes that the patient and the family need to make in the face of chronic illness depend on the nature and course of the illness. The life cycle stage of the individuals and the family as a whole are also important. In addition, the role played by the patient and the level of incapacitation experienced by him/her can be a major factor influencing the family's adaptation to the illness.

10.3.1 Role Shift

Often the family member who is ill may no longer be able to fully play the role that he/she played in the family before the illness. This forces other family members to take on some of his/her responsibilities. Our gender-related socialization may make this more difficult than we may imagine. The following case study can help illustrate this.

Rajiv and Sneha have been married for ten years and have two children of age 8 and 6. They live in a nuclear family. A few months ago Sneha was diagnosed with breast cancer. She is undergoing chemotherapy. Rajiv is the breadwinner and Sneha is the homemaker. She met the emotional needs of her children and her husband. She helped the children get ready for school, helped them with their homework, calmed them down when they got into a fight with each other and read bed time stories to them at night. She listened to her husband when he was frustrated with his boss at work. But now Sneha was not able to meet all of their emotional needs. She was overwhelmed by the diagnosis and the treatment and the implications it would have for her and her family. Rajiv had to take over many responsibilities of looking after the children and the home. He felt resentful about the new duties, guilt about his resentment and was worried about Sneha's health.

Sneha and Rajiv have had to deal with changes in the roles that they played in the family. After having played those roles for ten years, it can be difficult for them to make these adjustments. The process of counselling can help them adjust to this role shift and make the required transition.

10.3.2 Lifestyle Changes

The medical management of a chronic illness like coronary artery disease, diabetes or hypertension may require major lifestyle changes. The patient may need to make dietary changes, changes in the physical activity level, initiate smoking cessation and schedule administration of medicines in the daily routine. These changes both affect and are affected by family members. For example, the daughter-in-law who prepares the meals may now have to make sure that her father-in-law who has hypertension and coronary artery disease is served meals with low salt and fat content. The patient's wife may decide to give him company to encourage him to go out for an evening walk. The family's ability to adapt to these changes as a unit, and to discuss the issues these changes create will affect the overall coping.

10.3.3 Communicating and Finding Support

The diagnosis of a chronic illness that will impact the patient and the rest of the family may become the "pink elephant" in the room that everyone can see but no one wants to talk about. Individuals may be overwhelmed by emotions and may be scared of hurting someone's feelings if they talk about them. But this is also a time when it is very important for the family to communicate effectively in order to adapt to the illness. It may also be important to reach out to other people who have faced similar challenges. Reaching out can help normalize the experience of the family and it can also help them to learn from what has worked for others in similar situations.

10.3.4 Changing What You Can Control and Accepting What You Cannot

Often chronic illnesses bring a mixed bag of challenges. Some things are likely to get better if the patient and family make an effort to change. For example, after a single heart attack the patient may benefit from changing his/her eating habits as well as by increasing the amount of exercise. The family can benefit by increasing their sense of competency and agency around factors over which they have some control (McDaniel, Hepworth & Doherty, 1992). On the other hand, it is best to develop a sense of acceptance for things that are out of their control. For example, a person whose kidney can no longer function without having a regular dialysis has to accept that and follow the doctor's recommendations.

10.3.5 Finding Meaning in the Illness

After being diagnosed with a chronic illness, a very likely question the patient may ask is "why me?" and the family may ask "why us?". At the same time, the illness may give the patient and family a chance to reflect upon their lives and take the illness as an opportunity for change rather than as a curse. The family's attitudes and beliefs about illness are likely to influence the process of finding meaning in the illness. Being able to find meaning in the illness will most likely increase their feeling of peace and acceptance.

10.3.6 Grieving for the Losses the Illness Causes

The patient and the family may have to grieve for the anticipated loss of life associated with terminal illness (Rolland, 1994). Very often the patient and family avoid discussing death in order to protect themselves and the family. The illness may cause the patient to lose the ability to work, travel, dress and eat independently. The illness may sharply limit the activities of the family as well. The patient and family need to grieve for the change in function they experience (Ruddy & McDaniel, 2002).

10.3.7 Family Interactions with the Health Care Community

The patient and family's preconceived ideas about and past experiences with health care providers can influence the family's coping. For example, a family, which has experienced misdiagnosis, long waiting lists and lack of adequate information in the past, is likely to be skeptical about its interactions with health care providers. On the other hand, a family, which has received prompt and good quality care, is likely to have faith in health care providers. These ideas can either interfere with or facilitate the establishment of a relationship with health care providers.

10.3.8 Finances

Finances can also play a crucial role in hindering or facilitating coping with a chronic illness. Finances are likely to determine the kind of medical facilities the family can afford. The role played by the patient in the family can affect the financial situation of the family, which can in turn affect the kind of care the patient receives. Whether the patient is the breadwinner solely responsible for providing for the family, or is a child who comes from a wealthy family, can make a difference to the care received by the patient as well as the family's coping.

This also highlights the fact that the challenges faced by an adult or a child with a chronic illness can be somewhat different.

Check Your Progress Exercise 2

Note: a) Read the following question carefully and answer in the space provided.

b) Check your answer with that provided at the end of this Unit.

1. List some of the things that a patient with chronic illness may be able to control. List also some of the things he/she may not be able to directly control, and therefore may have to learn to accept.

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10.4 CHALLENGES FACED BY AN ADULT PATIENT

The life of an individual with a chronic illness can change quite drastically. The challenges faced by the patient are likely to be influenced by factors such as type of illness, age of the patient at onset of illness, personal characteristics of the patient, family responsibilities, other responsibilities and available family support.

The patient may now have to rely upon others for a lot of things that he/she could do independently in the past. For example, someone with a cardiac disease may now have to ask for help while lifting heavy objects. A person who got paralyzed after a stroke may be bed ridden and may need help even with basic things like brushing the teeth and eating.

Surgical procedures can often leave the patient's body disfigured. For example, a woman with breast cancer may have to get a mastectomy. Her altered body image could lead to feelings of low self-esteem and depression. She may socially isolate herself, which would further reduce the chances of getting any support.

Persons who get arthritis may have to take premature retirement because the illness no longer allows them to meet the responsibilities of the job. Being forced to give up a job due to an illness can often lead to financial strain especially if the patient is the primary breadwinner of the family. In addition to the loss of income, the treatment costs can further add to the financial burden. In such a situation, the other partner may be forced to take up a job to make ends meet. This may lead to disruption in the family given that the roles that the partners played have been altered.

10.5 CHALLENGES FACED BY A PATIENT WHO IS A CHILD

Given that children are at a different stage of development in their life cycle as compared to adults, some of the challenges that they face due to a chronic illness are also different. A child with a chronic illness like asthma or diabetes may have to miss many days of school during the year because of repeated hospitalization. This can put the child behind and may put extra pressure on the child to catch up with the classmates.

Often children with a chronic illness may do or use things that make them stand out among other children. For example, a child with asthma may use an inhaler and may not be allowed to participate in sports that may trigger an asthmatic attack. A child with Crohn's disease or diabetes may be on a special diet. A child with a tumour who is undergoing chemotherapy may have hair loss. Peers often do not have an understanding of the challenges faced by the child who is ill. This may result in the child being teased or bullied by the peers. This may lead to the child feeling isolated or left out at school. The child who is ill may be grappling with the differences between him/her and the other children at school. Since these differences would usually put the child at a disadvantage, he/she may develop low self-esteem.

The parents may be overprotective of a child with a chronic illness. This may make the child feel smothered. The parents may prevent the child from doing things that are otherwise age-appropriate. They may prevent their teenager from staying back in school for extra-curricular activities, going for trips from school or going out with friends. All this may make the child feel that he/she is missing out on a normal childhood.

Check Your Progress Exercise 3

Note: a) Read the following question carefully and answer in the space provided.

b) Check your answer with that provided at the end of this Unit.

State whether the following statements are true or false:

1. If the child has a chronic illness, over-protective parents are able to provide better care. _____
2. A major problem faced by a child having a chronic illness is facing ridicule from the peers. _____

10.6 CHALLENGES FACED BY FAMILIES DEPENDING ON WHO IS ILL

10.6.1 Parent with Chronic Illness

Parentified child

If a parent has a chronic illness, it is likely that the older children may be involved in caregiving and sharing some family responsibilities. In case of a progressive illness which leads to a high level of incapacitation, it is likely that a lasting shift in roles may occur and may create a parentified child who is forced into the role of a parent for the younger siblings, and in some cases, also for the ill parent. The parentified child may feel robbed of his/her childhood/adolescence.

In a family with traditional gender roles, this is even more likely to happen. In a family where the mother is ill, the eldest daughter may be expected to take on her responsibilities before examining how the father may be able to help. Similarly, if the father is ill, the eldest son may be expected to drop out of school/college to run the family business or find a job rather than the mother looking for a job outside the home. In such situations, therapists can facilitate the parents' renegotiation of rigid gender roles and encourage them to adopt more flexible gender roles.

Case study

Prashant was in his second year of college when his father met with an accident which caused the right side of his body to become paralyzed. Overnight his father went from being the head of the household and the breadwinner for the family to being bedridden. As a result of this crisis, Prashant was expected to give up his education and take care of his father's business in order to support his family. Prashant had feelings of resentment since all his friends were leading care-free lives and completing their education while he was carrying the burden of family responsibilities. Prashant felt guilty for feeling resentful.

If a child has to assume new responsibilities, the family should discuss issues of fairness and balance the competing priorities of a child's or adolescent's development. Even if the child has to provide caregiving to the parent, the ill parent must still remain a parent to the child.

Parents may try and hide information about a parent's illness from the children. The parents may be doing this with the intention of protecting their children. But often parents do not realize that children have the ability to sense danger and threat of loss despite secretive communication. Parents generally underestimate their children's resilience and ability to come to terms with parental illness and deal with adversity. If parents withhold information from children, it can actually make the children more anxious. Sharing information about the parent's illness with the children in an age-appropriate manner, clarifying their misconceptions and reducing their exaggerated fears can actually help the children cope with parental illness (McDaniel, Hepworth & Doherty, 1992).

Shift in parenting roles

The illness may force the parents to make adjustments to the role they play as parents. The parent who is ill may not be able to devote as much time, energy and effort toward parenting due to the demands of the illness. This may increase the parenting responsibilities of the partner. On the other hand, it is also possible that the ill parent may spend more time at home than before and may become more involved with parenting something likely to happen with fathers. Both these shifts may cause conflicts between the parents. The children may also be left feeling confused and anxious in response to the change in parenting roles.

Check Your Progress Exercise 4

Note: a) Read the following question carefully and answer in the space provided.

b) Check your answer with that provided at the end of this Unit.

State whether the following statements are true or false:

1. If a parent has a chronic illness, the therapist should facilitate the parents' renegotiation of rigid gender roles. _____
2. If a parent has a chronic illness, the children should not be told about it. _____

10.6.2 Aged Parent with Chronic Illness**Caregiver burden**

Middle-aged parents often feel sandwiched between their own parents and children, having to take care of both these generations. This role can become even more taxing if an aged parent has a chronic illness. Depending on the family structure, the role may vary. If the aged parent(s) and their sons with their partners and children, all live in a joint family, it may help divide the caregiving responsibilities. Sharing the responsibilities can prevent any one member from feeling overwhelmed. On the other hand, it can also lead to conflicts about who decides how these responsibilities are divided. Issues related to power, control and decision-making could create misunderstandings among family members. The parent who is ill may be the head of the household, but due to the illness may not be able to make decisions any more. The shift in roles this requires may take some adjustment on the part of the entire family.

If the aged parent(s) live with one of their children or have only one child, this child may feel extremely taxed due to the caregiving responsibilities. There may

be a feeling of resentment because the other siblings are not equally involved in the caregiving process. This may give rise to guilt associated with this resentment.

Case study

Mr. Gupta was 75 years old and lived in Delhi with his son, Animesh; daughter-in-law, Kavita; and grandchildren, Ananya and Shashank. Mr. Gupta had a daughter, Prabha and another son, Sunil. Prabha lived with her husband and children in Mumbai. Sunil lived with his wife and children in Bangalore. Mr. Gupta's symptoms of Alzheimer's disease had gradually worsened over the last couple of years. Now it was difficult for him to leave home and go to the park on his own since he was likely to forget his way back home. He often misplaced things at home and needed someone to find them for him. He would forget the steps involved in everyday tasks like making a phone call and taking a shower. Animesh and Kavita both had jobs outside home. Ananya was 13 and Shashank was 16. They were both in school. Animesh, Kavita, Ananya and Shashank shared the caregiving responsibilities for Mr. Gupta. They also had full-time help to look after Mr. Gupta while they were at work or in school. Animesh and Kavita took turns taking him to the hospital for check-ups. They made sure that he took his medicines everyday. They handled his emotional outbursts. The grandchildren would take him for a walk and bring him things that he needed. Often it would be hard to do that because he could not find the right word for what he wanted. The family's social and recreational activities were restricted because they could not leave him alone and go on trips and long outings. Animesh and Kavita felt that they were not able to give enough time to Ananya and Shashank. Animesh and Kavita did not voice their resentment about Sunil and Prabha having escaped the caregiving responsibilities even though they shared the same relationship with Mr. Gupta that Animesh did.

Grief over anticipated loss

Children of a parent with a chronic and terminal illness would have to deal with feelings of anticipated loss. It may be very difficult to accept that the person you have known the longest in this world and probably shared some of the most precious moments of your life with, may not be around for very long. This may be a time to address unfinished business from the past, to let go of past grievances, to forgive and make peace. This is also a time to remember fond shared memories and to talk about them.

10.6.3 Partner with Chronic Illness

Role shift

Women and men may face challenges due to gender socialization and traditional gender roles that they may have adopted in their lives. If a woman is ill, her socialization to be in the caregiver role may make it difficult for her to ask for or accept assistance when she needs it. Men may feel inadequate in their ability to provide care due to the way in which they have been socialized. On the other hand, if the man is ill and is no longer able to provide for the family due to the illness, he may take a long time to accept this change. Correspondingly, a woman may feel inadequate in her ability to provide for the family if her partner is ill.

Couple communication

The chronic illness may be like the pink elephant in the room that everyone can see but no one wants to talk about. It is possible that couples may be afraid to

talk about the illness because they want to protect the other person or they feel that the other partner will not be able to handle talking about the illness (Ruddy & McDaniel, 2002). This may make the couple engage in mind reading or talking around the issue instead of directly addressing it. In the process the couple may also avoid communicating about other things that they could easily talk about in the past.

Social isolation

The illness may reduce the activities the couple can engage in and also prevent them from socializing as much as they did earlier due to hospitalizations, treatment regimens and caregiving responsibilities. Friends and family members may also withdraw because they do not know how to support the couple and may also be dealing with their own emotional response to the illness. But this may be the time when the couple needs the most support.

Intimacy

A partner's chronic illness may interfere with the couple's physical intimacy and that may be something that needs to be addressed in therapy.

Caregiver burden

The caregiving responsibilities may take a lot of time and effort on the part of the partner who is well. This may prevent him/her from engaging in activities they engaged in previously and may force them to change their lifestyle. The caregiver may have higher chances of developing depression or anxiety due to the stress in their lives.

Case study

Mr. and Mrs. Kumar had been married for over 45 years and lived on their own in Delhi. Both of them were retired. The couple's children were working in Hyderabad and Pune. Five years ago Mr. Kumar developed chronic lung disease. Over the last year Mr. Kumar's chronic lung disease had become worse. Mr. Kumar found it difficult to climb stairs since that made him very breathless. He performed his daily chores at a slow pace since he became tired very easily. He often needed to use an oxygen mask. The doctors had advised him to attend pulmonary rehabilitation classes three times a week. Mrs. Kumar spent almost all her time looking after Mr. Kumar. She had to forego the kirtan at the neighbourhood temple since it clashed with Mr. Kumar's pulmonary rehabilitation classes. This further isolated her from women of her age in the neighbourhood. She often felt lonely and burdened by the caregiving responsibilities. She had not been very happy in her marriage over the last 45 years, which made her all the more resentful toward Mr. Kumar. This resentment in turn made her feel guilty.

10.6.4 Child with Chronic Illness

Parental guilt

Parents often feel guilty if their child has a chronic illness. They may hold themselves responsible for it in some way. They may tell themselves that the child may not have contracted the illness if they had taken certain measures or that the child got the illness because of something that they did. This can be a huge burden to carry around for the parents.

Grief over losing “normal” childhood and imagined futures

Once parents find out that their child has a chronic illness, they may mourn having to relinquish their dream of having a healthy child. The child is likely to be robbed of a normal childhood due to the illness. If the illness is likely to reduce the child's life expectancy or quality of life as an adult, the parents may grieve the loss of an imagined future for their child (McDaniel, Hepworth, & Doherty, 1992). It may be difficult for parents to get used to the idea that their child may not be able to hold a regular job or may not be able to have children.

Developmental issues

Parents may be highly over-protective of a child with a chronic illness and this may interfere with the child's psychosocial development. For example, the parents of a child who has asthma may not allow the child to go out and play on his/her own due to the fear that the child may get an asthma attack. This may limit the child's interaction with peers and as a result may interfere with the development of social skills.

Family dynamics that influence and are influenced by children's health

Minuchin, Rosman and Baker (1978) proposed that certain patterns of family interaction influence, and are influenced by, childhood chronic illness. These include enmeshment; overprotection; poor conflict resolution and conflict avoidance; rigidity and triangulation. *Enmeshment* is when family members are overinvolved with each other and are into each other's business all the time. A chronically ill child may feel like there is no breathing space in an enmeshed family. *Overprotection* means excessive nurturing and restricted independence. Families that are overprotective may become more so when they have a child with a chronic illness. The child may often not be allowed to do things he/she is capable of on the pretext of the illness. *Rigidity* is when the family maintains fixed patterns even if they are not working. A family with rigid patterns is likely to have a more difficult time adjusting to the child's illness. *Triangulation* is when focus on the child's illness detours marital or family conflict. The couple may use the child's illness as a distraction or an excuse not to address the issues in their marital relationship.

Challenges faced by healthy siblings

Healthy siblings often suffer invisibly in a family with a chronically ill child. They may feel neglected by their parents since the ill child often takes up a lot of the parents' attention. They may develop behavioural problems in order to attract their parents' attention, even if it is negative attention (McDaniel, Hepworth, & Doherty, 1992). Healthy siblings may be forced to assume caregiving responsibilities. They may not be able to talk about their feelings of anger with anyone. They may also have feelings of guilt for being “normal”.

Check Your Progress Exercise 5

Note: a) Read the following question carefully and answer in the space provided.

b) Check your answer with that provided at the end of this Unit.

Match the following:

- | | |
|-------------------|---|
| 1. Overprotection | A. Over-involvement with family members |
| 2. Enmeshment | B. Maintaining fixed patterns |
| 3. Triangulation | C. Excessive nurturing and restricting independence |
| 4. Rigidity | D. Pulling in a third party to reduce tension in the dyad |

10.7 FAMILIES COPING WITH TERMINAL ILLNESS

10.7.1 Facing the Inevitability of Death

Often even if death is imminent, family members avoid talking about it. Therapists can also make the decision to either ignore the issues of loss or to use this as an opportunity to bring the patient, family members and health care providers together, face realities and share their pain with one another.

10.7.2 Untimely Death

Usually we expect people to die in old age. But terminal illnesses such as cancer and AIDS can lead to untimely death and can have far-reaching consequences. It can be very stressful for parents to outlive their children. The loss of children can mean the loss of hope and dreams for the parents.

10.7.3 Special Stigma of AIDS

Even though terminal illnesses have many common characteristics, family therapy treatment must identify the different contexts of these illnesses including the family's social and demographic characteristics and their attitudes about the illness. The family members may have perceptions about AIDS that may make the patient feel subtly or overtly blamed for their illness. The family members are also likely to hide the diagnosis from others since a diagnosis of AIDS leads to the question of how it was contracted.

10.8 STRUCTURE OF THE THERAPY PROCESS

It is important for the therapist to have a clear rationale for who should attend the therapy sessions and the frequency of sessions. Since the client is being treated by a treatment team, it is important to include the treatment team in the therapeutic process as well. This makes issues of collaboration among health professionals very pertinent.

During the assessment phase, it may be important to include extended family members as well as people who are part of the support system to gather information. As therapy continues, the therapist can use his/her discretion to decide which of these people to include in sessions and at what stage based on the issues that are being addressed in therapy. It will also be important to include the physician, nurse, social worker or other members of the treatment team in some sessions to make sure that everyone is on the same page. Often the family may feel more comfortable asking the physician questions about the illness in a therapy setting than during a medical appointment. Including all these crucial people in therapy is of course the ideal situation. Often, due to different schedules and logistical factors, this may not be possible. In that case, the therapist needs to be creative in order to come up with ways in which information can still be exchanged with the members of the treatment team. Information could be exchanged on the phone, through letters or by organizing a meeting in which all the patients being seen by the treatment team could be discussed in one sitting.

Therapists who work with families facing chronic illness choose to work in the health care setting. This brings with it a unique set of challenges. The patients are

likely to be referred to the therapist by the physician. The patients may attend psychotherapy because their doctor told them to and not because they feel that they have some emotional issue to resolve. Therefore these clients may be at a different level of readiness for change as compared to clients that are self-referred (Ruddy & McDaniel, 2002). Therefore it may be important to assess the patient's willingness to attend therapy. It may also be important to discuss how the physician/health care professional can better prepare the patient and family for the referral.

Another challenge may be that since patients usually go to their health care providers on an "as-needed" basis, they may seek psychotherapy only when they feel it is immediately necessary. This pattern can disrupt the typical "joining/assessment-midphase-termination" cycle of psychotherapy (Ruddy & McDaniel, 2002). Even if the therapist stresses the importance of regular sessions, the family may not comply with it either because they are non-compliant or because of illness-related factors. Therefore the therapist may end up seeing the family for therapy only once or twice a month. The therapist may be able to make up for this to some extent by conducting longer sessions as well as by assigning homework that will help them make progress even when they are not able to make it for sessions.

The differences in the working styles of primary care and mental health professionals can also create challenges (McDaniel, Hepworth, & Doherty, 1992). The primary care professionals use medical language whereas mental health professionals use psychological or systems language. Primary care professionals are action-oriented, engage in advice giving, have brief sessions, and are available around the clock. Mental health professionals are process-oriented, avoid advice, have longer sessions and schedule their sessions. These differences can create challenges for effective collaboration. In order to collaborate effectively, it is important for the therapist to explore the referral question, clarify roles, have some joint sessions if possible, and report progress to the referral source (McDaniel, Hepworth, & Doherty, 1992). Once a patient is referred, the therapist can call the physician to find out why the patient was referred, the nature and stage of the patient's illness, and how the physician wishes to remain involved. The physician and therapist should clarify their roles to make sure that they neither overlap nor contradict each other, and eventually come to a coordinated treatment plan. It is important that the physician and therapist communicate with each other as treatment progresses. As McDaniel, Hepworth and Doherty state, "treatment without communication is like two blindfolded drivers on a racetrack; not colliding is a matter of luck" (p.57).

10.9 ROLE OF THE THERAPIST

Therapists who understand and are drawn to the complex interplay among biological, psychological and relational elements of the illness experience are more likely to enjoy helping families coping with illness. Therapists who like working as part of a team and are open to collaboration with other health care professionals are more likely to thrive in a medicalized environment.

It is helpful if the therapist takes a collaborative stance with the client. This will help the client feel empowered, which may be quite different from what they experience with other aspects of the overall treatment plan. The therapist may need to provide psychoeducation about the illness and how it affects families. The therapist may share resources in the community that can benefit the families. They

may also need to help the family collaborate with the school (if the child is ill), an employer (in the case of an adult) and with other health care providers. The therapist also needs to communicate with the other health care providers to clarify roles, establish a coordinated treatment plan and report the progress being made in therapy.

Therapists working with patients with a chronic illness need to be active. They may need to challenge the clients to discuss sensitive issues such as impending loss, unfinished business, especially in the case of a terminal illness. The client may require normalizing of feelings such as anger, resentment and guilt evoked in the patient and family members in response to the illness. It is important that the family has open communication which can be facilitated by the therapist.

The therapist needs to be aware of his/her experiences with health and illness in his/her family-of-origin. The therapist should have a good understanding of how these and other experiences influence the attitudes and beliefs that she/he has toward health, illness and the medical environment. The therapist needs to make sure that these experiences help inform and improve rather than hinder the work that the therapist does with clients.

10.10 ASSESSMENT

10.10.1 Timeline of the Illness and Illness Story

It would be essential to ask the patient and the family members about when the symptoms of the illness appeared and a description of the course of the illness. Along with this, a genogram could be used to find out the family history of this, illness as well as other illnesses. If illness has been a common feature in many family members, they may be able to tell their family story about illness and how the family has coped with it.

10.10.2 Family's History with the Health Care System

The patient's or the family's past experience with the health care system could contribute to their expectations, fears and beliefs related to the illness as well as the illness experience. If someone was misdiagnosed in the past and ended up suffering longer because of that, they may be skeptical about going to the doctor and may find it difficult to trust the health care system. On the other hand, someone who received prompt and accurate medical advice is likely to have more trust in the health care system. It is important to ask questions about past experiences because therapy can help alleviate some of the fears, misconceptions, and negative beliefs that families may have. It may also help reduce non-compliant behaviour in response to medical advice.

10.10.3 Health and Illness-Related Beliefs

During assessment it would be helpful to ask the family to talk about meanings associated with health and illness. The therapist could track beliefs about: (1) meaning attached by family or culture to symptoms and types of illnesses (e.g. life threatening); (2) assumptions about what caused an illness and what will influence its course and outcome; (3) cultural and gender-related beliefs about expected roles and behaviours; and (4) family rituals particularly related to healing and loss (Rolland, 1999).

10.10.4 Pre-Illness Level of Functioning

Assessing the pre-illness level of functioning will help the therapist understand the patterns in the family before they made the changes based on the illness. It is possible that the family had clear boundaries; well-defined family subsystems and hierarchies; open communication; and good conflict resolution and decision-making styles before the onset of the illness. Or it is also possible that the family had diffused boundaries; enmeshed sub-systems; and poor communication, conflict resolution and decision-making styles even before the onset of the illness. This will help the therapist tease out the weaknesses which already existed and were amplified by the illness in contrast with the problems which cropped up in response to the illness. This insight can be very helpful when formulating interventions that will work for the family.

10.10.5 Dysfunctional Triangles

A chronic illness may create a fertile ground for dysfunctional family dynamics to blossom. Dysfunctional triangles may take the form of detouring, in which parents retain their unity by focussing on a child with chronic illness, or cross-generational coalitions, in which one parent forms a coalition with the child against the other parent (McDaniel, Hepworth & Doherty, 1992).

10.10.6 Family Life Cycle Stage and Issues

Illness in the family often compels maintenance of the existing family form rather than go through life changes that would ordinarily unfold. For example, illness in a parent may prevent the older children from launching out. They may continue to stay on at home, and even decide not to marry because they have taken on a parentified role. Often family needs are also subordinated to the needs of the illness or the ill family member. Needs of the other family members, including important ones such as education, may be neglected which can lead to resentment, frustration and poor communication. It is important for the therapist to assess and attend to the fit between the stage of the illness and stage of family development.

10.10.7 Family Social Network

A family with a member with a chronic illness can really find interactions with other families going through similar experiences very useful. For example, if parents who have a chronically ill child are part of a support network that is active and committed, they can benefit from resources such as information and respite that it has to offer. It helps to know that you are not alone and that there are other people in the same boat. Other parents who have dealt with similar situations may be able to give them suggestions and solutions.

10.11 GOAL SETTING

The goals for treatment would be different for different families based on the specific presenting issues. After talking about the presenting problem and going through a thorough assessment, it is important for the therapist to establish treatment goals in collaboration with the family.

Some broad goals for a family coping with chronic illness would include adapting to the changes the illness has thrust upon their lives, improving communication among the family members and increasing collaboration with the health care system.

Two goals that underlie successful adaptation to illness are “agency” and “communion” (McDaniel, Hepworth, & Doherty, 1992). “Agency” involves active involvement in and commitment to one’s care. This may involve differentiating between aspects of the illness that are controllable and aspects that are not. The patient and the family can show agency by taking control over the controllable aspects of the illness and accepting the aspects that cannot be controlled. If the therapist can help the patient and family find meaning in the illness, it may make it easier for them to accept the aspects that are uncontrollable. Therapy can help facilitate “communion” or a sense of support and community. The therapist can draw family members who may have distanced themselves and can also help them connect with other families facing similar challenges.

Often a chronic illness in a family member may cause everything to come to a standstill. The illness may take over the family and everything may start revolving around the illness. The individual goals that family members have may now be governed by the illness. For example, the illness of a parent may decide whether a child should participate in activities after school or if the family can go on a vacation. Therapy can help the family put the illness in its place and live around it instead of allowing it to take over their lives completely.

The stress resulting from coping with a chronic illness may lead to problems with communication within the family. Therapy can address these problems and can help facilitate open communication among the family members as well as with other members of the health care team.

10.12 TECHNIQUES OF MEDICAL FAMILY THERAPY

10.12.1 Recognize the Biological Dimension

Therapists working with families that are coping with a chronic illness have the responsibility to pay attention to the physical illness. Often therapists in the traditional therapeutic setting pay attention only to the mental aspect of the client’s problem while ignoring the physical aspect. But in the medical setting if the therapist does that, the patient as well as the family members may feel invalidated. In the traditional therapeutic setting we also avoid using the term patient and instead prefer the term client. Family therapists avoid scapegoating one member of the family and treat the entire family as the client even if the family brings the symptom bearer as the identified client. But in medical family therapy a patient does exist — it is the person with the physical illness.

It is also important for the therapist to use psychoeducation to explain the difference between therapeutic and medical encounters to the patient and family. In addition, therapists help the patient and family cope with the illness. But they do not know the usual course of the illness, and the effect of psychotherapy on the course of a particular illness, if any. This is becoming increasingly important in view of the recent research on the mind-body relationship, and the significant therapeutic effect of positive thinking on part of the patient, and the love and intimacy the patient enjoys with the caregivers. Thus the medical family therapist can not only help the family cope with the illness but also influence positively the biological course of the illness.

10.12.2 Solicit the Illness Story

By listening to and understanding the illness experience of the patient and family members, the therapist enters the patient's and family's world. It is important that the therapist responds to the story with empathy, respect, and a lack of blame to emphasize the strengths exhibited by the family in response to the illness.

10.12.3 Provide Psychoeducation and Support

The therapist can provide information about the illness and how it can affect the life of the patient as well as the family. A physical illness in a family member can have a number of psychological repercussions such as depression and anxiety in the patient as well as the family members. This knowledge can help the patient and family gain greater control over the psychological impact of the illness and help reduce its intensity and duration.

10.12.4 Facilitate Communication with Health Care Professionals

There may be instances where the therapist notices a breakdown in communication between the patient and other health care professionals. The patient may have a number of unanswered questions or may not be satisfied with the medical care he/she is receiving. In such a situation, the therapist can arrange a joint session with the patient and other health care providers to help answer some of the questions and address the concerns. Or the therapist can also empower the patient and the family to ask the health care professionals for information that will allow the family to make more knowledgeable decisions about the patient's health care.

10.12.5 Respect Defenses, Remove Blame and Accept Unacceptable Feelings

Often the patient and family may respond to the diagnosis of a chronic illness with a sense of denial. Denial as a defense mechanism is a common method of dealing with illness. People resist change in themselves and their loved ones, especially if that change signals death, aging or making lifestyle accommodations. For example, a person who recently had a heart attack may resist a change in his/her diet or sedentary lifestyle. Initially, it may be important for the therapist to accept the denial and provide support and a positive reframe. Without the support, the patient may resist the medical treatment plan. If the therapist shows understanding for how hard it must be for the patient to make those changes after having lived his/her life a certain way, the patient is more likely to cooperate in making the changes.

Some patients and families focus so entirely on the illness that their entire life and identity becomes organized around the illness. For such patients and families, it is important to help them externalize the illness, that is, to separate the illness from the person who is ill. For this the therapist can ask the patient to describe the illness as another person or entity. What does it look like? What does it do to the patient? What does it do to the other family members? Does anything work to calm it? Such questions can be used to distinguish between the patient and the illness.

The patient and family often have their own theories about who or what is to blame for the illness. Often this is because ambiguity about what caused the illness as well as the uncertainty regarding the course of the illness makes the patient and family feel out of control. In order to gain some control and mastery over the situation, they feel that they need to blame someone or something. It is important for the therapist to help the patient and family accept these feelings of uncertainty and ambiguity; and get rid of blame when it is unwarranted.

The patient and family members may feel a number of emotions such as anger, resentment, guilt and sadness. They may hide these feelings from the others in the family in order to protect the other family members from the stress of their true feelings. Therapy can help give expression to and normalize these somewhat predictable negative feelings that occur for the patient and family members as a result of a chronic illness.

10.12.6 Maintain Communication

Family members may often avoid talking about the diagnosis of a terminal illness such as a late stage cancer in order to protect the other family members from the stress. Some families may even hide such a diagnosis from either the patient (in some cases) or other family members. Some families have a tendency to withdraw when faced with a stressful situation, which leads to the breakdown of communication. In some families, some members may want to talk about the illness and how it affects the family whereas other members may not. Families where members prefer different communication styles are more likely to report conflict and distress about the illness and their family relationships.

It is important for the therapist to facilitate open communication about the illness and its effects on the patient and family during the therapy session. Conflicts that arise due to differing communication styles of different family members can also be addressed in therapy.

10.12.7 Attend to Developmental Issues

In response to a chronic illness, some families become so paralyzed that they find it difficult to attend to the developmental tasks of the family as well as the members who are not ill. Their life revolves around the needs of the member with the chronic illness and his/her medical treatment. Therapy can help the family balance attention to the illness and the needs of the family as a whole. To put the illness in its place, it may be important to draw a boundary around the illness so that the family is not defined by the illness. This can be done if the family decides on certain times when the illness will be the focus of their conversation and other times when it is “off limits” (Rolland, 1994). The boundary can also be placed geographically, by prohibiting discussion about the illness in certain places.

10.12.8 Increase a Sense of Agency in the Patient and the Family

A chronic illness can be an out-of-control experience for many patients and their families. Therapy can help the patient and family develop a sense of competency and agency around factors over which they have some control and acceptance of factors that are out of their control (McDaniel, Hepworth & Doherty, 1992). Through collaboration between the medical team and the patient, the therapist can make sure that the patient is actively involved in making decisions about their

treatment. For example, if a patient is diagnosed with cancer during a late stage and the chances of survival are low, the patient could be allowed to have a say in whether he/she would like to go through invasive treatment or not. The invasive treatment may prolong the patient's life by a few months but may reduce the quality of life. Instead the patient may prefer to maintain the quality of life at a good level and take care of unfinished business in his/her remaining time. Having a say in his/her treatment allows the patient to feel less helpless.

Some patients may be resistant to the doctor's recommendations regarding making changes in their lifestyle such as diet and exercise. In such situations, the therapist can negotiate a compromise with the patient which gives the patient a greater sense of agency. For example, a patient who had a heart attack may be unwilling to give up the high fat food that his wife cooks and he enjoys. During therapy, the client and the therapist may collaborate to come up with a compromise food plan in which the patient continues to eat some of the foods he enjoys but eats them in smaller quantities. The wife may agree to experiment with ingredients that would be more healthy for the family.

10.13 COUPLES COPING WITH CHRONIC ILLNESS

10.13.1 Facilitate Couple Communication

Therapy can provide a platform for discussing painful issues such as the fear of impending loss; feelings such as guilt, resentment, anger or loneliness; and difficult changes that the couple has had to make after the onset of the illness. Often couples avoid addressing such issues in order to protect each other from the stress. Being able to address such issues will allow the couple to maintain open channels of communication. The therapist can help the couple recognize that open communication fosters a sense of support and teamwork.

10.13.2 Increase Intimacy

Often a chronic illness can interfere with the emotional and physical intimacy of the couple. Due to the fear of impending loss or lack of communication, the partner may start emotionally distancing himself/herself from the patient. The illness may interfere with the couple's physical intimacy. The therapist could actually help the couple see the threatened loss as an opportunity to live more fully in the present (Rolland, 1994). Even if there is a decline in the couple's sexual activity, they can make each other feel loved in other ways such as through holding hands and touching each other affectionately.

10.13.3 Rebalance Relationship Skews and Redefine the Illness as "Our" Problem

If the illness is defined as one person's problem, it can lead to inequality in the couple's relationship. The inequality in health may generalize to inequality in power and control in the relationship. To avoid this, Rolland (1994) suggests that partners redefine the illness as "our" problem. If they are able to do this, then instead of fighting the other person (who is considered the problem), they will be fighting the illness (which is the problem).

10.14 FAMILIES COPING WITH PARENTAL CHRONIC ILLNESS

10.14.1 Facilitate Parent-Child Communication

Parents are often secretive about their illness in order to protect their children. Therapy can provide a platform for parents to educate their children about a parent's illness in an age-appropriate manner. Trying to hide information only leads to greater anxiety in children. In the process, parents are also not giving credit to their children's ability to understand and come to terms with adversity. The children also need to be reassured that they will be secure and cared for, no matter what happens.

10.14.2 Sensitivity to Issues of Fairness

If the therapist finds that a child has been parentified following the onset of the illness and the child's normal development is being compromised, it is important for the therapist to intervene. The therapist could conceptualize the case by drawing a structural map of the family that identifies the subsystems, boundaries, hierarchies, power imbalance, alignments, coalitions and quality of relationships. If the child has been promoted to the level of a parent, the therapist can challenge the family by asking them whose decision it was to assign that role to the child. And what needs to change for the child to be a child and not a parent. Even if the child has caregiving responsibilities, it is important for the ill parent, to still play the parent role. Or at least before promoting a child to the role of a parent, have the parents first considered changing their balance of responsibilities? In families that have strict and traditional gender-defined roles, this step may be bypassed. In such situations, the therapist may have to encourage flexibility of gender roles in the co-parental relationship.

10.15 FAMILIES COPING WITH CHILDHOOD CHRONIC ILLNESS

10.15.1 Work with Issues of Denial and Unresolved Grief

Often denial and unresolved grief can prevent the family from accepting and adjusting to the chronic illness. In some cases, one parent may begin to accept the illness but the other parent may see this as a betrayal. The therapist needs to help the family accept the realities and limitations of a chronic illness, make a place for it in their lives and make changes in their behavioural patterns in order to adjust to the illness.

10.15.2 Help the Family Treat the Child as a Child and not an Illness

Parents who do not make a place for the child's illness develop under-responsible patterns. Similarly, parents who fail to put the illness in its place develop over-responsible patterns of handling the child's problems. Therefore it is important to help the parents to put the illness in its place and to treat their child as a child and not as an illness. This can be achieved by helping the parents draw a boundary around the illness by even using metaphors such as assigning a room in the house to the illness where the family does not have its most intimate interactions. Another

way to put the illness in its place is by emphasizing the normal developmental aspects of a child's presenting problems such as age appropriate rebelliousness.

10.15.3 Help Families Negotiate with Schools

It is important for the therapist to listen to the family and support them without scapegoating or triangulating against the school team. The families can be coached to empower themselves without being disrespectful to the school system. The family may have to negotiate crucial decisions with the school such as whether to mainstream their child or to provide out-of-classroom school services and in-home educational services. It is important for health care professionals and the school to communicate for such decisions.

10.15.4 Interventions to Deal with Unhealthy Family Patterns

The therapist may have to intervene to change unhealthy family patterns such as coalitions, triangulation and detouring. If there is a coalition between a parent and the ill child, the therapist may have to intervene to strengthen the marital relationship as well as the relationship between the ill child and the other parent. If the ill child has been triangulated, the therapist may have to intervene to detriangulate the child. If the child's illness is being used to detour marital and family conflict, the therapist may have to focus on the conflict as part of therapy. The guilt, resentment and behavioural problems of healthy siblings, if present, also need to be the focus of therapy.

10.16 FAMILIES COPING WITH TERMINAL ILLNESS

10.16.1 Facing the Inevitability of Death

If the therapist helps the family acknowledge the inevitability of death, it may actually allow the family members to share their feelings, fears and plans with each other.

The family members and caregivers of a patient with a terminal illness also need support. The terminal phase of an illness is shorter than the chronic phase but is still very exhausting and draining for the caregivers.

10.16.2 Dealing with Unfinished Emotional Concerns

The inevitability of death may force the patients and family members to deal with unfinished emotional business. Patients or family members who have been estranged for a long time may feel the need to reconnect. They may choose not to bring up all the past baggage but they may decide on what is important to say and what is important to let go. Therapy can assist in dealing with these unfinished emotional concerns and can facilitate the process of forgiveness and letting go.

10.16.3 Utilizing Rituals

Family rituals can help the family cope with phases of terminal illness and bereavement. The rituals should be carefully selected to represent what is meaningful for each family. The therapist can help the family choose their rituals but the process should be guided by the family. The family members can be asked how they will change the celebration of a festival in order to acknowledge the terminal

illness as well as the festival. Other questions could include, how they will incorporate the memory of a deceased family member on special occasions.

10.16.4 Saying Good-Bye

Therapy can create ways for family members to say good-bye to the dying patient. Often the death of the patient can lead to discord among the surviving family members. This may be either a repetition of their interaction patterns or it may be projected anger about having to say good-bye, since it may be easier for them to express anger rather than sadness. Family therapists can help family members limit blame toward each other and instead express the underlying feelings of sadness. At such times, the therapist can be available to the family at the hospital or via phone and at home if possible.

10.16.5 Making the Most of It

Chronic illness is a difficult period in the history of a family. However, nothing lasts for ever, and that includes tough times. But seldom does a family simply wait out the difficult period in the hope that one day it will pass. Apart from taking appropriate measures towards treating the disease and making the patient comfortable, is there something else that can be done? One positive development during the process of coping with chronic illness, specially terminal illness, which happens in many families is that the patient and the family undergo a psychospiritual transformation. A variety of factors contribute to the transformation. First, the illness brings the members of the family closer to each other. Second, it brings out the best in their friends, relatives and other contacts, giving them a glimpse of the goodness which they never thought existed in the world. This helps in stretching the ego boundaries beyond the circle of the immediate family. Third, the illness generates a climate of love and forgiveness. Finally, the patient and the family realize the limitations of their material and non-material resources. Their helplessness reminds them of their vulnerability, and makes them turn to a Higher Power, which they are now more ready than ever before to acknowledge, approach and surrender to. The overall result is tremendous spiritual growth for the patient and the family. The degree of growth in a few years of difficult circumstances might exceed that in several decades of the so-called normal life. This is a great gain, because spiritual growth is the ultimate purpose of life. Thus, what looks like a curse, can be a blessing in disguise. While many families are able to make use of the opportunity provided by difficult circumstances to take a few big steps towards the fulfillment of the ultimate purpose of life, many other receptive families can be guided unobtrusively in that direction by the therapist. The result may be not only the spiritual growth of the patient and the family but also that of the therapist.

10.17 LET US SUM UP

In this Unit we have learnt about the valuable role a counsellor might play in helping a family cope with chronic illness. To play that role, the therapist first needs to understand how the patient and the family affect each other, the factors which influence their mutual adjustment, and the techniques available to the therapist for assessing and treating such families.

- The adjustment of the patient and the family to the situation and to each other may be understood in terms of the family systems-illness model.

- Chronic illness typically goes through the crisis phase, chronic phase and terminal phase, and each phase calls for unique strengths, attitudes or changes on the part of the family.
- Chronic illness may necessitate role shifts in the family, lifestyle changes and financial problems, to which the family has to adjust.
- The challenges posed by chronic illness differ somewhat depending on whether the patient is an adult or a child, the breadwinner or the housewife or an aged parent, and whether the illness is terminal or otherwise.
- The therapist first needs to assess the positive and negative features of the way the family has responded to the chronic illness.
- Next, the therapist needs to set, in collaboration with the family, goals of the therapy.
- Next, the therapist needs to use the techniques most appropriate for helping the family cope with the illness, and if possible, use the illness as an opportunity for spiritual growth.

10.18 GLOSSARY

Agency	:	It is a term used to describe active involvement in and commitment to one's own care.
Alliance	:	It is to affiliate with a particular member of the family.
Alzheimer's Disease	:	It is a disease, essentially restricted to the elderly, characterized by progressive deterioration of cognitive function. Initially it resembles senile dementia. It can incapacitate the patient and tax the caregivers' patience when the patient gets irritable, asks the same question repeatedly, fails to recognize even members of the family, runs the risk of getting lost even in the neighbourhood, or cannot perform even routine tasks required for taking care of the body.
Arthritis	:	Arthritis, literally, means inflammation of the joints. Its commonest chronic form is osteoarthritis, which usually affects the knee and hip joints. Osteoarthritis is at least partly due to wear and tear of the joints, and is therefore age-related.
Asthma	:	Asthma, without qualification, refers to bronchial asthma. Bronchial asthma is a chronic respiratory disease characterized by relapses and remissions, and may sometimes be punctuated by acute life-threatening attacks due to severe constriction of airways.

Although allergy to some agents such as dust or pollen is a basic underlying cause, exacerbations are made more frequent and more severe by exposure to cold, respiratory infections and mental stress.

- Boundaries** : Invisible lines of demarcation within a family, which may be defined, strengthened, loosened, or changed as a result of structural family therapy. Boundaries range from “diffused” to “rigid”. Ideally, boundaries are “clear”.
- Boundaries, clear** : Clear boundaries around subsystems are ideal because they are firm yet flexible, permitting maximum adaptation to change.
- Boundaries, diffuse** : Diffuse boundaries imply enmeshment where everyone is into everyone else’s business. In this case, no one and everyone is taking charge and effective guidance during times of change is impossible.
- Boundaries, rigid** : Rigid boundaries imply disengagement among family members or subsystems. The prevailing non-communication hinders support and limits effective adaptation.
- Cancer** : Cancer is due to excessive proliferation of cells in some part of the body. The proliferation is due to uncontrolled cell division. In cancer, not only do the cells divide rapidly, but the resulting cells are also incapable of normal function. Thus there is a growth or swelling (called *tumour*) in the organ, and the function of the organ suffers. Some of the ill-effects of the tumour are due to the pressure it exerts on neighbouring structures. One more characteristic of cancer cells is their tendency to detach and spread far and wide in the body. Cancer cells have a tendency to settle in liver, lungs, bones and brain, grow there, and impair the function of these organs also. Dissemination of cancer cells in this way is called *metastasis*. Since metastasis is generally to vital organs, metastatic cancer usually indicates that the disease has reached the terminal phase.
- Chemotherapy** : Although chemotherapy literally means treating disease by using chemicals, in practice its use is restricted to only certain types of treatments. In the context of the present Unit, it means the treatment of cancer

using certain chemicals which may be given orally or by injection. Chemotherapy is specially used for the treatment of metastatic cancer (see 'Cancer') because only a chemical which circulates throughout the body can reach every part of the body, and thereby act wherever the cancer cells might have spread.

Coalition : A (usually) covert alliance between two family members against a third.

Coalition, cross-generational : When one parent joins a child in a coalition against the other parent.

Communion : It is the sense of being cared for, loved, and supported by a community of family members, friends, and professionals.

Compliance : A patient's adherence to a recommended course of treatment.

Coronary artery disease (see Coronary heart disease)

Coronary heart disease : Coronary arteries are the arteries which supply blood to the heart. In coronary artery disease, the coronary arteries undergo a narrowing of the lumen due to deposition of fatty substances in the walls of the arteries. That leads to a reduction in the blood supply to the heart. One of the common symptoms of the disease, called coronary artery disease (CAD) or coronary heart disease (CHD), is chest pain on exertion. Blockage of blood supply to the heart due to an aggravation of the block is called a heart attack, which may lead to sudden death.

Crohn's disease : In Crohn's disease, there is a chronic inflammation of the intestine leading to impaired absorption of nutrients. The result is malnutrition on one hand, and diarrhoea characterized by greasy, frothy and foul smelling stools on the other. The disease is chronic, but shows waxing and waning.

Detouring : A process whereby stresses between spouses get redirected through a child so that the spouse subsystem gives the impression of harmony.

Dialysis : Dialysis is typically done for patients whose kidneys are not working well. Because of impaired kidney function, these people accumulate several unwanted substances in the blood to an unduly high level. The

principle of dialysis is to bring the patient's blood very close to a fluid which does not have those unwanted substances, the blood and the fluid being separated by a very thin membrane. The result is that the unwanted substances travel across the membrane to the dialysis fluid, and thus the blood gets purified.

Diabetes : The term diabetes, without qualification, refers to diabetes mellitus, which is a disease characterized by high levels of sugar in the blood. The common variety of diabetes (type 2) has its onset in middle or old age, and may present as loss of body weight, excessive appetite, passing too much urine, and drinking too much water. The urine may contain glucose, and the blood level of glucose is high. The treatment needs attention to diet and physical activity, and may also need medication.

Down's syndrome : Down's syndrome is present at birth. A child inherits half the genes from the father and half from the mother. The genes are arranged on thread-like structures called chromosomes. Each person has 23 pairs of chromosomes, one member of each pair coming from the father, and one from the mother. Each pair is identified by a number. In Down's syndrome, there is an extra chromosome no. 21; that is, instead of a pair, there are three chromosomes no. 21. The child has a characteristic appearance, and is mentally challenged.

Enmeshment : An extreme pattern of family organization in which family members are so tightly locked that autonomy is impossible. Boundaries among family members are typically diffuse.

Epilepsy : In plain language, epilepsy is essentially the same as convulsions. The convulsive attacks come at an unpredictable frequency, but many forms of epilepsy need long-term, or even life-long medication to prevent the attacks.

Erikson's psychosocial stages of development : Erikson articulated eight stages of human development from infancy to late adulthood. During each stage the person confronts a psychosocial crisis and is expected to

complete certain tasks. Each stage builds on the successful completion of earlier stages.

- Family of origin** : It is the family a person was born into.
- Family subsystem** : Units within a family, based on characteristics such as sex, age or interest. For example, the children form the sibling subsystem and the parents form the parental subsystem.
- Hierarchy** : A boundary that differentiates the leader of an organization from the other members. In a family, the parents are often higher in the hierarchy, meaning that they have a greater say when it comes to making decisions on how the children are expected to behave.
- Hypertension** : Hypertension is commonly called high blood pressure. It is one of the commonest lifestyle disorders. Treatment requires lifestyle modification, and sometimes also medication.
- Inhaler** : An inhaler is a device which delivers medication while breathing in. Inhalers are commonly used in bronchial asthma.
- Invasive intervention** : In clinical practice, an intervention may be in the form of an investigation (e.g. a blood test or an x-ray) or a treatment. An intervention which requires entering the body (e.g. surgery, or even drawing blood) is considered invasive. In contrast, investigations such as an x-ray or an electrocardiogram (ECG) and drug treatment are examples of non-invasive investigations.
- Kubler-Ross' stages** : Elisabeth Kubler-Ross, a pioneer in working with dying patients, has summarized her observations on those having a terminal illness in terms of stages through which they characteristically pass in the course of coping with the episode. These stages are denial (I do not have the illness: the diagnosis is wrong), anger (why me?), bargaining (with God: if you make me well again, I will do this for you), depression, and acceptance (exactly the opposite of denial).
- Lifestyle** : This term has gained immense popularity in medicine after the increase in the prevalence of disorders such as obesity, hypertension, coronary heart disease, diabetes, etc., to the causation of which an unhealthy lifestyle makes an important contribution. The major

components of lifestyle are physical activity, diet, sleep and attitude to life. A healthy lifestyle includes adequate physical activity, a balanced diet, abstaining from tea, coffee, alcohol and smoking, enough of good quality sleep, and an attitude to life conducive to lasting mental peace.

- Medical Family Therapy** : Biopsychosocial treatment of individuals and families dealing with medical problems.
- Multiple sclerosis** : A chronic disease of the central nervous system. It affects primarily the nerve fibres (white matter) rather than the cell bodies of nerve cells (grey matter). The symptoms are varied, and may include muscular weakness and incoordination, abnormal sensations, and abnormalities of speech and vision. The disease shows relapses and remissions, and may go on for years.
- Parentified child** : An overly responsible child who has power and authority that more appropriately belongs to the parents. This typically reflects an inappropriate generational boundary within the family.
- Parkinson's disease** : It is a chronic progressive disease due to impaired function of parts of the brain known as basal ganglia. The disease is characterized by muscular tremors, rigidity and incoordination; a shuffling gait in which the person walks with small steps, stoops forwards, and seems eager to catch his centre of gravity; and a mask-like face.
- Pink elephant in the room** : This is an English idiom for an obvious truth that is being ignored or goes unaddressed. It is based on the idea that an elephant in a room would be impossible to overlook; thus, people in the room who pretend the elephant is not there might be concerning themselves with relatively small and even irrelevant matters, compared to the looming big one.
- Psychoeducation** : Psychoeducation refers to the education offered to people who live with a psychological disturbance. Research has shown that the more a person is aware of their illness and how it affects their own lives and that of others, the more control that person has over their illness.
- Scapegoating** : It is an insidious family pattern of blame and shame on one family member. In

scapegoating, one of the authority figures has made a decision that somebody in the family has to be the bad guy.

- Stroke** : Stroke, without qualification, refers to sudden blockage of, or bleeding from, the blood vessels supplying the brain. Although the onset of the disease is acute (i.e. sudden), its consequences are often chronic. The patient may be left with paralysis, loss of sensations, or speech abnormalities, from which the recovery may be rather slow and incomplete. It may, therefore, lead to long periods of incapacitation, and need patience and prolonged nursing care and physiotherapy.
- Systems theory** : General systems theory was originally proposed by biologist Ludwig von Bertalanffy in 1928. He proposed that a system is characterized by the interactions of its components and the nonlinearity of those interactions.
- Terminal illness** : As the term indicates, it refers to an illness from which the patient is likely to die within a relatively short period of time. Such a patient may not interest doctors because they cannot do much to change the course of events, but the patient and his family can benefit from the intervention of a mental health specialist.
- Triangulation** : A process in which two family members demand that a third family member (often the child) side with each against the other. The triangulated family member may feel paralyzed.

10.19 ANSWERS TO CHECK YOUR PROGRESS EXERCISES

Check Your Progress Exercise 1

1. acute
2. more
3. chronic
4. terminal

Check Your Progress Exercise 2

Some things a patient with chronic illness can control are: diet, exercise, smoking cessation, compliance with the doctor's recommendations.

Some things a patient with chronic illness cannot directly control: course of the illness, outcome of the illness, exacerbation of symptoms, incapacitation caused by the illness.

Check Your Progress Exercise 3

1. False
2. True

Check Your Progress Exercise 4

1. True
2. False

Check Your Progress Exercise 5

1. C
2. A
3. D
4. B

10.20 UNIT END QUESTIONS

1. Compare and contrast the adaptation of a poor well-knit family with that of an affluent but dysfunctional family when faced with chronic illness.
2. Enumerate a few situations in which chronic illness enforces reversal of customary gender roles.
3. Enumerate some of the abnormal forms of communication, which may replace normal and open communication in families going through chronic illness.
4. Mention some family developmental tasks at different stages of the family life cycle that may not be completed or may be delayed if a family member has a chronic illness.
5. What will help you work with a patient who comes in with overwhelming feelings of self-pity and constantly asks the question “why me?” in response to the chronic illness?
6. Describe some interventions you can use with a child with a chronic illness who is being teased and bullied by peers at school?
7. What is psychoeducation? Why is it particularly important for a family coping with a chronic illness?
8. Briefly describe the techniques of medical family therapy.
9. What are some specific family interventions that may be helpful in cases where the patient is a parent, child or partner?
10. Describe some issues that need special consideration in the case of patients with a terminal illness.

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UNIT 11 DEALING WITH HIV/AIDS

Structure

- 11.1 Introduction
- 11.2 HIV Specific Family Issues
 - 11.2.1 Stigma and Discrimination
 - 11.2.2 Fear of Acquiring Infection
 - 11.2.3 Helplessness
 - 11.2.4 Disclosure
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 - 11.4.7 Liaison Skills
- 11.5 Family Assessment
 - 11.5.1 Family Interactions Prior to HIV Diagnosis
 - 11.5.2 Present Family Interactions
 - 11.5.3 Coping Patterns of Family Members
- 11.6 Intervention
 - 11.6.1 Components of Counsellor Intervention
 - 11.6.2 Unique Family Counselling Issues
- 11.7 Let Us Sum Up
- 11.8 Answers to Check Your Progress Exercises
- 11.9 Unit End Questions
- 11.10 Further Reading and References

11.1 INTRODUCTION

The impact of HIV/AIDS on the family system is similar to the impact of any chronic illness on the family. Families with an infected person also experience the various stages of grief as underlined by Kubler-Ross (1969). However similar it may be to any other chronic illness, in the case of HIV/AIDS, the family

members have certain concerns which are very unique for them. These concerns often cause stress on the family members who in turn try to cope with the situation either in an adaptive or maladaptive manner. Presence of any illness can at times serve as a centrifugal force where the members of the family are drawn towards the nucleus of the family in order to deal with the stressful situation (Rolland 1984, 1987). However, some family members drift further from each other in the context of an illness or a catastrophic event.

Patients and family members dealing with HIV cope well with professional intervention. This Unit provides an overview of concerns or issues that family members dealing with HIV face, and details some counsellor interventions to help these families to deal with those issues more efficiently and empower them to be self-reliant.

Objectives

After studying this Unit, you will be able to:

- Analyse the impact of HIV on the family system;
- Understand the concerns of family members of persons living with HIV at various stages of infection;
- Develop essential skills to counsel family members dealing with HIV;
- Know the various domains to be assessed prior to counselling;
- Delineate interventions for families based on the stage of HIV infection; and
- Discuss the unique issues in counselling families affected by HIV.

11.2 HIV SPECIFIC FAMILY ISSUES

There are several salient issues and concerns that family members living with a seropositive person are faced with. The intensity of these may vary across the illness trajectory.

11.2.1 Stigma and Discrimination

“... We both wanted to kill ourselves and I was making plans for the same. My wife too agreed but she was extremely worried about leaving children, so she went on postponing the idea of suicide...” (Husband of Mrs. LN, Seroconcordant couple)

“I hate to go to that hospital....last time when I visited that hospital that doctor kept me waiting till the end...even then... forget touching me while examining, he did not even ask me to sit on the stool meant for patients...” (Mr. PS’s experience in a State Government Hospital)

“I heard from my eight year old daughter that my sisters were very nasty towards our daughter when we visited them... they did not allow her to play with the rest of the children and I was extremely upset, unhappy and angry about this...since then we stopped visiting our relatives and friends...we prefer staying at home”. (Wife of Mr. S, serodiscordant couple).

Stigma by definition refers to marginalizing targeted individuals, excluding them from community life, or denying them access to resources. It is thus a powerful

means of social control, whereby individuals are labelled, depersonalised and isolated. The stigmatisation of people with AIDS has been recognized since the beginning of the epidemic. Stigma has also been reported as a common concern expressed by the family members of the infected person. The extent to which caregivers fear stigmatisation, they may avoid discussing with others the fact that they are caring for a relative or friend with HIV/AIDS. Their attempt to manage the stigma isolates them from potential sources of mediation of the other stressors or burdens.

Instances of family members shunned by others, denial of treatment in the hospitals, and losing jobs are common consequences of stigma. Bharat (1999) observed that in India, discrimination was most spontaneously reported in the contexts of health care, household, and community while other contexts were found to be unsupportive and even oppressive. Similarly, Ravies and Siegel (1991) found that sources of support and assistance for informal caregivers of people with AIDS are diminished as a result of the stigma associated with the disease, rendering caregiving relationship more stressful. Additionally, AIDS often occurs in association with the disease, which contributes to difficulties in caregiving and making the caregiving relationship more stressful. Added to that, AIDS often occurs in association with socially stigmatized behaviours (that is sexuality, or drug use), and a potential caregiver may fear that social censure will result. Hence to protect themselves, families try to become socially invisible, a process which shrinks the existing social support system. Maintaining the HIV diagnosis as a secret becomes an adaptive response of the family. However, family members also experience intense stress while maintaining the secrecy, as they have to give socially accepted explanations to prolonged hospitalisations, frequent infections, or sudden death of the infected member.

11.2.2 Fear of Acquiring Infection

“In the past I had eaten several times from my son’s plate and I continue to do that. One day he could not finish some food and I continued to eat the leftovers but she (mother) insisted that I should not have eaten that food and instead she wanted to throw it to dogs...” (Parent of M)

“I was terribly scared and worried.... I wanted to tell him to stop.... but could not open my mouth and I somehow pushed him away that night...and later he was very upset and felt very ashamed and went on saying sorry to me...”. (Wife of Mr. PS, Serodiscordant couple, during a sexual act)

“My major fear is that of my son getting the infection...because people say that children too will get the disease from parents and I don’t think that I’ll be able to survive if anything happens to him...sure that I’ll kill myself...my only hope is that he’s healthy.” (Mrs. S, mother of 3-year-old son)

Maintaining safe interpersonal and sexual relations is another major concern expressed by family members. Since its emergence as a public health concern, HIV/AIDS has been associated with tremendous social fears of contagion. Such fears have had a widespread social impact ranging from a decrease in voluntary blood donations (Callero et al. 1986) to reduced willingness of nurses and other hospital personnel to care for people with AIDS (Barrick, 1988; O’Donnell et al. 1987). Despite evidence that the means of transmission are limited to direct exchange of bodily fluids through sexual contact, intravenous drug use with contaminated needles, administration of infected blood and blood products, and

in-utero transmission from infected mothers to their children, there is little indication that public fears have been calmed (DiClemente et al. 1987 and Forstein, 1989).

Family members of people with AIDS are likely to experience the same fears regarding contagion as other people, and such fears may be present even when relatives know rationally that there is no basis for concern (Macklin, 1988). Fear of contagion may limit the willingness of a family member to assume caretaking tasks, such as bathing the ill person or changing soiled bed linens. The fear of acquiring the infection may manifest into severe negative feelings, such as anger or blame towards the infected individual. Also, many families feel torn between the desire to create a supportive environment for the AIDS patient and their sense of responsibility for the well-being or health of other family members. This dilemma is the most common source of intrafamily distress (Frierson et al. 1987).

11.2.3 Helplessness

“.... We’re extremely worried, do not know what to do. We had these neighbours and relatives who frequently visit us and enquire what was happening with my brother. We were telling everyone that he had typhoid and developed complication...but it is extremely difficult to lie constantly.” (Sister of Mr. AN)

“We continued to be in a confusion since we’re not aware what has to be done next”. (Mr. S and Mrs. SH, Serodiscordant couple)

“I was feeling miserable and helpless since I cannot talk much at home to my parents because I’m worried that they cannot take it. But, I needed to talk to somebody and I knew that I can trust this friend of mine who constantly supported me so I spoke to him...” (Brother of Mr. VE)

The uncertainty and the unpredictable nature of the infection is a common concern raised by all the family members. It also creates a sense of helplessness among the family members. This helplessness may take the form of over involvement at one extreme and total neglect at the other extreme. A shift in the family roles is an usual consequence of HIV infection. When the individual becomes disabled, the healthy family members are expected to take up the additional roles for maintaining the functioning of the family. A commonly observed phenomenon is of women being forced to take up earning and running the family since their husbands are sick and can no longer work. The feeling of helplessness mounts when the person caring for the sick relative is also infected with the virus. Many family members feel burdened by having to maintain a delicate balance between preserving the infected individual’s autonomy and dignity and meeting the legitimate needs of the family (Frierson et al. 1987).

11.2.4 Disclosure

Disclosure of HIV infection to others is a significant issue that both people living with HIV and their family members are concerned about. It is often related to fear of stigma and discrimination. Families report helplessness associated with disclosure since they are confused about what to disclose, to whom to disclose and how much to disclose issues. While the fears related to consequences of disclosure are genuine and based on true incidents of stigma and discrimination, they are also at times exaggerated due to the fact that family members are stressed out psychologically. Family members rarely consider that disclosure to the right persons can lead to support and care. One of the major tasks while counselling families

is to help them understand that the consequences of careful disclosure can be positive as well.

“I wanted to talk to somebody...but I knew that I cannot talk about it in the family since all of them were worried and my talking only causes more worry to them and it is not going to help anyone of us. Finally, I decided to discuss with my neighbour who’s also a good friend of mine. He was extremely supportive; he listened to me and offered his help in whatever way possible”. (Brother of Mr. VE)

11.2.5 Revelation of Lifestyle

The simultaneous revelation of lifestyle of the infected individual which is not socially acceptable such as sexual promiscuity, drug use etc. and a diagnosis of terminal illness is another stressful factor for family members. Often women complain that they were unable to express anger concerning their husband’s sexual activities because of the prospects of imminent death of the positive person. They also express guilt that they had somehow “driven” their spouses to another way of life, thereby “condemning them”. For a few it is extremely difficult to accept the lifestyle of positive person and form judgements. These families tend to be hostile and hold the individual responsible for his illness. These revelations can be extremely stressful to both the family members and the infected family member.

11.2.6 Marriage and Childbearing

“My relatives and others insist that I should get him (the son) married and I don’t know what I should be telling them and I get very hassled. Initially I used to tell them that he is unwell but they used to ask me back what illness he has since he is looking all right. Sometimes, a few relatives even brought alliances home...I know that they’re trying to help me but they’re not aware of our condition. Finally, I started telling them that he has fits (seizures) and is on treatment and the doctor asked us to wait for some more time. This way I don’t feel bad too since he’s really having fits.” (Mother of Mr. M).

Life issues that are related to marriage and childbearing are concerns reported by majority of the families. The HIV diagnosis becomes a family secret and the family members find it extremely difficult to find convincing replies to all those who inquire about marriage and childbirth. The asymptomatic individuals often face curiosity from their neighbours and relatives. Marriage and childbearing are given extreme importance in Indian society and couple being married for a year or two and not bearing children becomes a major issue for discussion and inquiry. This is observed most commonly in the rural communities in India.

11.2.7 Disturbance in Family Roles and Functioning

“My husband stopped working long back because he was frequently falling sick. We have a house but we need to survive and also need to send our child to school. So I started working as a cook in a house. They knew that my husband is sick so they are very supportive.... but I feel extremely tired by evenings to do anything. I find it very difficult to visit my husband in the hospital but he insists that I should manage to see him.... I really find it difficult to manage the time and more so I don’t have so much strength.

I get easily irritated and sometimes I show it on my son... I don't get sleep at all these days..." (Mrs. S, wife of Mr. SK, Seroconcordant couple)

"Once in a while I used to visit my friends or go out with them for shopping after my office work but these days I have totally stopped going out. One reason is that they keep asking me what's happened to my husband and other things...secondly, if I go out I'll be totally preoccupied and worrying about him. I'll be thinking about his medication, food and so on..." (Mrs. Y, wife of Mr. PS, Serodiscordant couple)

HIV infection has a tremendous impact on the role functioning of the family members. The frequent opportunistic infections and prolonged hospitalisations often disable a person from performing adequately and efficiently in their expected roles and hence the roles get drastically altered. The healthy family members take up the roles of the sick family members in order to ensure a smooth family functioning. However, the healthy family members are burdened with these additional responsibilities apart from the caregiving demands. This situation is typically seen when the breadwinning male is ailing and then the other healthy family members such as the parents, siblings or the spouse take up the additional role. In most cases, the women as spouses take up the additional role of earning for the maintenance of the family, which gets further complicated in cases where the woman is also infected with the virus. They are torn between the caregiving demands and their own fears about the looming death. They often face a dual dilemma of the basic responsibility towards oneself and caretaking of the sick spouse. In this dilemma the spouses often choose the latter and neglect their own health.

In a few cases, the issue of dependency and interdependence may arise as the chronically ill family member experiences conflicting messages from the family regarding his or her role (Springer, 1985). For example, the family may convey subtle messages of resentment regarding the financial burden created by the person with AIDS, while overtly insisting that the patient is too ill to contribute monetarily to the family even through part-time or limited employment. Families whose roles are inflexible are more likely to convey conflicting messages to the person with AIDS, which creates a learned helplessness in the infected person and further exacerbates his or her difficulties with respect to social and family roles (Cates et al. 1990).

11.2.8 Economic Burden

"There was no money in the house and all of a sudden his condition worsened...and the doctor suggested that we take him to Bangalore. I had to borrow two thousand rupees from neighbours and felt so shameful. Like this we borrowed so much money and we have to clear all our debts now..." (Mrs. H, wife of Mr. SS, Seroconcordant couple)

"...he needs good food these days and it is really expensive! Money is so important and we are really worried what are we going to do in the future. We're so careful these days with money that we think several times before spending on anything. In that way we're making lots of compromises and it is very upsetting at times". (Mrs. Y, wife of Mr. PS, Serodiscordant couple)

"We do not have any money and have already taken loans. The house rent is due since several months and the owner ordered us to vacate the house

by next week...my brother is in the hospital now and we don't know what to do in this situation....". (Sister of Mr. AN)

Economic/financial burden has the major impact on families affected by HIV/AIDS. AIDS usually leads to the loss of an earning member, often the only earning member. In several instances, even when the HIV positive person is alive and healthy, he/she still may lose the job due to discrimination at the work place. Family economic well-being is thus severely affected (McGrath et al. 1993). It is further drained by repeated hospital care and the cost of drugs for treating the opportunistic infections (Davachi et al. 1988). As days go by, living standards of the family also drop and the patience of other family members especially those requiring financial assistance for education, business, marriage plans wears thin. Long term care has been observed to force families to divert resources to other healthy members of the family, particularly to males, thus pushing HIV persons to the periphery of the family and providing only the bare essentials (Ankrah 1991a).

11.2.9 Burden of Caregiving

"We trusted him so much that he would look after us but we never expected something like this to happen to us.... both of us are working at this age to support the family ..." (Parents of Mr. R, who developed paraplegia and was bedridden)

"I find it very difficult to work at this age as a watchman...I feel very helpless but I know that we have no choice...." [Father of Mr. AN, who has lost his eyesight due to CMV (Cytomegalovirus)]

"After he got back from hospital my responsibilities have increased because of HIV. The increase in responsibilities was mainly with regard to taking care of him in terms of his food. Ensuring that he gets good food is a major job...I get up early to make fresh food and these days I prepare fresh food every time unlike earlier...and all these things involve money and he's still not regular to work so I work extra hours so that I get some more money...." (Mrs. Y, wife of Mr. P, dual earning and serodiscordant couple)

"I stayed with him in the hospital when he was admitted. He was there for almost a month and I went home twice during that period to get a change of clothes. Otherwise, he needed me most of the time...the nurses in the ward were taking care of him but I was there helping him in having food, bathing and taking him to toilet...." (Mrs. S, wife of Mr. DR, Serodiscordant couple)

The caregivers experience intense stress especially due to progressive, terminal and stigmatising nature of HIV infection, with its opportunistic infections and intermittent periods of normalcy. An aspect of critical importance in family care for people living with HIV/AIDS is that the elderly parents who are physically and financially weaker, or wives/partners who are dependent on others have to care for the physically active, economically productive and mentally fit adults (Krishna, 2005). In other words, people with prime roles in society have to be cared for by those who have resigned themselves to more subsidiary roles (Bharat, 1995a). Literature from the African region suggests a demographic trend towards an increasing dependency ratio as a fallout of the epidemic (Ankrah, 1991b; Carswell, 1988; Armstrong, 1991). There are instances cited of villages where the women and the elderly form the bulk of the population and of households in which the grandparents are left behind to care for orphans (Barnett and Blaikie, 1992).

The impact of the illness is enormous both on the infected individual and the family. It has been seen that it is almost impossible to isolate and treat the individual alone for better results. HIV/AIDS, as we have seen earlier, affects the individual at the psychological, social and occupational levels. The families too are affected in the same areas but the concerns and issues are different. However, these different concerns and issues of the individual and family are so enmeshed that they cannot be addressed in isolation. On the other hand, the quality and quantity of care a family provides to its infected individual is not only determined by the degree of impact of HIV infection on the system but also on other factors such as psychosocial environment of the family, which includes the earlier interpersonal relations and adaptive patterns; the family developmental stage; the value and belief system of the family; and the level of HIV/AIDS related knowledge and attitudes.

11.2.10 Impact on Women and Children

Women and children need special mention in the context of HIV/AIDS. In most developing societies, including India, women not only assume major responsibility for nurturing and socializing the young, homemaking and ensuring the healthy development of family members, but are also engaged in formal/informal production and market activities. HIV/AIDS puts women in a very precarious situation. With heterosexual transmission as the major route of infection, women will face the double burden of caring and living in fear of contagion. Women in India have a lower social status and are powerless within the sexual relationship in negotiating for safer sex practices. Thus for reasons of their reproductive, productive and socially productive responsibilities women, while providing care, will have little leverage to ensure that their own health needs are met. On the emotional plane, the female partners may experience feelings of anger, shame, and embarrassment. This to some extent may interfere with their caregiving role or, in the case of newly married women, to a termination of relationship. However, in the Indian context, the wife may have little choice as she may be forced to carry out her role of a 'good wife' and nurture the sick spouse.

Children are another main source of concern for many women who are infected with the virus. They are concerned about their parenting efficacy; the care of children in future; fear of infecting negative children; guilt of having infected one's child who is diagnosed positive, and denial of motherhood following HIV diagnosis. Losing the existing social support after the disclosure of HIV is also a common experience of many positive women which leads to compromise on help seeking (Joseph, 2000).

"We have changed our daughter's school since we were unable to pay the school fees and requested my aunt who is in Delhi to look after our second daughter for sometime on the pretext that he (child's father) is having TB (Tuberculosis). But, imagine what she might think of us if she gets to know about this?" (Mrs. SH. wife of Mr. S, Serodiscordant couple)

"My children were going to school regularly all these days but we don't have enough money to support their education". (Sister of Mr. AN, who lost his eye sight due to CMV related to HIV)

"Our children like to watch TV very much and I had no choice but for selling it off...they insisted that I should keep it, but.... (cries). It is extremely

difficult to realise that I cannot provide them certain basic things..." (Husband of Mrs. LN, dual diagnosis of Cancer and HIV)

There are a growing number of children infected with HIV due to vertical transmission on one hand, and on the other hand, there is an increasing number of orphan children due to the death of both parents because of AIDS. Parentification of children, a phenomenon where children prematurely take up the adult roles to run the family either by earning or care taking of the sick parents or nurturing their young siblings is commonly seen as a consequence of HIV. Thus, many children lose their precious childhood. These children after the death of both parents due to AIDS are either taken care of by the extended family, grandparents or reach an orphanage. In India, community based resources for these children are very minimal and this is a major concern for several HIV infected parents.

11.2.11 Anger and Hostility

"He is a priest in a temple and ours is such a traditional family and I cannot imagine that he can do something like this...I am so angry, I lost respect for him. Being a priest he should be pure...." (Wife of Mr. SS, Seroconcordant couple)

"My brother who stays in Krishnagiri knows about my condition. I called him up several times and he reduced visiting our family. He never offered any support. He at least used to visit us more frequently before...now even that has stopped". (Mr. AN about his brother who stays in a different place)

"After the discharge from the hospital we noticed our eldest son being very reserved and silent towards all of us and more so towards him (patient). He was interacting less with him so one day I asked him what has happened with him and he made subtle remarks that he's just being careful in the house...." (Mother of Mr. R about her other son who is supporting the family)

"I feel very upset and angry with my husband...sometimes, I just feel like slapping him on his face. Will he accept me as his wife if I had done the same thing what he had done?" (Mrs. S, wife of Mr. HN, Seroconcordant couple)

The above excerpts are just a few expressions of anger and hostility by family members towards their relative with HIV. Anger and hostility can be due to several reasons such as: getting to know their relative's lifestyle, feeling shameful, loss of prestige and family image in the society, breach of trust, infecting the partner/spouse to list a few (Krishna, 2005). Family members due to anger might refuse to take part in counselling or they may be uncooperative during sessions. Counselling often helps these family members overcome the negative feelings they harboured.

11.2.12 Fear of Falling Sick and Dying

"We realised that the illness is serious and I started to think that we're going to lose our son. But we continued to do whatever the doctors suggested us...they shifted him to the exercise ward (Neuro-Rehabilitation) and they were making him do exercise everyday. The worst thing is that he lost control over his urine and bowel and I had to help him out in all this. I guess he was embarrassed and he rarely looked into my eyes..." (Father of Mr. R)

Both patients and their relatives during the initial days of diagnosis or coming to know about HIV would be extremely concerned about falling sick and dying soon (Krishna, 2005). This is partly due to the initial media and HIV prevention strategies that focused predominantly on fear inducing messages. It is rooted in several minds that HIV diagnosis is equivalent to very near death. Educating families about the nature of HIV, the disease process, advancements in the management of HIV and instilling hope would alleviate their fears related to falling sick and dying early.

Check Your Progress Exercise 1

Note: a) Read the following question carefully and answer in the space provided.

b) Check your answer with that provided at the end of this Unit.

1. Delineate six specific family issues faced by people suffering from HIV.

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11.3 ISSUES SPECIFIC TO SERO- CONCORDANT AND DISCORDANT COUPLES

The needs and issues of Sero-concordant (couple is infected with HIV) and discordant (only one partner is infected) couples differ significantly. It is essential that counsellors recognize that these couples have unique needs and hence need specific intervention. For instance, the common concerns of sero-concordant couples would be childbearing if they do not have children yet, while couples with children are extremely concerned about the future of their children and leaving them as orphans. They are extremely worried about caregiving issues and finances. Sero-discordant couples are concerned about maintaining safe sexual relationships and child bearing if they have not had children. Counsellors have to discuss various options these couples have during the counselling process.

“He used to insist to have that (sex) whenever he drinks. Even though he drinks these days he reduced asking for sex. On a few occasions he forced me to have sex with him and reassured that the doctors advised to use nirodh (condom) and it is safe. I yielded to him unwillingly and I’m always scared of that...” (Mrs. SK wife of Mr. D, Serodiscordant couple).

11.4 ESSENTIAL SKILLS REQUIRED TO COUNSEL FAMILIES DEALING WITH HIV/ AIDS

To counsel families dealing with HIV/AIDS, the counsellor needs to possess certain specific skills in addition to the general counselling skills such as non-judgemental attitude, empathy and ability to communicate the same to the client. The following are some of the essential skills/tools for effective HIV counselling:

11.4.1 Information about HIV/AIDS

Possessing accurate scientific information about HIV/AIDS is vital when counselling individuals or families dealing with the infection. Counsellors need to have basic information about the modes of transmission, disease process (i.e. the various stages of disease and common symptoms in each stage of infection), prevention of infection among adults and vertical transmission (i.e. mother to child transmission of infection). It is also essential that counsellors update themselves periodically about the prevalence rates and distribution of HIV infections across different groups of individuals specific to the region where they are working.

11.3.2 Non-judgemental Attitude

Unfortunately HIV is associated with facts that are hard to talk about, such as sexual promiscuity, unprotected sex, sexual orientation, injection drug use and sharing of injection paraphernalia. Clients may bring in along with them to the counselling situation any of such realities and are often concerned about being judged. In addition, clients with HIV also fear discrimination in health care settings and they fear the same during counselling situations as well. Until adequate rapport is built, most clients may not volunteer information. Hence during the initial stages of counselling, the counsellor should make conscious and deliberate efforts to demonstrate his non-judgemental attitude and genuine respect for the dignity of the clients. It is highly essential that counsellors try not to be moralistic and impose on the clients. If not, there is always a risk of clients dropping out of counselling and also that they are less likely to seek help anywhere else after that. Family counsellors need to be aware that through their counselling they are not only helping clients and families deal with HIV infection, but are also preventing further transmission of HIV to others. Hence, it is highly essential that counsellors respect the dignity of every individual irrespective of the lifestyle of the HIV infected individuals and their relatives.

11.4.3 Ability to Deal with Difficult Issues

In addition to being non-judgemental, HIV counsellors need to explore their own attitudes and bias towards issues such as sex and sexuality; substance use; and death and dying. Patients and families in the context of counselling may raise any of the above concerns. In fact, clients themselves feel uncomfortable and hence try not to bring these issues for discussion though they are worrying them. It is the job of the counsellor to explore concerns and help clients deal with them. Inexperienced counsellors often get worried when such difficult issues are raised by the clients and counsellors with blocks towards such issues often try and avoid exploring and addressing such difficult issues. Such counsellors brush them away as trivial concerns or postpone talking about them. It is very important to mention here that no issue is trivial and when not addressed, they remain as unresolved concerns and continue to trouble the patient and family members.

11.4.4 Engaging Family in Counselling Process

Engaging the family members in the counselling process is a skill that is acquired only through practice. It is not necessary that all the family members are always in agreement with the counsellor or counselling itself. Counsellors often encounter that a few members of the family or the entire family may not be willing for counselling or might have a different opinion than the counsellor and hence may not agree with the counselling process. Family members who have anger towards

their infected relative are more likely to be indifferent and hostile towards their infected relative. Such family members at times refuse to attend counselling sessions or might not extend complete cooperation during the counselling process. These reactions of family members are very much normal and legitimate and can be resolved by acknowledging them as normal reactions and helping them talk about those issues.

In some instances, family members attending counselling have different or multiple agenda amongst themselves and expect the counsellor to see the problem from their view point or attempt to override the issues of the other family members. Such situations can often become volatile with high noise levels in the counselling session. Such interactions, though they might seem to be effecting the session and counselling process, often provide valuable insights about the existing interaction patterns and internal dynamics of the family that is essential to understand the family.

11.4.5 Family Interviewing

Interviewing families is a skill that is different from interviewing in individual counselling scenario. However, the underlying principles of interviewing remain the same. The basic difference is that in family counselling, the counsellor has to interview more than one individual simultaneously; that can involve just a couple or couple with their children, and at times, people of different generations might be present in the interview. Subsequently, counsellors should carefully choose and invite the required family members to the sessions than having everybody— for instance, excluding relatives from the extended family if they have very little to do with the presenting problem. Conversely, invite them whenever a need arises. Counsellors should treat family as one unit and exercise caution and give equal importance to all the participants in the session. Counsellors should remain neutral as far as possible without aligning with any one family member. Family members should be conveyed that the counsellor in general is interested and concerned about the whole family than just one individual. This is something counsellors can demonstrate by giving equal opportunity to all the participants to speak, and taking the opinion of all participants during discussions.

11.4.6 Home Visiting

Visiting the client at home has been an integral part of service delivery. Especially, home visits are useful when the client is unable to reach the counsellor's office/hospital or if the counsellor has to meet other members of primary/extended family for the purpose of assessment and counselling. Home visits enable the counsellor to make a social diagnosis and formulate a social treatment plan for the client and family (Richmond, 1917). Among other advantages, home visits provide a valuable means of assessing clients and their interactions within their environment. Thus, home visits serve a dual purpose of investigation as well as helping. In addition, home visits allow the counsellors to understand the physical environment of the client; this includes the home and its structure, conditions prevailing within the home and the surroundings and the support network of the family. This information becomes a significant basis for intervention in several cases.

Family counselling and care in the context of HIV cannot be done in isolation. The very nature of illness is such that it causes a myriad of physical, psychological and social consequences. Families and patients present to the counsellor with varying needs and might require different services that are not necessarily provided by the counsellor or the agency. However, care would be incomplete if their needs are not met. Hence, counsellors should liaison extensively with organizations that are providing a range of services in order to refer families whenever necessary. Only then can counsellors ensure holistic care to families and individuals dealing with HIV. The following excerpts detail further the different concerns and requirements families present to the counsellor:

“His children were going to school regularly all these days and now they stopped because we don’t have enough money to support their education”. (Sister of Mr. AN, who lost his eye sight due to a complication related to HIV)

“My major fear is that of my son getting the infection...because people say that children too will get the disease from parents and I don’t think that I’ll be able to survive if anything happens to him...sure that I’ll kill myself...my only hope is that he’s healthy....I am also extremely worried about what would happen to him after I die...who will be looking after him...” (Mrs. S, mother of 3-year-old son)

“The doctors in the government hospital suggested that he could be sent to a home for AIDS patients. We don’t know where he would be going... he also has TB (Tuberculosis)...are there places that would take someone like my brother?” (Brother of Mr. VE)

11.5 FAMILY ASSESSMENT

Family assessment is an essential and integral part of family counselling. A complete assessment of family should be carried out as far as possible and the intervention planned based on the findings of the assessment. Assessment and intervention go hand-in-hand, that is, they are conducted simultaneously. For instance, a family approaches the counsellor with fears about getting infected through everyday casual interactions and they are also concerned about the treatment options. The foremost thing that a counsellor should do here is, assess the level of knowledge, understand their myths and misconceptions and assess what kind of treatment options they are expecting. Then provide them the right information to alleviate their fears and worries, provide them the right information about the treatment options and where such facilities are available with contact information of the concerned centres or persons. Thereafter, either in that session or in the next session, assess the family further for additional information and provide counselling based on that.

Assessment in counselling is as important as intervention and in fact, counsellors should remember that most families gain a lot of insight into their problems during the process of assessment itself. In other words, the assessment serves as intervention in some cases. Hence, counsellors should give adequate time and conduct a comprehensive assessment.

The following components are assessed during preliminary assessment with all families without fail.

- *Knowledge and attitudes* – Gauge the information that the family has about HIV, its symptoms, modes of transmission, prevention, fears of family members, and myths and misconceptions, if any. Similarly, understand the attitudes of family members towards the infection and infected relative. In your interview assess how the family responded to the diagnosis of HIV and risky behaviour of their relative if any;
- *Impact of HIV on the family system* – Assess to what extent HIV effected the family system and the members in the family;
- *Willingness to patient care* – The extent the family members are willing to provide care and compassion to the infected relative has to be assessed. In addition, the following domains need to be assessed in detail whenever families present with complex interaction patterns.

11.5.1 Family Interactions Prior to HIV Diagnosis

Family counsellors without fail should gauge the quality of pre-HIV relationship between the family members. Though not always the case, family members who shared a healthy and cordial relationship among themselves are usually known to be more supportive and caring towards the infected individual and often express their willingness to care and support in case of need. On the other hand, family members who had a pre-existing disturbance in their interactions are likely to complicate their adaptation to HIV infection and HIV infected relative. An illness like HIV/AIDS that carries a definite stigma and life threat can further complicate the situation. Certain experiential accounts and research studies conducted both in the West and India confirm that a pre-existing disturbance in family interactions can complicate the coping process with HIV. The quantum and quality of care provided to the infected individual is often determined to a large extent by the quality of interpersonal relationships in the family prior to the diagnosis of HIV (Bor et al., 1993; D'Cruz, 1998; Bharat, 1996; Bharat et al., 1998; Bharat and Aggleton, 1999 and D'cruz, 2002).

It is often difficult to engage families with pre-existing disturbed interaction in the counselling process. Members in such families tend to focus more on the past conflicts and hurt during counselling. They are more likely to hold patient and his/her lifestyle responsible for HIV infection and thus deny support and care as well as refuse to take part in counselling sessions. Counsellors should acknowledge past conflicts in relationships but make sure that the family members move on and focus on the current situation and future concerns.

The following anecdotes refer to family members who had a strained relationship prior to HIV diagnosis:

“Parents used to have frequent arguments with each other and subsequently, when patient grew up he started making remarks at father that he is useless and was not as smart as mother. This used to annoy father who in turn used to fight back with the patient. Similarly, there used to be several arguments between mother and patient...” (Interactions between Mr. M and his parents)

“He believes that he need not discuss anything with a woman and he used to tell me that I need to worry about cooking and children and that's all.

I tried giving my opinion on a couple of issues like savings and expenses; he never appreciated and always used to shout at me...now I have reached a stage where, I don't expect anything from him. Whatever he wants to do, he'll do...." (Mrs. HV, wife of Mr. SS, seroconcordant couple)

"I had seen my husband pick fights with his parents and brothers.... he used to drink and never earned regularly...He used to trouble me a lot too... I realised that my husband and I are a total mismatch..." (Mrs. SH, wife of Mr. S, serodiscordant couple)

11.5.2 Present Family Interactions

Likewise, the present family interaction patterns need to be assessed as well. Remember that the present interaction patterns are often a reflection of the past interactions and experiences. Family interactions would give a clue to the counsellor about – how the family is going to deal with HIV infection in their relative, how crisis situations would be approached and resolved, and the existing social support to the whole family as well as to the HIV infected individual within the family, and the connectedness or cohesiveness among family members. Counsellors should try and understand the following components in a family that will give a comprehensive picture of the family functioning and will form basis for intervention. The following are essential components of family functioning:

☞ *Alliance and Coalition:* Within the family unit, some members are closer to each other and share a special and unique relationship what is usually referred to as an *alliance* between those members. Sometimes, some members form an alliance against another person in the family. This is referred as a *coalition* against another person. Understanding these kinds of interactions within the family will help the counsellor to be aware of the persons in the family who are strong, controlling, and influential as well as the ones who are weak (if any). Counsellors need to exercise caution as powerful members within the family are capable of interrupting or influencing the counselling process if they perceive the goals of counselling to be against their interests or beliefs. Hence, take power holders in the family into confidence and use them to steer lead and bring positive changes within the family to accomplish what is needed to deal effectively with the crisis situations.

☞ *Role Structure:* Every member in a family unit plays a certain role that is necessary for the functioning of the family. At times, members play multiple roles as well, such as breadwinning along with homemaking. The roles that members play differ from family to family though there are similarities in the roles. HIV infection and the associated opportunistic infections, hospitalizations, disability and death complicate the role structure of the family. Members are forced to take up multiple roles unexpectedly and prematurely. Caregiving role in the context of HIV can be long-term and often results in stress and burden on the family members who assume the caregiver role. Disability and death force aged parents and other healthy family members to take up the responsibility to provide for the family or care for the orphaned children. A change in the role structure affects the homeostasis of the family; counsellors should look for signs of stress and burnout in family members and help them alleviate stress.

☞ *Communication patterns:* Communication pattern in families varies – it varies from family to family and varies between individuals within the family

unit. While understanding communication patterns in a given family, it is essential to know who communicates to whom, how messages are communicated and what is communicated. As we all know, communication is both verbal and non-verbal; direct and indirect. In direct communication pattern, members communicate verbal and non-verbal messages to each other directly while in indirect communication pattern, messages are sent through a third party. Most families have certain restrictions or said/unsaid norms as to what has to be communicated and who communicates to whom; usually referred to as 'boundaries'. In a few households, the father is not approached directly; instead, messages are sent through the mother. A pattern of this kind in itself does not indicate any communication disturbance; however, communication between couples and other grown-up members in a family is usually expected to be direct and face-to-face. Likewise, it is also essential to assess how praise, appreciation, unhappiness, anger, disappointment and other feelings are communicated in a given family.

- ☞ *Adaptive skills:* Adaptive skills or problem solving skills of a family refer to the ability of a family to come up with alternate solutions to deal with a crisis situation. A rule of thumb is that communication and problem solving in a family go hand-in-hand. Usually, both are be disturbed or intact and adequate.
- ☞ *Social support:* Social support by definition is, "the formal and informal relationships and groups through which an individual receives moral cognitive and supports necessary to master stressful experience" (Caplan, 1974). Social support is usually of different kinds. For instance, *Information Support* refers to any kind of information that the family receives, such as information about a new treatment, a hospital, community based facility, a welfare measure and so on. *Material Support* mainly refers to tangible, physical things such as food, clothes, gadgets etc. *Emotional Support* refers to psychological support that the family members receive such as encouragement, soothing words, consolation, a person with whom one can ventilate and feel relieved etc. Families receive social support from the *Primary Support System*, that is the immediate family; from *Secondary Support System*, which often involves relatives, friends and neighbours; or *Tertiary Support System*, which refers to hospitals, clinics, religious institutions, employer and other community based systems. Families receive support from either one or more than one support system. At times, different needs of the family are met by different support systems. Usually, in the context of HIV, family members isolate themselves from the support networks due to the fear of stigma and discrimination. Thus, the family support system weakens and the stress levels of the family members escalate. Several research studies have found high correlates between adequate social support and positive mental health and well-being (Nunes et al. 1995; Grant and Ostrow 1995; Hays et al. 1992).
- ☞ *Cohesiveness:* It is the level of connectedness and we-feeling that family members share with one another. Cohesiveness refers to the forces both positive and negative that hold together a relationship. It is understood from the level of we-feeling and commitment that family members express towards each other. Families express their we-feeling through taking part in shared activities such as family rituals, celebrating festivals together and by being supportive during stressful situations and so on. It is highly essential to assess if the cohesiveness is at a *Social Level*, where family members express their we-feeling and demonstrate their bond for social reasons and can fall apart in case of a crisis situation. *Conseveness at Emotional Level* implies that members are connected to each other emotionally.

11.5.3 Coping patterns of family members

Family members adopt various strategies to cope with the stress of HIV infection in their relative. Some family members embrace active and positive ways to cope with this stress such as seeking help, maintaining a positive attitude, resolving crisis situations through discussions, reading more or knowing more about their situation, and engaging in activities that are soothing like music, reading, praying etc. There are others who deal with stress by denying it, not talking about it, and undermining the gravity of the situation. Some family members even resort to using substances such as alcohol, drugs and smoking etc to deal with the stressful situation. Predominantly, the coping strategies could be classified as cognitive strategies, behavioural strategies and avoidance strategies. Assess the ways in which family members cope with the stress and address them to develop more healthy coping ways during counselling.

11.6 INTERVENTION

Intervention in the context of HIV/AIDS varies from family to family and across the illness trajectory. The unique needs or issues of the family members change across the stage of HIV infection and counsellors should always bear this in mind during counselling (Krishna, 2002). The issues and concerns of the family across the stages of HIV infection and the counsellor interventions vary with the level of infection. As stated earlier, the needs of the families vary and should the counselling that is provided to them. Counsellors should always let families lead, ensure that the family is ready to discuss certain difficult issues related to death and dying etc., and not prematurely discuss such issues as most families assume that death is looming in the corner and their relative might die very soon. The purpose of counselling is to make families self-reliant and not to foster over dependence on the counsellor.

11.6.1 Components of Counsellor Intervention

- *Providing information about HIV/AIDS* – Provide factual information to the family to help them understand the nature of infection, its modes of transmission and prevention. Emphasize on compliance with treatment of opportunistic infections and anti retro-viral treatments if needed. Stress the relevance of changes in lifestyle, in order to live healthy and delay the progression of infection. Correct information alleviates fears of family members and is also essential to bring in change in the attitudes.
- *Providing hope* – People with HIV and their relatives benefit from hope. Instil realistic hope during the counselling process. However, never show undue optimism to the patient or family.
- *Ventilation* – Provide a comfortable counselling environment to help families ventilate their emotions related to anger, fears, disappointment, breach of trust, loss etc. associated with their relative's HIV status. Families have several concerns related to stigma, death and dying; role-reversal and changes in life-style etc. They most often bottle them up and never would have expressed to anyone prior to approaching the counsellor. Hence, recognize the need of family members to talk and express as well.
- *Communication and problem solving skill training* – Encourage family members to rely on open and direct communication among them regarding

the infection or any other important issue. Families benefit when they break the silence and discuss issues related to HIV/AIDS among themselves. Often family members resort to silence or avoid talking about such issues. This pattern only increases the stress levels in the family. In addition, members cannot resolve problems when there is inadequate communication. For problem solving, help families to make a list of problems or concerns and help them prioritise them. Subsequently, encourage family members to discuss, initially in the presence of the counsellor, all possible solutions for each problem and implement a solution that is considered by all as the most viable, and review if the problem is resolved or not. Subsequently encourage family members to engage in such problem solving discussions at home without the counsellor. Reward families for even minor efforts towards positive change.

- *Strengthening social support system* – Help families understand the relevance of support networks in dealing with stressful life situations. Encourage family members to identify safe networks in their circle of relatives, friends and neighbours to whom they can disclose and whose help they can solicit in case of need. Encourage families to come up with their own ways of disclosing to others and never force them to disclose HIV status to others when they are not ready. However, always caution families about inadvertent ways others get to know about the HIV status of a member in a family through common friends, doctors or known nursing or other support staff working in hospitals and clinics.

Similarly, family members need to recognize the need for staying in contact with various government and non-governmental organizations for HIV/AIDS related services and self-help groups. These organizations and groups would be of immense help to families when they are dealing with crisis situations. Also, the families and HIV infected individuals would start to feel confident when they are meeting other families and individuals who are in a similar or worse situation than theirs.

- *Improve coping skills of the family members* – Involving actively in the care and staying in touch with HIV/AIDS care services in the community itself is one of the positive coping strategies. Discuss the relevance of positive coping with family members – maintaining hope, seeking information are all examples of positive coping. Encourage family members to continue pleasurable or recreational activities if they have been engaging in them. Often, caregivers, especially during symptomatic HIV stage, give up their routine pleasurable activities to take care of their relative. Caregivers should be cautioned about the likelihood of burnout due to that. Hence, motivate family members to continue with their previous pleasurable/recreational activities atleast to some extent without feeling guilty. Talk to families that simple activities such as watching their favourite TV show, reading a book, listening to music, praying, writing etc. can have positive impact on their mental health as well as their caregiving, and inspire members to think of ways in which they can cope better with their situation. Some family members might adopt other strategies such as denial or use of substances etc. to deal with their stress. Such coping ways would give momentary relief from stress, but would not contribute to problem solving. Referrals should be made to specialists whenever the counsellor feels that the family members would require more than counselling to deal with their problems.

- *Liaison and Referral* – Liaison with other treatment centres, clinicians, counsellors, governmental and non-governmental organizations specialised in offering services to people living with HIV/AIDS and their family members is highly essential when offering counselling in the context of HIV. Given that HIV care cannot be done in isolation and that there are several bio-psycho-social issues involved in the management of HIV and related issues, counsellors should always maintain a network of professionals and services meant for this issue. Stay active within the network and let others know what services you/your organization offers and explore the specialised services others have to offer that can be used by your clients and families.

While most families would benefit from counselling to deal with issues related to HIV/AIDS, some families might require an intensive and specialised service of a mental health professional or a trained psychotherapist. Always make timely and quick referrals to a specialist or at least discuss with a specialist the nature of the problem and get inputs to manage the problem.

11.6.2 Unique Family Counselling Issues

There are certain counselling issues that are very unique to HIV and normally, counsellors dealing with non-HIV conditions are less likely to encounter them. The following are some of those issues:

- *Venue of counselling sessions* : In a traditional counselling or therapy situation, the client and family visits the counsellor/therapist in their respective clinics or organizations. Families who fail to do this are often termed as ‘resistant’ to intervention. Counsellors need to exercise caution before concluding a family or individual as resistant due to the unpredictable and complex nature of the HIV infection. Suddenly, the patient’s symptoms could have worsened and he/she may have been admitted in the hospital or may have had to attend another important appointment for investigations etc. Infact, it is recommended that counsellors be flexible with regard to the venue where families are seen and sessions are held, rather than insisting that sessions be conducted only in their respective offices or clinics. It is reported that sessions could be conducted in various settings such as general hospitals, hospices, patients’ home and other rehabilitation centres (Serovich and Mosack, 2000; Krishna 2002).
- *Counsellor versus Physician* : In a conventional family intervention scenario, the family counsellor/therapist joins the family by building adequate rapport and eventually, the counsellor/therapist will be identified as one of the family members by the family. However, in the case of HIV, it is more likely that the physician is identified as a family member due to the very nature of HIV infection and frequent opportunistic infections and treatment for the same. Counsellors should be careful not to conclude any such inclinations as their unwillingness for counselling or family therapy intervention.
- *Ongoing Intervention* : Family intervention in the context of HIV is ongoing and does not end with the death of index patient (Krishna 2002). Usually, there may be other infected individuals; for instance, the spouse may be still living and may need help in dealing with her infection and future. If not, families need counselling during bereavement period to deal with grief and loss. If the deceased had children, then families often require assistance to deal with childcare, education etc. In some instances, children manifest certain

emotional problems following the death of their parent/s, and may who require counselling or mental health intervention. Hence, family counselling in HIV is an ongoing process.

11.7 LET US SUM UP

With the advancement in the management of opportunistic infections and the anti retro-viral treatments, people with HIV live longer and healthier. This means, caregiving is a long-term issue as well. Individuals and families benefit immensely with counselling and hence, counselling and family therapy constitute an essential component of care in HIV. Counsellors and therapists however, should remember that each individual and family is different, and hence, the issues they perceive as stressful and present to the counsellors, are different as well. Therefore, it is highly recommended that the counselling intervention should be adaptive in nature; that is tailored and contextualised as per individual needs. The content of this Unit is aimed to give an overview of the impact of HIV on the family system and the possible intervention that may be carried out to help them. Counsellors should keep in mind that the goal of counselling is to make individuals and families to make them more self-reliant and not overly dependent. Given that every family and individual has potentials, counsellors should encourage families to realise and use them to the fullest.

11.8 ANSWERS TO CHECK YOUR PROGRESS EXERCISES

Check Your Progress Exercise 1

1.
 - a) Helplessness
 - b) Stigma and discrimination
 - c) Disclosure
 - d) Burden of caregiving
 - e) Economic burden
 - f) Fear of falling sick and dying

11.9 UNIT END QUESTIONS

1. Explain the role of counsellor in helping family members of HIV patients.
2. Discuss the impact of HIV/AIDS on the person and the family members.

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UNIT 12 DEALING WITH SUBSTANCE ABUSE

Structure

- 12.1 Introduction
- 12.2 Assessment of Substance Use Disorders
 - 12.2.1 Clinical Interview and History Taking
 - 12.2.2 Examination
 - 12.2.3 Use of Structured Tools for Assessment
- 12.3 Treatment of Substance Use Disorders: Principles and Overview
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- 12.4 Psychosocial Approaches for Treatment
 - 12.4.1 Motivation Enhancement
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- 12.7 Answers to Check Your Progress Exercises
- 12.8 Unit End Questions
- 12.9 Further Readings and References

12.1 INTRODUCTION

The commonest terms that one associates with drug use are “Drug Addiction” and “Drug Addict.” These terms however have fallen to disrepute because of their pejorative and derogatory implications, and new terms like “Substance Use Disorder(s)” and “Substance User(s)” have taken their place. Debate rages on whether to refer to substance users as “patients” or as “clients”, reflecting the dichotomous understanding of substance use as a medical illness or as a psychosocial behavioural problem. Perhaps both the viewpoints merit credit and reflect the interplay of complex factors which results in these drug problems.

Additionally, there is no single, precise definition of the word “Drug”. Its meaning changes from time to time (Cocaine, now a drug was once a constituent of a popular soft drink! and as per the current understanding of a potential for harm which can be caused by a substance (by many definitions coffee and tea, because of their psychoactive properties, will be considered a drug). New substances of use are constantly coming in vogue (inhalant abuse, which was

Assessment however is not a one-time phenomenon. Generally it is done in the beginning to define the problem and formulate a treatment plan. It also needs to be repeated during treatment to monitor progress, and even after treatment to assess maintenance of abstinence status. In this section we look into various methods of assessment.

12.2.1 Clinical Interview and History Taking

Clinical interview and history taking is a process/skill where the objective is to gather relevant and correct information quickly about various aspects of the problem. Therefore the interview should neither be a social chitchat nor a rigid checklist tally. Rather, interview should begin by asking open-ended questions. This should be followed by the guiding questions to steer the conversation in meaningful direction. In light of the above, the guidelines given below are meant to highlight important aspects of drug use, which are necessary for management.

Table 12.1: Examples of Open Ended and Closed Questions

<i>Open ended Questions</i>	<i>Closed Questions</i>
What brings you here?	Do you want to stop drinking?
Could you tell me a little bit about your marriage?	Do you often quarrel with your wife?
How did you feel as a child?	Did you feel left out as a child?
Tell me about your drinking pattern?	Do you drink excessively?

Guidelines for taking history in a substance user:

1. Allow the patient to settle down, and ask about his socio-demographic profile i.e. name, age, sex, marital status, qualification, occupation, type of family and place of residence.
2. Details of drug use are then inquired into. This includes:
 - a) age of initiation
 - b) various drugs used
 - c) frequency of use of those drugs
 - d) quantity of drug taken usually (usual dose)
 - e) time lag since the dose last used
 - f) If the patient has needed to increase the quantity of drug consumed in order to produce the same effect (tolerance)
 - g) If the patient has experienced any symptoms of intoxication
 - h) symptoms and signs when the particular drug is not taken or taken in reduced amounts (withdrawals), and
 - i) if patient feels compelling need/ urge to take the substance (craving)

12.2.2 Examination

A detailed clinical examination is best left to the clinician. However commonsense examination for routes of drug use; as evidenced by burn marks / nicotine stains on fingers in cigarette use and heroin by inhalational route; injection marks in case of injection drug use (IDU); may help to corroborate history. Similarly, a detailed mental status examination is best conducted by a trained professional but the counsellor should enquire about the mood state of a patient (whether feeling low, depressed, anxious, angry, suicidal) and any abnormality reported. It is more important to assess the motivational stage of the patient. Motivation is simply the will to change (or maintain the changed behaviour). For the purpose of substance use the most influential model of change has been the “transtheoretical model of Prochaska and DiClemente” (1984). This model states that motivation is dynamic, fluctuating and cyclical in that patient progresses from one stage of change to the next. The stages proposed are pre-contemplation, contemplation, preparation, action and maintenance along with the issue of relapse or recurrence.

Essentially during pre-contemplation, individuals ‘do not feel impelled to do anything’ about their behaviour, perhaps as a result of denial or selective exposure to information. As they become ‘aware of existence of a problem’, they enter the contemplation stage, which is characterized by conflict and dissonance. Preparation is defined as a time when the individual drug user ‘formulates action plans and is serious about his or her intention to alter behaviour’. Action is a period when ‘overt changes are made’, after which successful individuals enter the maintenance stage when ‘new behaviours are strengthened and consolidated’. The individual who does not relapse during this stage eventually exits the change system to termination, or in other words favourable long-term outcome. Most people do not immediately sustain the new changes they are attempting to make, and a return to substance use occurs known as relapse. These stages follow a cyclical pattern in that people may move back from action to contemplation and pre-contemplation before eventually achieving long-term resolution of the problem. One of the essential purposes of counselling is to enhance the motivation of the patient to move further along the continuum of pre-contemplation to maintenance.

Additionally laboratory assessment to confirm, corroborate drug use and to find the physical complications may be done in specialized treatment centers.

12.2.3 Use of Structured Tools for Assessment

Structured tools are questionnaires and scales that have been specifically developed to measure some aspect of substance use. They offer the advantage of being brief, easy and rapid to administer, and their results can be objectified and compared. However they are limited in their scope, and can augment but not replace the clinical interview.

- **Screening**

Screening is usually applied to a large group of individuals and is very brief by nature. It is usually applicable in those settings where the individuals are encountered for problems that may not appear to be related to substance use, yet the association of the problem with substance use may be strong. Such settings may include a general medical setup, community clinic, and ante-natal checkup or in a legal setup (e.g. prison wards, individuals caught for drunken driving).

check and no prior training is required for administration. The Readiness To Change Questionnaire Treatment Version (RTCQ-TV) is a modification of the RTQC with three additional items and is used to assess motivation in persons under treatment.

Check Your Progress Exercise 1

Note: a) Read the following questions carefully and answer in the space provided below.

b) Check your answers with those provided at the end of this Unit.

1. Which of the following is not a part of CAGE questionnaire?
 - a) Have you ever felt that you should Cut down on your drinking?
 - b) Do you spend a lot of money on Alcohol?
 - c) Have you ever, felt bad or Guilty about your drinking?
 - d) Have you ever, had a drink first thing in the morning to steady your nerves or get rid of a hangover (i.e. drink as an Eye-opener)?
2. Which of the following is an example of an open ended question?
 - a) Do you often quarrel with your wife over your Alcohol use?
 - b) Is drinking the only thing which helps you sleep?
 - c) How do you feel on the day when you do not drink?
 - d) Has your boss threatened you about loss of job, if you continue drinking?
3. The correct sequence of stages of change is
 - a) Pre-contemplation, contemplation, preparation, action and maintenance
 - b) Preparation, pre-contemplation, contemplation, action and maintenance
 - c) Action, preparation, pre-contemplation, contemplation and maintenance
 - d) Preparation, action, pre-contemplation, contemplation and maintenance

12.3 TREATMENT OF SUBSTANCE USE DISORDERS: PRINCIPLES AND OVERVIEW

More than medicines and techniques of psychotherapies, the successful treatment of substance users requires understanding of the illness, empathy for the user and patience on part of the counsellor. Substance Use Disorders require long term treatment and users generally go through a period of being in and out of drugs (which may span years) before finally leaving. Establishing good rapport with the user helps them stay in treatment, which has been shown by research as the single most important predictor for successful outcome.

and re-integration with family. Long-term goals consist of prevention of relapse, re-integration into the society, occupational rehabilitation and improvement in overall quality of life.

Treatment Goals:

- Abstinence
- Harm minimization
- Improvement of health, social, occupational functioning
- Improved quality of life

12.3.3 Phases of Treatment

Comprehensive treatment of drug abuse comprises of initial, middle and late phases. In the pretreatment period acceptance of the problem by the patient occurs and the patient prepares himself for treatment. The peer group and family members play a significant role. The initial phase is of detoxification, which usually lasts for 2-4 weeks. Here efforts are made to free the person of all intoxicants, treat the symptoms of withdrawal (stopping the drugs) and attend to the immediate medical consequences of drug abuse. The middle phase is aimed at maintaining a drug free status (relapse prevention) and initiates the process of reintegration into the society. It may last for 3-6 months. During the late phase, adoption of a healthy life style and alternate coping strategies are promoted. Usually treatment is multimodal, which includes pharmacological and non-pharmacological treatment approaches.

Treatment Phases

Initial	2 to 4 weeks
Middle Phase	3 to 6 months
Late Phase	> 6 months

12.3.4 Treatment Modalities

Certain basic principles of management are common, irrespective of the nature of substance being abused. Broadly speaking, there are two modalities: pharmacotherapy and psychosocial interventions.

Goals of pharmacotherapy are

- reversal of acute effects (intoxication and overdose),
- amelioration of withdrawal symptoms,
- decline of craving,
- prevention of relapse
- restoration of normal physiological functions.

Currently, various pharmacological agents are available for the above purposes.

Various domains of outcome of substance use treatment are as follows:

12. Abstinence
2. Employment
3. Decrease in Crime
4. Stability in housing
5. Service capacity
6. Retention to treatment
7. Social support
8. Perception of care
9. Cost effectiveness
10. Evidence based practice

Check Your Progress Exercise 2

Note: a) Read the following questions carefully and answer in the space provided below.

b) Check your answers with those provided at the end of this Unit.

1. Effective treatment of substance use disorder involves
 - a. Only short term detoxification of a few weeks
 - b. Both short term detoxification and a long term maintenance of years
 - c. A long term therapy with drugs
 - d. Psychotherapy only
2. The goal of treatment is to
 - a. Harm reduction
 - b. Complete abstinence from any substance use
 - c. Prevention of further complication
 - d. Varies according to the type of treatment and the patient's condition
3. Outcome of SUD is best when
 - a. Only pharmacotherapy is given
 - b. Pharmacotherapy and psychotherapy is given
 - c. Only psychotherapy is given
 - d. Social interventions are added to the above types of therapy
4. Single most important factor for outcome of SUD
 - a. Duration of substance use
 - b. Type of substance used
 - c. Retention to treatment
 - d. Type of treatment used

- Express concern. “It indeed is a worrying thought that if you continue to drink this way, you may lose your job as well as respect of your own family.”
- Keep the door open, i.e., do not terminate a session on a negative, pessimistic note. “Well, today you do not appear in a mood to take this conversation further. But I am sure we will have another opportunity to discuss your drinking issues very soon. Should you feel like discussing them, you are always welcome.”

The specific approaches in the motivation enhancement may differ depending upon the stage-of-change the patient is currently in. Let us take a look at the same.

Contemplation phase: Here the major goal of the counsellor is to help the patient decide. Therefore normalize ambivalence; help the patient tip the decisional balance scale towards change by eliciting and weighing pros and cons of substance use and change (“Can you imagine your life five years down the line in both situations: if you continue to drink and if you stop drinking?”). Examine the patient’s personal values in relation to change. Emphasize the choice of responsibility (“Only you can change yourself, no one else can”) and self-efficacy (“Yes, with our help, you can certainly change yourself. You have it in you”). Elicit self-motivational statements of intent and commitment. Elicit ideas regarding perceived self-efficacy and expectations towards treatment. Summarize self-motivational statements.

Preparation phase: Clarify the patient’s own goal and strategies for change. Offer a menu of options. With permission, offer advice. Negotiate a change or treatment plan and behaviour contract. Help the patient enlist social support. Explore treatment expectancies and the patient’s role. Elicit what has worked in the past for him or others whom he knows. Assist the patient to negotiate finances, childcare, work or other barriers. Have the person publicly announce plans to change.

Action phase: Engage the patient in treatment and reinforce the importance of remaining in recovery. Support a realistic view of change through small steps. Acknowledge difficulties for the person in early stages of change. Help in identifying high-risk situation and develop appropriate coping strategies to overcome them. Assist in finding new reinforcers of the change. Assess if the person has strong family and social support and help in building them.

Maintenance phase: Help in identifying and trying drug free sources of pleasure. Support life style change. Affirm person’s resolve and self-efficacy. Assist the person in practicing the use of new coping strategies to avoid return to drug use. Maintain supportive contact. Develop a ‘fire-escape’ plan if the patient resumes substance use.

Motivational enhancement is a client centered directive therapeutic style to resolve ambivalence and promote greater commitment to change.

12.4.2 Brief Intervention

As described in the earlier section, not all substance users are dependent users. Indeed most problem-users do not fall in the category of dependence, but in the categories of abuse or harmful use. There is evidence that many of the harmful

using friends on the street, who welcomed him heartily and offered him a puff. His protest was soon drowned by their repeated suggestion and he took the heroin filled cigarette which felt even better than before. Next morning however he was remorseful. He thought that what people said about him was right, “Once a drug user, always a drug user.” He decided to continue smack use.

Substance use is best seen as a chronic, relapsing condition. Almost 60 – 80% of patients after treatment, relapse i.e. start using substances again within one year. Thus, prevention of relapse is an important issue in the treatment of addictive behaviours. Relapse prevention is a generic term for a variety of approaches to the treatment of drug and alcohol abuse, primarily aimed at those in the maintenance stage of change. However, it must be remembered that just a single instance of using substance after achieving abstinence does not mean relapse. Most experts would term an occasional slip as ‘lapse’ while ‘relapse’ is a return to the original pattern of intake (just before treatment). Researchers have found that relapse is more likely in individuals who had few coping resources and who have encountered a relatively large number of risk situations. The following illustration makes it simpler to understand the factors affecting abstinence, lapse and relapse.

Relapse prevention is a set of techniques broadly derived from social learning theory. In this programme, individuals are first taught to recognize that the possibility of relapse is real and hence to plan it out, rather than to suppress it as feared failure. Essentially the client receives training in specific coping strategies. These can include broad-based skills training like behavioural rehearsal (what to do in a party?), assertiveness training (how to say ‘no’ to a friend) or change in ways of thinking (relapse means need to come back to treatment and not to despair) and lifestyle interventions (relaxation and physical exercises). Clients are taught to recognize early warning signals and made aware of apparently irrelevant decisions that can increase the possibility of relapse. Emphasis is placed on the modification of faulty beliefs or dysfunctional assumptions. All throughout the client is encouraged to practice these strategies using rehearsal, role-play and homework tasks.

A **coping skill** is a behavioural tool which may be used by individuals to overcome adversity or disability without correcting or eliminating the underlying condition. There are two primary styles of coping with stress.

Emotion-based coping skills reduce the symptoms of stress without addressing the source of the stress. There are both positive and negative coping strategies that can be defined as emotion-based. Emotion-based coping can be useful to reduce stress to a manageable level, enabling action-based coping, or when the source of stress cannot be addressed directly:

- Relaxation strategies (breathing, meditation etc)
- Reappraisal (what is still good and what could have been worse)
- Humour (making joke, taking things lightly)
- Distraction (watching movie, playing, sleeping)
- Discussing the stress with a friend
- Denial, Repression, Wishful thinking (negative emotional coping, but temporarily helping to manage the problem)

stigmatized for leading an unhealthy sedentary life, why should substance-users be admonished for their novelty seeking lifestyle? Another important quality is possession of good communication skills. It must be remembered that communication entails not just talking but active listening too. Communication occurs at both verbal and non-verbal level and certain non-verbal gestures can go a long way in establishing rapport. Greeting the client in a culturally appropriate manner, offering a chair shows a warm counsellor and opens up the interview. Leaning forward, looking into the eyes communicate interest. Nodding, gesturing in between, while the client is speaking shows attention without breaking the flow of the client's thought. Finally summing up a history shows that the counsellor has understood the client's perspective. Sometimes patients ask "How can you understand, what I am going through without being in my position?" Modern mental health-care approaches are based on the belief that it is not necessary to have other people's literal experience to understand them. The shared experience of being human is often sufficient. Such ability of the counsellor to understand the mental state of the client without being affected by it is called empathy. The attitude of the counsellor should be logical and informative. A paternalistic and dominating attitude becomes a hindrance to development of rapport as drug users associate the counsellor to other authority figures they have come across. Similarly the counsellor should also constantly be on his guard to prevent his own personal life experience cloud the current objectivity. The counsellor should be pragmatic and compassionate and should show knowledge and authority on the subject to gain confidence of the client. Indeed patients often draw comfort from the fact that the counsellor has not been mystified by their condition. The counsellor should always instill hope and reinforce that quitting is possible. This apparently easy point becomes difficult as time progresses and counsellor suffers from "burn out". Then it is very easy to give up on the patient. A "hopeless" counsellor undermines the confidence of the patient and his motivation to quit. It is helpful to remember at such times that change always occurs slowly and in small steps. Setting onto oneself miraculous tasks are generally counterproductive. Lastly the counsellor should be able to exercise the golden virtue of patience, as substance use disorders often require long-term treatment. To summarize, the skills a counsellor should have is given in the Table 12.5.

Table 12.2: Qualities of a Counsellor

<i>Should Have</i>	<i>Should Avoid</i>
• Objectivity	• Bias (religious, moral)
• Trust worthiness	• Ambiguity
• Non intrusiveness	• Authoritation attitude
• Sensitivity	• Insensitivity
• Respect for confidentiality	• Boundary violation
• Empathy	• Impatience
• Knowledge	• Judgemental view

fewer women use substances than men, however, it may also be the case that very few women substance users come forward for help and hence substance use among women remains a hidden phenomenon. This is because substance use by women is much stigmatized by the society as compared to substance use by men. Indian studies have found that the patterns of substance use among women vary across the country but some common themes appear to be an early age of onset, use in the context of a heterosexual relationship, marital and sexual abuse, greater emotional problems and poor social support. Women are more vulnerable to the adverse physical consequences of substance use than men. Studies suggest that women experience greater medical, physiological and psychological impairment earlier in their drinking career. In addition, women seem to progress between landmarks associated with the developmental course of alcoholism (e.g. regular drinking or loss of control) sooner than men (commonly referred to as “telescoping”). Important issues to consider in dealing with women substance users are those related to reproductive health. Substance use makes women vulnerable to various reproductive health problems including reduction in fertility. Consumption of alcohol and other drugs by pregnant women also results in abnormalities in the unborn child. Foetal alcohol syndrome (FAS) has been identified as one of the leading cause of mental retardation in the western world. Yet another problem faced by women substance users is enhanced vulnerability to physical and sexual abuse. While dealing with women substance users, counsellor needs to be aware of these issues.

Another group of substance users who are a cause of concern are minors and adolescents. Though adolescents constitute a very small proportion among the patients seeking treatment for substance use in the clinics, various studies have found that adolescence is the period when most substance users initiate their drug using careers. Thus adolescence is typically a period of experimentation with substances and initiation of substance use and NOT usually the period when treatment is sought for substance use problems. Still increasingly substance use by minors and adolescents is being noticed in the clinical population. Among the adolescent substance users, the favourite substances are tobacco and alcohol; some even report using cannabis and heroin. However, a sharp increase in the use of inhalants (solvents like eraser fluid, paint thinners, petroleum products etc.) has been found in the recent years. This rise in the use of inhalants has been noticed among both – school students as well as street children. Drug abuse among minors is a cause of concern because use in this age group is associated with increased risk of accidents, violence and high-risk sexual behaviour. Behavioural characteristics like impulsivity, aggression, sensation seeking, low harm avoidance, inability to delay gratification, low achievement striving and lack of religiosity have been postulated as cause of taking up drugs. Familial factors like stressful life events, deficient parental support or supervision, poor discipline, ambiguous parental attitude towards substance use, parental and sibling substance use also contribute. Co-morbid psychiatric disorders have been found to be more common in adolescents who have substance use disorder. The intervention in substance using adolescents remains a challenge, as it requires involvement of parents as well as teachers. The family needs to be counselled about nature of treatment and the process of recovery. Other challenging issue in this population is related to confidentiality. Adolescent substance users may request the counsellor to keep information about their substance use confidential from their families, while the counsellor may be keen to involve families in the treatment.

children, which would otherwise not have happened) thereby ultimately causing suffering to the whole unit. In family therapy the whole family is helped to stabilize. One generally starts by working with the most motivated family member or members, convening other family members as needed. The problem is defined and a contract is negotiated. The crisis faced by family members when they go through the change is managed and help given to members in need. Roles of family members are defined and they are counselled about their own behaviour patterns. Thus the family unit is helped to achieve closeness, intimacy and a substance free life which they otherwise lacked.

In marital and couples therapy the spouses are taken as a unit and helped to tide over the problem behaviour of drug use in one of its members.

Before concluding however it must be emphasized that in real life, counselling is often a judicious mix of various therapy styles depending on the need and resources of the patient (the eclectic approach) and the counsellor should be able to exercise “presence of mind” and “common sense” to shift from one style of counselling to another depending on the need of the hour.

Check Your Progress Exercise 3

Note: a) Read the following questions carefully and answer in the space provided below.

b) Check your answers with those provided at the end of this Unit.

1. An alcoholic after treatment quit drinking for 6 months. He went to a party and upon insistence of the hosts had a beer. Which of the following is correct?
 - a) All his efforts to stay away from alcohol have failed.
 - b) This is an example of lapse and this person is definitely going to relapse.
 - c) Teaching this patient how to cope with social pressure may help him.
 - d) A dependent person, even after treatment cannot stay away from alcohol for more than six months.
2. Which of the following statements about counselling is NOT correct:
 - a) A counsellor should behave like a friend or a family member of the client.
 - b) A counsellor must have a non-judgmental attitude.
 - c) Listening is as important as saying during counselling process.
 - d) A counsellor should try to instill hope in the client.
3. A counsellor discovers that a male client is HIV positive, but has not disclosed this to his wife. What should the counsellor do?
 - a) Inform the wife irrespective of client's wishes since she is at risk of getting HIV infection.
 - b) Take legal / police help so that police can inform the wife.
 - c) Meet wife separately and ask her to divorce the client.
 - d) Encourage and motivate the client to disclose.

12.7 ANSWERS TO CHECK YOUR PROGRESS EXERCISES

Check Your Progress Exercise 1

1-b, 2-c, 3-a

Check Your Progress Exercise 2

1-b, 2-d, 3-d, 4-c

Check Your Progress Exercise 3

1-c, 2-a, 3-d

12.8 UNIT END QUESTIONS

12. Enumerate six common substances of use listed by WHO in the context of Substance Use Disorders.
2. Discuss the environmental causes of substance abuse and dependence.
3. Analyse the harmful consequences of substance use.
4. Outline the significance of motivation enhancement in treatment of Substance Use Disorders.
5. What role can a Counsellor/Family Therapist play in the prevention and treatment of Substance Use Disorders?

12.9 FURTHER READINGS AND REFERENCES

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UNIT 13 WORKING WITH SUBSTANCE DISORDER FAMILIES

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- 13.9 Let Us Sum Up
- 13.10 Answers to Check Your Progress Exercises
- 13.11 Unit End Questions
- 13.12 Further Readings and References

13.1 INTRODUCTION

Families having a person suffering from substance abuse are vulnerable to harm. The individual with the substance use problems is often seen as the main victim and the focus of counselling is limited to the affected person. We should remember that the other family members; be it the spouse, children or the parents, are also affected but may often hide their own problems. All this adds to dysfunction and unhealthy family interactions at home. Counselling should be directed to at other family members (including children) as well, to enhance their own individual well being, and at the same time equip them to manage future problems that may be experienced by the person recovering from addiction.

After studying this Unit, you will be able to:

Understand why there is a need for families be included in intervention such as counselling for substance abuse;

Explain the problems faced by families (including children) having a family member with substance abuse;

Appreciate the role of protective factors within families;

List the issues and problems faced by recovering persons; and

Describe the purpose of counselling for families, the objectives and intervention.

13.2 THE NEED FOR FAMILIES TO BE INCLUDED IN INTERVENTION FOR SUBSTANCE ABUSE

Families living with a person with a substance use disorder face many problems. We should remember that substance abuse is characterized as family illness and overall family dysfunction, including behaviour problems in family members, are common. Unfortunately, spouses and children (or parents in some cases) of the substance abuser's family are often silent viewing the substance use disorder as a shameful secret. Financial difficulties and indebtedness furthers their distress — this is worse for families coming from low socio-economic backgrounds.

Many studies reveal that children having a father with the substance abuse problem are at a higher risk. They could develop substance abuse at an earlier age and male children are found to be more vulnerable and have a four - fold risk (Schuckit, 1994; Goodwin, 1988; and Winokur et al, 1970). Negative family influences add to the children's risk of developing behavioural and emotional problems.

Counselling Issues in Addiction Treatment

Counsellors working in the field of addiction could often neglect family members and counselling is usually directed at the person with substance problems. Families are involved at the most to engage in the addicted parent's recovery (Wolin, 1991). The needs of the family members, especially the children's is in danger of being ignored. Remember, besides helping the person with addiction problems, counsellors are ideally positioned to also identify, screen as well as prevent future problems in children and their families.

Check Your Progress Exercise 1

Note: a) Read the following questions carefully and answer in the space provided.

b) Check your answers with those provided at the end of this Unit.

1. Families having a member with substance related problems are more likely to face.

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2. Children having a father with substance abuse have a higher risk of developing.

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3. Counsellors working in the field of addiction can help families of substance users to —

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Note: Throughout this Unit, the ‘addicted person/ parent’ is referred to as the father and the ‘non - drinking substance using spouse/ parent’, the mother. This is purely for maintaining a uniform term while writing.

13.3 PROBLEMS FACED BY FAMILIES (INCLUDING CHILDREN) HAVING A FAMILY MEMBER WITH SUBSTANCE ABUSE

Substance abuse related problems in a family member (especially a parent) can affect family structure and functioning. The impact on the family is discussed below.

13.3.1 How are Families Affected?

A. *Overall family functioning* can be unhealthy

- *Leadership* is ‘stop-gap’. This is normally the case when the father who was previously the leader, now currently facing substance abuse related problems is ineffective to continue this task. This void or gap may be filled by another member who is unprepared to shoulder responsibilities (usually

spouse or eldest child). *Poor problem solving abilities* in both parents and others in the family can worsen the situation. Some may make conscious attempts (especially children) to distance themselves from various problems arising at home.

- *Communication between family members is disrupted.* The person with the substance problem may refuse to talk about it and the spouse may be reluctant to confront the issue or discuss it with the children. In some cases, important issues related to daily life are often ignored and substance abuse related issues may dominate all conversation.
- *Reinforcement* of what is appropriate behaviour or what is not; or disciplining children (usually punishment or coercion) may lack clarity and established boundaries of what is expected behaviour or norm may be vague. The non-drinking parent (often the mother) may simply have less time or emotional resources to discipline the children.
- *Support systems* for the family are often inadequate. This may occur as the family tends to become isolated, choosing to avoid social activities out of fear or embarrassment caused by the unpredictable behaviour of the drinker. Also, the stigma associated with substance abuse problems may prevent the spouse and children from discussing it with relatives or friends, leaving the family to face the problems alone.
- *Roles:* There is role strain in the family. The addicted spouse is often burdened as there is a strain on her role due to multiple tasks (as the substance abuse dependant parent becomes gradually dysfunctional). Juggling with daily chores, making rules, taking decisions and dealing with increasing financial problems are some of the challenges.
- *Cohesion* – Emotional bonding and family rituals (recreation, spending time together at home, attending family functions, and celebrating festivals) may lessen due to the disruptive behaviour of the drinker. This may weaken ties and even mutual trust amongst them. *Common family goals* may be absent, each family member may be highly individualistic and poor communication may worsen the situation.

Alcohol and the family

Ranjan has serious alcohol problems since the past 3 years. He has been unable to go to work because of this. One evening, his son puts on the television at home. Ranjan slaps his son saying the noise is disturbing him. The child starts crying. At the same time Sumana his wife reads a letter she found from Ranjan's office saying he is unfit to work due to poor attendance and frequent arguments with his colleagues. She is shocked and shows her anger on the child and shouts at him. She is scared and confused about the situation at home and feels she has no one to talk to. The family goes to bed without dinner that night. She soon avoids attending family functions to avoid questions from relatives about why her husband has stopped working.

B. Co-dependency – As the substance abuse problem escalates and intensifies over time, the family tries to deal with each new crisis resulting in their lives becoming as dysfunctional as the addicted family member. The addict or the 'dependent' may be protected by the 'enabler' i.e. family members who deny the problem and at the same time try to control the situation. Here, the families'

attempt to maintain an equilibrium or balance in their lives (also referred to as homeostasis).

Check Your Progress Exercise 2

Note: a) Read the following questions carefully and answer in the space provided.

b) Check your answers with those provided at the end of this Unit.

- 1) In case of substance abuse, family functioning is affected in areas such as –

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- 2) 'Co-dependency' means –

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C. *Violence* – The family members, especially the spouse of the drinker are exposed to high levels of violence. Many of the perpetrators are usually found to be under the influence of substance abuse prior to the assault. Children witnessing these scenes may be left with emotional scars.

Alcohol and violence at home

Mohan always gets argumentative at home after drinking. When he asks his wife for money to buy a bottle of whisky she refuses. This makes him angrier and he starts shouting at his wife. When he once pushed her against the wall, her head was injured and she had to be rushed to the hospital. His eldest son even locked up Mohan in a room throughout the night as he started shouting and throwing the plates. Now his wife is too tired to ask Mohan to stop drinking but she cannot stop worrying about the future of her children.

D. *Non-drinking spouse's problems:*

- Some parents (as mothers) may be prone to neglecting their children – this could result in emotional distancing. Poor school performance and early acts of deviant behaviour in children are common. The older child or an only child faced with greater responsibilities may be more vulnerable to psychological damages.
- The more serious the alcohol or any other substance abuse problem in the person, the spouse may be less able to perform competently the various roles and responsibilities. Many spouses may have psychological problems such as depression, anxiety, low esteem including disturbed sleep and appetite – they may also require help.

- The spouse may be vulnerable to drinking problems herself. Sometimes, the drinking may be used as a coping mechanism or as a misguided exercise to control her spouse's drinking. Remember, self-medication and misuse of tranquilizers are both common and harmful.

Check Your Progress Exercise 3

Note: a) Read the following questions carefully and answer in the space provided.

b) Check your answers with those provided at the end of this Unit.

1) The non-drinking spouse may also face problems like –

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2) Coping by spouses may be through unhealthy means like –

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13.3.2 How are children affected?

The love and trust of caring adults is important for the children's development of a healthy personality. Unfortunately, this may be threatened for children living in homes with a substance abusing parent.

- A. *Parental conflicts:* Witnessing parental conflicts (even non-violent ones), separation, divorce, loss of a parent and ambivalent parenting; inconsistent child care and low parent-child intimacy are some factors that tend to increase the likelihood of children of substance abusers experiencing continuous problems. This may occur at the time when children mostly need a stable home.
- B. *Three unwritten laws of 'don't talk, don't trust, and don't feel'* Black, 1985 reigns in their homes. Here, the children do not share or talk freely about the chaos at home; the parents' broken promises lead to greater distrust towards other individuals; there is also a loss of 'feeling words' to describe their emotions. If emotions are expressed, they are often met with reprimand, hostility or rejection. These suppressed feelings of children increase their vulnerability to behavioural and emotional problems. They also have the risk of early use of substance abuse or other substances.

'Don't trust'

George and his family are going to the Mysore Zoo. George's father goes out to get a taxi. On the way he passes a bar and returns home much later after drinking. The mother is upset and George is disappointed. His father has broken his promise of an outing. He wonders: Can I trust my father? Do all adults behave in this way?

- C. *Emotional and behavioural problems:* Some of the problems experienced by children of alcoholics (COAs) reported in an Indian study are summarized below in the box (Shah & Vasi, 2002):

Problems Experienced By Children of Alcoholics

- Lack of positive role models, witnessing repetitive negative behaviour
- Difficulty in forming, sustaining relationships by adult children of substance abuseics
- Loss of self-esteem due to dual messages, negative feedback
- Lying to protect family dignity
- Witnessing constant fights, violence at home
- Depression, anxiety and ‘pseudo maturity’ having no one to share problems
- Helplessness and wish for stability or a normal family
- Stigma of being labeled as a child with an substance abuseic father
- Taking up ‘survival roles’
- Dropping out of school to work due to financial crisis at home
- Poor contacts or concern by relatives and others

The problems experienced by children of other substance abusers, including drug addicts, are likely to be similar.

- D. *Survival Roles* are donned by children whose parents suffer from substance use disorders such as alcoholism. According to Wegscheider (1981), they are described as follows (see box):

The Survival Roles

The ‘hero’ or caretaker who tries to correct the imbalances and organizes the day-to-day survival tasks in the chaotic home (normally the eldest child); *The ‘lost child’* who is a loner and may interact less with the outside world; *The ‘joker’ or clown* is the peacemaker at home but may deny his / her own needs; *The ‘scapegoat’ or ‘rebel’* may often be held responsible for all family problems and they in turn can act out feelings to fulfill their own emotional needs.

These roles are reportedly due to inconsistent parenting and poor emotional support. They may also pre-dispose the children (in adulthood) to relationship problems; some may marry substance abusers or have substance problems themselves.

An Indian study reports that children coming from families with an addiction problem blame parents for being inadequate role models (Monteiro, 1987). Another study reveals that children below fifteen years of age often work to supplement income. They compromise on basic needs due to financial difficulties taken by the substance abuseic parent (Benegal et al, 2000, Pandian, 1999).

- E. *Imitating their parents:* According to Bandura's social learning theory (1986), a child's substance use is shaped through imitative social learning or modeling — for example, parents with tolerant attitudes or norms may ask a child to light a cigarette or get the drinks. The absence of parental monitoring for substance use may also increase the risk in children of substance abusers. They often may imitate the same sex parent's substance use levels (eg., the son imitating his father).

An Indian study reveals that the average age when males start drinking lowered from 25 to 23 years (Benegal et al, 2003) – the risk was higher (of using substance abuse, drugs and tobacco) when they are exposed at a relatively young age to the key adult with the problem.

- F. *Adult Children of Substance Abusers* - Many adult children substance abusers may have negative adjustment, depression and face difficulties with relationships. Remember, adult children of substance abusers may face problems that are not necessarily substance abuse related.

Check Your Progress Exercise 5

Note: a) Read the following questions carefully and answer in the space provided.

b) Check your answers with those provided at the end of this Unit.

- 1) Children of alcoholics may be affected in the following ways –

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- 2) The three unwritten laws are –

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- 3) Adults children of substance abusers may have problems such as —

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13.4 PROTECTIVE FACTORS WITHIN FAMILIES

It is important to remember that many families also manage to remain intact and relatively harmonious despite substance abuse problems. For instance, many children of substance abusers may emerge largely undamaged with no substance abuse problems as adults. These may be due to certain positive influences or

protective factors within families (Orford and Velleman, 1995). The mediating role of the family in such an adverse circumstance is recognized. The combination of certain family factors present in the home environment is found to help the family to distance itself from the substance abusing member. The factors are presented below:

- *A cohesive relationship between parents* despite substance abuse problems
- *The other parent (non-substance using) providing* a stable and supportive environment
- *Family cohesion maintained through family rituals and activities* at high levels
- *Strategies used to cope* with adverse circumstances by spouses and children including coming up with alternatives

According to Orford and Velleman (1995), the above factors serve to protect the psychological well-being of children and reduce their likelihood of experiencing continuous problems in adulthood. They add that it is important for these factors to be identified by helping agencies and Counsellors. Measures can be taken to help families to reduce the worst effects of substance use problems.

A. Cohesive parental relations and family interactions: Families have the ability to buffer the risk of substance abuse problems in children through the following ways:

- Attention from the primary caretaker (usually parent or a close relative)
- Having adequate emotional supports
- Effective disciplining, monitoring and supervision of children
- Voicing norms/ attitudes about substance use including tobacco (indicating clear disapproval or non-use by adults at home)
- Meaningful family involvement
- Consistent roles / responsibilities (by parents)
- Absence of parental conflict

B. An effective non-substance using: The mother's relationship with her children, supervision and monitoring, proper communication, fostering feelings of intimacy, joint activities and experiences of good life events are some of the factors that play in role in providing stability at home.

C. Family rituals and activities: Families that maintain their important rituals despite severe parental substance abuse are found to have a strong collective sense of identity (this identity is separate from the identity of that of a 'substance abusing family'). Pre-existing rituals are actively protected by the family members and the substance abusing parent's intoxicated behaviour is rejected by confrontation and clear expression of disapproval. The idea is that the rituals may often be continued by the children when they turn into adults. These communicate important messages to the children that there is a possibility of taking effective control of the present and future life events.

What Comprise Family Rituals?

Family celebrations are standardized rituals specific to the sub-culture through holidays and festivals e.g. Republic Day, Dipavali, Ramzan, Christmas etc;

Family traditions are less culture specific and are special activities for families e.g. vacations, visits with extended families, celebrating birthdays, anniversaries, pilgrimages etc;

Patterned routines are frequently enacted but least consciously planned activities reinforcing a sense of identity, defining roles and responsibilities of family members e.g. mealtimes, watching television.

D. Strategies used to cope: The process of learning to tackle problems at an early age play a protective role and help families to distance themselves from the adverse circumstances. Through this, children of substance abusers learn to make decisions and choices as adults – they can consciously plan on how to be same or different from their family of origin. This determines whether they will continue the legacy of substance abuse problems or instead choose to be different from their family of origin. The available support (emotional and material) also plays a role by helping the family to tide over difficult times. The supports for the family comprise the parent who is not into substance use; siblings (especially older ones as surrogate parents); grandparents; teachers (as role models); local priest or clergy in temples; churches; neighbours; friends; peers and employers.

Before proceeding to the section on the goals and purposes of counselling for families, the various problems faced by persons recovering from treatment intervention for substance use disorders related problems will be presented.

The common reactions by the family to these problems (at the time of recovery) would be simultaneously discussed as they would be addressed during the counselling sessions.

13.5 ISSUES/PROBLEMS FACED BY PERSONS RECOVERING FROM SUBSTANCE ABUSE

Family members can have high hopes, experience great relief and express joy over the person's abstinence from substance use after treatment intervention. We should remember that addiction is a chronic problem (like diabetes or high blood pressure) and there are ups and downs in the recovery period. The role of the counsellor is to prepare the family for this long and continuous process of recovery.

What are the common issues/problems associated with recovery?

a. Taking responsibility: The family members should remember that it is the responsibility of the recovering person and not their task to keep the person away from activities related to substance abuse/ drugs. An example to illustrate this is when the spouse may call up old friends to say that her husband has taken treatment and should not be forced to drink substance abuse again. If they do so, they will have to face her.

b. Brittle doll: Families tend to treat the person with caution or like a 'brittle doll' that may break at the slightest touch due to fear or belief that anything

they say could cause conflict and make the person turn to substance use again. This lack of open communication will result in more stress for the family.

c. Taking up old roles: The family needs to start including the recovering person by helping him to *undertake old roles* again; e.g. as a father or husband. To enable this, the spouse may have to give up her previous roles / functions and help the person to gradually take up small tasks. Her initial reluctance to do so is natural due to the unsuccessful experiences in the past. We should remind the family to lower their expectations to a realistic level and that the successful completion of tasks / managing roles and greater involvement would help in increasing the self worth of the recovering person.

d. Not letting old feelings go: Even when the recovering person is making progress, the family may be reluctant to acknowledge it; instead, they may remark on the negative aspects, or may keep on making their own plans for him or come up with solutions. This continuing resentment or lack of a meaningful relationship with the family members may lower the person's self esteem or self confidence. The family needs to shift their perspective and this should be addressed in the counselling sessions.

e. Poor contact: The family may find it difficult to participate in social activities/ occasions that are pleasurable. The lack of social contacts may be due to the years of embarrassment and humiliation at public occasions caused by the alcohol or drugs related problem in the family member. Facilitating the re-establishment and renewing of contacts outside the family is important.

f. Continuing problems: Some problems may continue to linger during recovery e.g. poor family interactions, unsettled debts/ financial problems, difficulty with job, sexual problems etc. We should use locally available resources to tackle some of the issues or make referrals.

g. Learning to trust: Often, the family members can mistake the recovering person's reddening eyes to drinking; his irritability or tiredness as a sign of relapse. This constant fear or suspiciousness could undermine the genuine efforts made by the recovering person. We should help the family members change their old attitudes towards the recovering person. Discussing the process of relapse is important.

Check Your Progress Exercise 5

Note: a) Read the following question carefully and answer in the space provided.

b) Check your answer with that provided at the end of this Unit.

- 1) After the person receives treatment for substance abuse related issues, the Counsellor has to prepare the family members to face certain issues/ problems. What are the areas you would discuss?

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13.6 COUNSELLING FOR FAMILIES: OBJECTIVES AND INTERVENTION

Alcoholism and other substance related problems in a family member create a strain on the family system. Family members (spouse, children, parents, relatives) are usually affected and vulnerable to physical and emotional problems. We have also seen how some problems could continue during the recovery phase. This has been discussed in the previous sections. The family's involvement from the beginning keeps the person's denial low and at the same time helps counsellor to plan recovery at a more realistic level. Hence, the counsellor should make special efforts to include them as part of the treatment process.

What are the broad objectives of counselling for families?

1. To empower families to tackle future issues effectively, including providing support to the addicted person by giving information on the concept and definition of substance use disorders, its consequences, impact on the family and relapse prevention;
2. To equip families (including children) with skill-based methods to restore healthy family functioning and individual wellbeing by improving family interactions, parenting, stress and anger management, assertiveness;
3. To enhance protective factors within families with an attempt to prevent or delay similar substance abuse or drug related problems in their children; and
4. To create a safe, accepting and supportive environment for the family members to openly discuss their problems and needs by paying attention to their own inner feelings and struggles that they face due to the substance related problems.

Skill - based methods to restore family functioning are presented below. The Counsellor should help the individuals to work upon specific skills during the sessions.

13.6.1 To Improve Family Interactions

The interconnected relationships within the family are widely recognized and addiction often affects family functioning. The focus is to help the family to revive positive family interactions after de-addiction. Two areas that need to be strengthened are promoting healthy styles of communication and learning effective problem solving methods.

Communication processes: Open emotional expression during crisis situations fosters mutual trust, tolerance towards each other and enables family members to express a wide range of feelings. Individuals at home may be used to keeping 'family secrets'; usually common in families with addiction problems. Talking to each other, maintaining eye contact, using personal statements ('I' statements), and non-verbal cues are some of the methods of improving communication between family members, including children.

Problem solving: There may be many situations in life where families are faced with the inability to solve problems. Many problems may be related

to issues arising out of substance abuse, such as alcoholism e.g. facing life after addiction treatment can be stressful—it may mean clearing old debts and bills, finding a job, staying away from drinking friends etc. The steps in problem solving are as follows:

Select and state a problem (be specific and descriptive about the issue)

List the possible alternatives/ options available

Decide the consequences of each option

Choose the best option

Agree on the final option

Implement the chosen option

Evaluate option that is selected to see if it tackles the problem or not.
Return to first step if the chosen option has not helped.

13.6.2 To Improve Parenting

Parenting skills may be seriously affected especially due to alcohol or drug related problems in one of the parents. We should remember that effective parenting contributes to healthy interactions and spending time meaningfully together increases a sense of togetherness and ‘we’ feeling at home. The counsellor should help both parents to rebuild a trusting and healthy parent-child relationship (especially for the parent having the addiction problem) and at the same time provide the child with healthy role models. The specific areas that need attention are as follows:

Spend quality time – Allotting time and doing activities together as a family can be part of a daily structure viz. assisting children with studies, sport activities and hobbies.

Be a positive role model – Encourage parents to voice disapproval about non-use of substance abuse and other substances; demonstrate values such as honesty, patience and punctuality in daily life; set clear limits.

Get to know the friends – Interest in the children’s friends, and maintaining a warm relationship with them should be genuinely expressed i.e. preparing simple snacks when they come home unannounced may be a welcoming gesture. This would also enable regular monitoring of the negative influences of some friends.

Understand children’s feelings – Hurt, anger, fear and joy may be some of the emotions expressed by children of substance abusers. Keen listening, physical touch, eye contact, giving feedback can reassure children about the parents’, respect and concern for them as individuals with feelings and foster re-bonding.

Encourage participation in family activities – Children of substance users should be appreciated when they help in routine activities e.g. washing dishes, folding clothes, watering plants or shopping. The child’s efforts in self-reliance and responsibility should be acknowledged clearly and considered as worthy and valuable by the parents.

Recognize children's strengths – Every effort made by the child should be encouraged to the best of his/ her abilities. Communicating this message to the child is important as it reaffirms the parents' sincere appreciation.

Family members also need to 'recover' and improve their well-being as we are aware that addiction is a family disease. We should remember that this is independent from the addict's own recovery. For this, the counsellor should help them to learn healthier ways of tackling stress, anger, and improve their self-esteem and assertiveness in the long run.

13.6.3 Managing Stress and Anger

Family members are at a high risk of using unhealthy methods to deal with difficult situations. Some may misuse substance abuse, tobacco or even tranquilizers as ways of coping with stress. They may have no one to talk about their feelings or problems or may not want to due to the shame associated with addiction. Similarly, anger may be suppressed inside the person or may be directed to those around them (especially children). Frequent arguments, shouting or hitting children may be common at homes facing addiction related problems. The counsellor should help the family members (spouse, children, parents, and support persons) to learn healthy ways of tackling both stress and anger.

13.6.4 Increasing Assertiveness and Self-Esteem

Family members living with a person having addiction related problems often experience a lack of well-being compounded by the loss of one's self respect in society. Being assertive by expressing feelings or thoughts that are both positive (praise, happiness) and negative (anger, guilt, fear) without hurting the other person is a skill that should be taught during counselling. It helps the person to act in harmony with one's values and increases one's self-esteem.

What is it to be assertive?

Assertion is a specific way of communicating

There is regard for the other person's feelings and values

The person expresses thoughts, feelings and values about a situation openly and directly

It focusses on the rights of the individual including consideration of the rights of others.

Check Your Progress Exercise 6

Note: a) Read the following question carefully and answer in the space provided.

b) Check your answer with that provided at the end of this Unit.

- 1) What are the areas/skills that need to be strengthened for family members to improve overall family functioning?

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13.7 SRENGTHENING PROTECTIVE FACTORS WITHIN FAMILIES

The counsellor should make efforts to strengthen protective factors within families to prevent or delay similar substance abuse or drug related problems in their children. Restoring family functioning is one such factor. The other factors that need to be addressed are presented below:

Revitalizing rituals and routines – Structured plans (both short and long term) for the recovering parent and the family is important. Daily routines that would engage the family to participate as a unit e.g. eating at least one meal together, watching television, spending time at home, celebrating family traditions, visiting relatives, religious places, going to the cinema, park, shopping, celebrating birthdays; celebrating festivals or holidays such as Republic day, Dipavali, Ramazan etc. These activities reinforce a sense of family identity and are repeated by the children in their adulthood.

Addressing children – Many children (including teenagersn) may not show any obvious problems and may function well. However, the counsellor should be alert to the children's physical, emotional and behavioural status plan intervention if there are any problems. Strengthening their self esteem, teaching them to be assertive (learning methods to refuse when pressurized to take substance abuse or drugs by friends) and helping them to adopt healthy coping styles are specific areas that should be facilitated by both counsellor and parents.

Strengthening Supports – The family's inner and outer resources (emotional and material) need to be strengthened. External supports can be strengthened through use of self-help groups that afford anonymity e.g. groups for families; arranging vocational training / job placement / micro credit schemes (for economic independence) are helpful. Separate counselling sessions for support persons (extended family, friends or well wishers) should be offered as part of intervention.

Optimistic approach – The counsellor should provide the families including children a chance to make meaning out of a difficult situation or adversity – in this case, the addiction treatment itself may be a traumatic experience. Helping the family view and approach crisis situations is important for well- functioning families. This in turn helps in better coping styles and contributes to resilience among the family members.

The counselling and family therapy process should create a safe, accepting and supportive environment for the family members to openly discuss and address their problems. Equipping them with skills to improve their well being is one. Allowing them to vent their negative feelings of anger, guilt, shame and fear about the future is another important aspect. Carrying these feelings is unproductive and increases the tensions at home. Counselling and family therapy would help them to refocus on themselves and their own needs (away from the addicted person) and enable positive changes in their own behaviour.

Methods used when working with families

Besides counselling (which may be one-to-one), other methods which can be included while working with families:

- Psycho-education to provide information on substance related issues, relapse etc (also for support persons). Audiovisual aids such as flip charts, posters, activities, chalk and talk can be used.
- Participative methods such as Games, Role plays, Discussions can be used.
- Group sessions to facilitate sharing with others having similar problems is effective and also strengthens hope.
- Self help groups for families (including children) and, sustainability.

The Counsellor should have a directory of services and networks which can be used during family counselling to make referrals where necessary. The families can continue to remain in touch with them as and when required. For instance, these include information on Addiction Treatment Centres (both private and government services at District / State levels), Tobacco Cessation Clinics, Vocational guidance / training centres, Legal aid, Micro credit groups for women, Voluntary Organizations / Self Help Groups, etc.

Check Your Progress Exercise 8

Note: a) Read the following questions carefully and answers in the space provided.

b) Check your answers with those provided at the end of this Unit.

- 1) The counselling process should create an atmosphere for the family that is:

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- 2) Allowing family members to vent their negative feelings of anger, guilt, shame and fear about the future is important because (state 2 benefits):

i)

ii)

13.8 ADDITIONAL INFORMATION

13.8.1 Tips for Families to Reduce or Prevent Relapse

As a Counsellor you have to remind the family that addiction to substance abuse is like any other chronic illness (like hypertension or diabetes) and relapse is often recurrent.

The following tips should be recommended during family counselling:

- *Maintain regular follow-up*

You need to inform the family that treatment does not end with detoxification and counselling. Psychiatric problems (i.e. anxiety, depression including suicidal thoughts, psychosis and personality disorders) may persist and alcohol /drugs are often used as a coping mechanism by the recovering addict. Marital problems may also be present. Hence, the family members have to ensure that there are *regular visits* to meet the counsellor go to the treatment centre for three to six months to address these issues (medication, relaxation techniques, individual/family counselling, self-help groups, life skills training etc. would be continued in this time period).

- *Medication to maintain abstinence*

The counsellor should make the recovering person understand the importance of taking the prescribed medication for maintaining abstinence daily. Tell him that it serves as an additional support and helps to maintain abstinence by protecting him when he may have sudden urges to consume the substance or wants to give in to pressure from friends. The side effects of substance use while on medication should be made known to the addicted person and family (flushing, nausea, vomiting etc.). Consent for agreeing to take the abstinences aiding medication is necessary from the addicted person (in a written form and signed by the addicted person).

- *Involve extended family and friends*

As a counsellor you must involve relatives or friends as allies from the start, as they are often aware of events or situations when relapses occur that may be hidden from the addicted person. Encourage regular contact with self-help groups and other supportive groups. Remember, to also provide long term support for the family at a time when counselling may be less frequent and phased out.

- *Keep a dairy*

Asking the addicted person questions like ‘What were the past triggers of relapse?’ and ‘What are the new methods / and alternatives to handle them?’ is a must. Also, discussing helps both the family members and addicted person to plan ahead together and reduce risks in future.

- *Watch out for warning signs of relapse*

As relapse and recovery are a part of the same coin, one can anticipate it at any stage of recovery. The family members and the addicted person should be prepared for this at any time.

13.8.2 Communication Skills

Communication Process

Sender is the one who sends a message, for example by putting an idea into words.

Listener / or Receiver hears the words and decodes or tries to understand what the person said (‘what does the speaker mean when she says that?’).

Feedback is given by the listener back to the sender after decoding the message.

Good communication strengthens relationships and well-being, especially in families coping with substance related problems. Most of our communication is non-verbal (using our body, facial expressions, gestures, tone of voice, and our eyes). The process is complete only after the receiver gets the right interpretation of the message from the sender. The context plays a role e.g. friends talk in a particular way; parents and children talk in a different context; the context of a client and counsellor is different etc. Sensitivity to the environment including culture is important. The words we use to express ourselves reflect our true feelings and genuineness. There are 'feeling' words e.g. happy, sad, scared, angry, hate etc.

Feelings conveyed through body language — Openness / confident/ interested:

- Standing with arms by the side
- Open palms
- Leaning forward
- Eye contact maintained

Insecure/ Nervous:

- Looking down
- Biting nails
- Arms crossed over chest/ legs crossed
- Wringing hands/ clenching fists
- Sweating, covering mouth

What should I do to communicate well?

Make eye contact

Looking at the person directly helps to form a bond. Averted eyes or looking away from the person may indicate that you are distracted or not interested in what the other has to say.

Effective sending

It is worthwhile to spend a moment clarifying within ourselves about what we wish to convey before we speak, the choice of words and the appropriate moment. The response from the listener often gives us an idea about what they have understood. If needed, we can ask the listener to repeat what we have said.

Use the word 'I'

When the person uses the word 'I' or 'I think' or 'I feel', they provide direct

information about the person's own feelings and a sense of responsibility for their behaviour and feelings.

Attending

This refers to non-verbal methods of conveying that you are paying attention to what the other person is saying e.g. nodding, leaning forward etc. This is called active listening or when the person hears with empathy in the 'here and now' of the situation.

Reflective listening

Repeating statements or reformulating what the person has just said conveys that you have understood what the other person said.

13.8.3 Managing Stress and Coping Effectively

Stress is a reaction of the mind and body to any event that brings about a change. When we are compelled to do something, the body experiences a kind of discomfort which is termed as stress. We may encounter these situations in various stages of our lives. How we perceive these stresses, and how we tackle them is important.

Types of Stresses

There are two types of stresses:

a. Positive stress (or 'eustress') – This can motivate a person to do better, accomplish goals and optimize potential. Some examples are an athlete who is geared up for competition, parents getting their daughter married or a student getting admission in college or the farmer getting a good market price for his crop.

b. Negative stress or distress – This can affect our body and mind and lead to psychosomatic diseases e.g. backaches, peptic ulcers, headaches, skin problems and low immunity. Often, there may be a psychological problem underlying them. Travelling in a crowded bus, sitting for the final exams or a couple whose marriage is falling apart or family member facing a serious illness are some examples.

What are some of the causes of stress?

Problems related to home life, debts, too much work, boredom, examinations, physical injury or illness (BP, diabetes), irritants like heat, crowd and noise may be some of the causes of stress. There are others such as shifting to a new place, living alone, pressure to get married and death of a loved one. Hence, stress can be caused by events that are not only negative but also positive (like a promotion at work, which means a better pay but also more responsibilities).

Some physical symptoms of stress

Psychological symptoms include excessive anxiety, feeling lonely, depressed, lack of concentration, confusion and difficulty in taking decisions, feeling helpless and insecure and problems due to excessive use alcohol / drugs including tobacco.

Tension headache, sleeplessness, digestive problems, vague pains (back, neck), constantly feeling tired, loss of appetite, feeling nervous are often symptoms of stress. Many physical disorders can be caused due to some psychological origin e.g. migraine headaches, respiratory disorders, peptic ulcers and sexual disorders.

Some psychological symptoms of stress

Psychological symptoms including excessive anxiety, feeling lonely, depressed, lack of concentration, confusion and difficulty in taking decisions, feeling helpless and insecure and problems due to excessive use alcohol/drugs including tobacco.

Some ways of coping

Positive coping – These may help the person to reduce stress and cause no side effects. Talking about the problem with someone (friend, relative, teacher, attending self help groups relaxing through physical activity (walking, sports, yoga, and gym), hobbies or just laughing the problem off may help a person. Changing our attitude to the stressor, lowering our expectations and prioritizing our needs are ways to reduce our stress.

Negative coping – Some of them are smoking heavily, excessive use of substance abuse/ drugs, taking medication and use of aggression (beating, shouting). Some can turn negative in the long run e.g. sleeping, postponing and fantasizing.

13.8.4 Handling Anger

We all get angry and it is a normal human emotion. There are many ways of expressing anger. It may be indirect where both the person and the target may be unaware. Anger may be disguised in many ways i.e. through verbal and non verbal language, having aches and pains, injury to self or others, showing anger on others, becoming withdrawn or depressed, self pity, and abusing substance abuse/ drugs including tobacco are some of the ways of expressing anger.

What the person says and what he actually means (hidden anger):

‘I am so upset’ meaning the person is disappointed.

‘I feel like killing myself’ meaning the person may be depressed

‘Ah! Very smart’. There is hidden sarcasm.

‘Only I suffer’ meaning the person feels sorry for self.

Steps to deal with anger

- First, I must recognize that I am angry
- I must examine the feelings caused by it
- I should find out what I am angry about (the source of anger)?

Examples of the source of anger and how it is vented out:

‘I am not able to pay off my debts, so I shout at my spouse’;

‘My school bus is late so I shout at my brother’

- Now, whom have I shown my anger to?
- I will ask myself whether the anger was realistic or not?
- As I know the source of my anger, could I have handled my anger differently?

Some healthy ways to handle anger

Active sports, gardening, cleaning, walking, listening to music, chanting a prayer, writing the source of anger/ talking about it, yoga and relaxation are healthy ways of reducing or getting rid of anger. They help the release of pent up anger in us. The person is also in a better frame of mind to communicate more openly at a later time. Bottling up anger or showing it on others can make it extremely difficult to understand the real problem.

13.8.5 Assertiveness Training

Through practice and role playing, we can teach a person to be assertive. The counsellor helps the person to act out various interpersonal interactions in different situations that occur in daily life.

In a conflict or difficult situation, three types of behaviours may be used - *assertive*, *aggressive* or *passive*.

A passive person ignores one’s own rights and feelings, respects other’s rights and feelings;

An aggressive person respects only one’s own rights and feelings, ignores other’s rights and feelings;

An assertive person respects one’s own rights and feelings, and also respects other’s rights and feelings.

What are the benefits of assertiveness?

- It instills a feeling of well-being in the person; and
- Significant social rewards can be gained through the change (dignity, respect, recognition).

Decide:

What is the specific behaviour that needs changing?

Plan systematic steps to achieve the result.

Types of assertive responses

Non-verbal: Maintain eye contact; Speak in clear voice; Keep erect body posture; Let your face talk; Use gestures.

Verbal: Talk with feelings; Express your opinions when others disagree; Use ‘I’; Accept responsibility; Accept compliments; Give compliments.

The above steps can be used to role play situations where the person (includes school going child or adult) may be under social pressure to use substance abuse or drugs including tobacco.

Situation for role play:

1. You have got admission into a College you had applied for. Your friends are insisting that you take them to a hotel to celebrate with substance abuse and food. You do not want to celebrate it this way.
2. Your boss wants you to stay after office hours but you have promised to take your children shopping
3. There is substance abuse served a function. Your relatives and friends insist that you have a drink. You do not want to drink as you are recovering from addiction and have been advised to stay away from substance abuse.
4. Your wife suspects that you have started drinking again (after treatment)

(In psycho education sessions, the role play can be done in front of a group where the rest will be observers)

How can I strengthen my self esteem?

- Give positive strokes generously, directly
- Say a few appreciative words often
- Give a gentle touch, a friendly pat, a warm smile
- Express with warmth and genuineness
- Receive positive strokes / compliments with grace
- Feel comfortable about them; accept them
- Reject unconditional negative strokes

13.8.6 Improving Self Esteem

What is self esteem?

Self esteem is a measure of self worth and importance.

When self-esteem is strong in a person:

- The person feels happy about self
- The person can handle difficult situations
- The person can see to see good in others
- Mainly, the person enjoys life

A weak self esteem is when a person often says “I feel low” or “I am not worthy”. The person has a negative self-image and poor self concept.

Our various life situations would then be tackled from either a position of strength or weakness and result in success or failure. Remember, people with strong self esteem relate well with others and develop a circle of close friends; the

person does not get discouraged by failures. When the person's self esteem is weak, there is resentment, discontentment and constant criticism of others. Personal life becomes a mess.

What can you do when you feel low?

Sharing your worries, talking to someone trustworthy helps. You could feel lighter and relieved.

How can I strengthen my self esteem?

- Give positive strokes generously, directly
- Say a -few appreciative words often
- Give a gentle touch, a friendly pat, a warm smile
- Express with warmth and genuineness
- Receive positive strokes / compliments with grace
- Feel comfortable about them; accept them
- Reject unconditional negative strokes

13.9 LET US SUM UP

Intervention in substance related problems should integrate counselling/family therapy counselling families having persons with substance use disorders is important for two reasons: It equips them to effectively manage future problems during the recovery phase; it also helps family members to address and tackle their own neglected needs.

13.10 ANSWERS TO CHECK YOUR PROGRESS EXERCISES

Check Your Progress Exercise 1

1. Families having a member with substance related problems are more likely to face – overall dysfunction, feeling of shame, behaviour problems; financial difficulties and indebtedness.
2. Children having a father with substance abuse have a higher risk of developings – substance problems at an earlier age and male children are found to be more vulnerable.
3. Counsellors working in the field of addiction can help to – identify, screen as well as prevent future problems in children and their families.

Check Your Progress Exercise 2

1. In case of substance abuse, family functioning is negatively affected in areas such as – leadership, problem solving methods and communication between members, reinforcement of appropriate behaviour, support systems, roles and cohesion at home.

2. 'Co-dependency' means – the family members deny the problem, become as dysfunctional as the addicted person, try to control the situation and attempt to maintain a balance.

Check Your Progress Exercise 3

1. The non-drinking spouse may also face problems like – neglecting children leading to emotional distancing; difficulty with carrying out roles and responsibilities; psychological problems and low self esteem.
2. Coping by spouses may be through unhealthy means like – drinking (leading to serious substance abuse problems); self- medication and misuse of tranquilizers.

Check Your Progress Exercise 4

1. Children of alcoholics may be affected in the following ways – They witness parental conflicts; observe the three unwritten laws; face emotional and behavioural problems; don survival roles; imitate their parents especially drinking.
2. The three unwritten laws are – 'don't talk, don't trust, and don't feel'.
3. Adult children of substance abuses may have problems such as – negative adjustment, depression and relationship difficulties.

Check Your Progress Exercise 5

1. Let the recovering person take responsibility; not treat the person with caution or like a 'brittle doll': help the person to undertake old roles; let the old feelings go; strengthen social contacts; improve family interactions, discuss unsettled debts/ financial problems, help in difficulty with job, sexual problems; increasing trust.

Check Your Progress Exercise 6

1. Improving family interaction – better communication between family members; problem solving skills;
Parenting skills;
Managing stress and anger effectively; and
Increasing assertiveness and improving self esteem.

Check Your Progress Exercise 7

1. There important areas/skills that need to be strengthened for children of substance abusers are:
 - i) Increasing their self-esteem
 - ii) Assertiveness (refusal methods)
 - iii) Healthy coping

Check Your Progress Exercise 8

1. The counselling process should create an atmosphere for the family that is: Safe, accepting and supportive where family members can openly discuss their problems.

2. Allowing family members to vent their negative feelings of anger, guilt, shame and fear about the future is important because:
 - i) Carrying these feelings is unproductive and increases tensions at home.
 - ii) Refocussing on themselves, their needs (away from addicted person) enables positive changes in their own behaviour.

13.11 UNIT END QUESTIONS

1. With the help of examples, analyse the need for families to be included in intervention with reference to substance abuse.
2. Discuss protective factors within families of substance abusers that we should seek to foster and strengthen in the course of counselling and family therapy.

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UNIT 14 DEALING WITH DELIBERATE SELF-HARM

Structure

- 14.1 Introduction
- 14.2 Meaning and Definition
- 14.3 Extent of the Problem
- 14.3 Causes of Self-harm
 - 14.4.1 Intentions and Motives
 - 14.4.2 Functions Served by Self-harm
 - 14.3.3 Social Factors
 - 14.3.4 Mental Health Factors
- 14.4 Prevention
- 14.6 Management
 - 14.6.1 Assessment
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- 14.7 Referral
- 14.8 Let Us Sum Up
- 14.9 Glossary
- 14.10 Answers to Check Your Progress Exercises
- 14.11 Further Readings and References

14.1 INTRODUCTION

Self-harm, *self-inflicted violence, self-injurious behaviour or moderate self-mutilation is defined as a deliberate, intentional injury to one's own body that causes tissue damage or leaves marks for more than a few minutes.*

Several synonyms have appeared in the literature including *para-suicide, attempted suicide, deliberate self-harm, deliberate self-poisoning*, and more recently simply “self-harm”.

Objectives

After studying this Unit, you will be able to:

- Define what is self-harm;
- Gauge the extent of the problem of self-harm;
- Understand the risk-factors associated with self-harm and suicide;
- Understand why someone self-harms;
- Explain the functions served by self-harm;
- Describe the importance of prevention of self-harm;
- Assess for risks and needs of the patient; and
- Understand how to manage a patient who self-harms using various modalities.

14.2 MEANING AND DEFINITION

World Health Organization (1986) defined self-harm as, “an act with non-fatal outcome, in which an individual deliberately initiates a non-habitual behaviour that, without intervention from others, will cause self-harm, or deliberately ingests a substance in excess of the prescribed or generally recognized therapeutic dosage, and which is aimed at realizing changes which the subject desired via the actual or expected physical consequences”. On the other hand, suicide is defined as the act of deliberately killing oneself.

Self-harm is a complex behaviour that can be best thought of as a maladaptive response to acute and chronic stress, often but not exclusively linked with thoughts of dying. It is a form of non-fatal, self-destructive behaviour that is believed to occur when an individual's sense of desperation outweighs this/her inherent self-preservation instinct.

Check Your Progress Exercise 1

Note: a) Read the following question carefully and answer in the space provided.

b) Check your answer with that provided at the end of this Unit.

1. Which of the following terms should not be used interchangeably with self-harm?
 - i) Self-injury
 - ii) Para-suicide
 - iii) Self-inflicted violence
 - iv) Deliberate self-poisoning
 - v) Suicide

14.3 EXTENT OF THE PROBLEM

Data from developed countries suggest that about 1 in 200 people attempt self-harm. Two thirds of patients who self-harm are less than 35 years old and two thirds of people in this age group are female. There is particular concern that the rate in young men aged 15–24 years of age is rising more quickly than in any other group. Here, it should be emphasized that self-harm and suicide are related yet somewhat different phenomena, and this is best illustrated by the differences in their epidemiological features. Suicide is more common in older men while self-harm is more common in younger women; and the gap between the two genders seems to be widening as the rate of suicide among men is increasing (as is the case also for self-harm in young men). Not many epidemiological studies have been reported from developing countries, but in a large study, self-harm and suicide rates were found to be five times higher in Sri Lanka as compared to United Kingdom.

The importance of this behaviour is illustrated by the subsequent risk of suicide, which, in the subsequent year, is at least 100 times more in those who have self-harmed as compared to the general population and the risk of suicide is about 3% even after 10 (or more) years of the first attempt. The risk of repetition of self-harm is also extremely high; up to 40% will go on to repeat, including 13% in the first year. Self-harm is found to be one of the top five causes of acute medical admissions for both men and women.

Check Your Progress Exercise 2

Note: a) Read the following question carefully and answer in the space provided.

b) Check your answer with that provided at the end of this Unit.

1. While interviewing a client who is facing family-related stressors, you see cut-marks on her wrists. On asking, she reveals that she indulged in self-harm (i.e. slashed her wrists) on a few occasions about 6 months back after a break-up. She also informs that now she is much more stable and settled in life. Should you be concerned about the possibility of recurrence of self-harm? Give reasons for your answer.

★ Yes

★ No

.....
.....

Table 14.1 gives the features that predict repetition of self-harm or eventual suicide.

Table 14.1: Features which predict repetition of self-harm or eventual suicide

<i>Repetition of self-harm</i>	<i>Eventual suicide</i>
● A history of self-harm prior to current episode ● Psychiatric history, especially as in-patient ● Current unemployment ● Lower social class ● Alcohol or drug-related problem ● Criminal record ● Antisocial personality ● Hopelessness ● High suicidal intent	● Older age ● Male gender ● Previous attempts ● Psychiatric history ● Unemployment ● Poor physical health ● Living alone

14.4 CAUSES OF SELF-HARM

This aspect can be viewed from several perspectives, such as:

- Individual's motive for committing the act;
- Intentions at the time of the act;
- Functions served by the act of self-harm;
- Social precipitants; and
- Mental health reasons.

14.4.1 Intentions and Motives

Self-harm may involve little pre-mediation or may have been contemplated for some time. Some individuals, especially the elderly, may have serious suicidal ideas before the act and survive only as a result of misjudgement or chance events. The motivation for self-harm may appear to be complex and very personal. Given below are examples of motives given by some individuals who have self-harmed:

- *"It expresses emotional pain or feelings that I'm unable to put into words!"*
- *"It's a way to have control over my body because I can't control anything else in my life"*
- *"I usually feel like I have a black hole in the pit of my stomach, at least if I feel pain it's better than feeling nothing".*

Suicidal intent is said to be the extent to which the person wishes to die at the time of committing the act. While it can be difficult to assess the difference between an attempt to self-harm and to commit suicide in some situations, as many individuals are ambivalent about the intent to die and the reported intent may change fairly quickly, it is clear that most people who attempt self-harm do not wish to die; rather it serves various other functions, e.g. an attempt to regain some control over oneself; to combat feelings of inner emptiness; or simply to express unbearable pain. This is discussed in greater details in the next section.

14.4.2 Functions Served by Self-Harm

Klonsky (2007), on the basis of examination of empirical literature, delineated seven functions served by the act of self-harm; as shown in Table 14.2.

Table 14.2: Functions of Self-Harm

<i>Function</i>	<i>Description</i>
Affect Regulation	To alleviate acute negative affect or aversive affective arousal
Anti-suicide	To replace, compromise with, or avoid the impulse to commit suicide
Feeling generation	To end the experience of depersonalization or dissociation
Interpersonal-influence	To seek help from (or manipulate) others
Interpersonal boundaries	To assert one's autonomy or a distinction between self and other
Self-punishment	To derogate or express anger towards oneself
Sensation-seeking	To generate exhilaration or excitement

Affect-regulation: It is believed that an early family environment that does not validate (support or corroborate) the experiences of the growing child may impair his/her ability to cope with emotional distress. Individuals from these environments and/or with genetic disposition for emotional instability are more prone to use self-harm as a maladaptive affect-regulation strategy.

Anti-suicide: Individuals may use self-harm as a coping mechanism for resisting urges to attempt suicide. From this perspective, self-harm may be thought of as a means of expressing suicidal thoughts without risking death.

Feeling generation: It has been suggested that individuals who self-harm may have experienced dissociation (a perceived detachment of the mind from the emotional state or even from the body) when loved ones were perceived as absent (e.g. a very erratic or depressed mother) for prolonged periods (this is psychologically very distressing to the child). Episodes of dissociation or depersonalization may then recur (later in life) in response to intense emotions. Causing injury to oneself creates physical sensations that interrupt a dissociative episode, and leads one to regain a sense of self.

Interpersonal-influence: At times self-harm may be used to influence (or even manipulate) people. Self-harm has often been conceptualized as a cry for help, a means of avoiding abandonment, or an attempt to be taken more seriously or otherwise effect people's behaviour. For example, an individual might self-injure to elicit affection from a significant other (e.g. parents, spouse).

Interpersonal boundaries: Individuals who self-harm are thought to lack a normal sense of self due to insecure attachment with early attachment figure(s) and a subsequent inability to individuate (form a cohesive self-identity). Self-harm (e.g. cutting) as a deliberate or autonomous act is perceived as an assertion of one's identity or autonomy; and thus an affirmation of a distinction between oneself and others.

Self-punishment: Self-harm can be an expression of anger or derogation towards oneself. It has been hypothesized that individuals who self-harm have learned from their environments to punish or invalidate themselves.

Sensation-seeking: Self-harm may be perceived as a means for generating excitement or exhilaration in a manner similar to Russian roulette (a potentially lethal game of chance in which participants place a single round in a revolver, spin the cylinder, place the muzzle against their head and pull the trigger).

14.4.3 Social Factors

Those who are isolated or living in areas of socio-economic deprivation have increased rates of suicide and deliberate self-harm. Vulnerability or predisposing factors such as early loss or separation from one or both parents, childhood abuse, unemployment, and absence of living in a family unit are also found to be contributory. Evidence also suggests that the person may have suffered an excess of life events, especially in the month before the self-harm attempt. Frequently, the type of events experienced by younger people is related to relationship difficulties, but in older people it is more likely to be health or bereavement related.

Certain factors in the family's environment may also be important, such as parental discord and violence, parental depression or substance abuse, role models of suicidal behaviour in the family, abuse of all kinds (e.g. physical, verbal or sexual) and bereavement.

14.4.4 Mental Health Factors

Mental health difficulties are frequently seen in individuals who self-harm. Individuals diagnosed with certain types of mental disorder are much more likely to self-harm. These include depression, psychotic illnesses like schizophrenia, phobias, alcohol and substance problems and personality disorders. Sometimes, repetitive self-injury is also seen in individuals with mental retardation; however, this must be differentiated from the deliberate self-harm caused with a conscious intent of harming oneself.

Certain psychological characteristics are more commonly found among the group of people who self-harm; including hopelessness, impulsiveness, aggression, inflexible and impulsive cognitive style, impaired decision-making, poor coping skills, poor frustration-tolerance, and poor problem-solving abilities.

Check Your Progress Exercise 3

Note: a) Read the following question carefully and answer in the space provided.

b) Check your answer with that provided at the end of this Unit.

1. Self-injury should not be termed self-harm if it is due to:

- i) Desire to seek attention
- ii) Desire to manipulate others
- iii) Childhood abuse
- iv) An underlying mental illness
- v) An inability to solve problems
- vi) Mental retardation

14.5 PREVENTION

The ideal method of protection against self-harm is prevention, i.e. reduction of number of new cases as well as prevention of further self-harm in individuals who have harmed themselves at least once. The former can be attained by using public health measures that can modify social, economic, and biological conditions, such as reduction of poverty, violence, divorce rates, and promotion of a healthy lifestyle. Also, measures for mental health promotion and life-skill training (e.g. in schools) are useful ways of prevention.

Clinicians can minimize the risk of self-harm among their patients/clients by thoroughly assessing for the presence of psychiatric illnesses, being aware of clinical and social situations that might precipitate self-harm and initiating treatment with or facilitating access to treatment for patients with psychiatric disorders. Also, they can do a careful risk-assessment; provide easy access to help for psychosocial problems and also scrutinize prescriptions (medication). Educating patients and their families about mental illness (if any), and the safe storage of medications and pesticides also is useful in prevention of self-harm.

14.6 MANAGEMENT

Important principles of management are:

- Establishing adequate rapport with the patient
- Privacy and maintenance of confidentiality
- Conduct interview safely and with adequate time
- Let patient tell their story
- Question relatives and friends about what patient has recently said

Illustrative Case

A 24-year-old man presents to a counsellor's office complaining of difficulty falling asleep. During the interview, he says that something is wrong — he has no energy, is crying almost every day, has lost his usual healthy appetite, and has started using alcohol frequently in an attempt to fall asleep. He admits that he sees the world as hopeless and has considered driving his motorcycle into a wall. He says that he would not kill himself, however, because suicide is a sin, and his parents would be saddened and shamed by such a death. Until his girlfriend left him two months earlier, he had never had these symptoms. Also due to not being able to sleep, he is reaching office late since a few days and getting scolded by his boss everyday. In frustration, he has started engaging in cutting himself whenever the thought of suicide or his girl-friend occurs to him. He wants help in sleeping but fears the impact of treatment on his ability to continue his job which involves a lot of driving. History also revealed presence of depressive symptoms in mother, and frequent fights between the parents. Patient's premorbid personality revealed poor frustration-tolerance and a high need for achievement.

14.6.1 Assessment

There are countless ways that someone may self-harm, the most common being cutting, used by over two thirds of those who self-harm followed by self-poisoning (e.g. overdose of medications, use of pesticides). The other methods of self-harm include burning, punching, etc. A person with self-harm may exhibit signs like cuts, scratches, burns or scars, bruises or even broken bones. There may be other give-aways like missing razors or pills or razors/medicine wrappers/pesticide bottles found in the dustbin.

The purpose of the assessment is to identify factors associated with suicidal behaviour, to determine the motivation for the act, to identify potentially treatable mental disorders, and to assess continuing risk of suicidal behaviour. It also includes assessment and treatment of the patient's physical condition, having a basic understanding of medico-legal issues, and drawing up and implementing a treatment plan.

All patients presenting with deliberate self-harm should be offered not only a sensitive assessment of risk, but of psychological and social needs as well. The main issues to be determined in the assessment process are:

- What were the patient's intentions?
- Does the patient still want to die?

- Are there current mental health difficulties?
- What is the risk of further self-harm or suicide (assessment of risk)?
- Are there any current medical or social problems (assessment of need)?

Check Your Progress Exercise 4

Note: a) Read the following question carefully and answer in the space provided.

b) Check your answer with that provided at the end of this Unit.

1. A 13 year old girl comes to you with presenting complaints of not being able to adjust to new school and feeling low, and you see lots of cut-marks on her arms. How should you react?
 - i) Ask the child
 - ii) Ask the parents
 - iii) Ignore, as no one has complained of self-harm

Assessor should regularly inquire about current depression, hopelessness, and suicidal-ideation. The risk of suicide should be considered imminent if the patient reports the intention to die, has a suicidal plan, and has lethal means available. Expressions of despair and hopelessness also suggest an imminent risk. A common myth is that enquiring about suicide would put ideas into the patient's mind. However, that is not the case and it is important to ask in detail about whether the patient has any intention of committing suicide and he/she should be allowed free expression. Useful questions in relation to hopelessness, wish to die, and suicidal ideas that should be considered in any evaluation for self-harm can be formulated as follows:

- Are things so bad to make you take such a step?
- Who all are there in your family? What do they think about this?
- How do you see the future? Do you think that things would work out?
- Do you ever feel that life isn't worth going on with?
- Do you think that you might do something to harm yourself?
- "What stops you from carrying it out?"
- "Have you ever felt like this before?" If so, how frequently and under what circumstances?

On the basis of assessment, a formulation may be reached that includes:

- *Long-term vulnerability factors:* For example, early loss or separation from parents, difficult relationships with parents, or abuse in early life. Although sexual abuse has been highly associated with self-harm, emotional or physical abuse is also important. Enduring psychological characteristics and other psychiatric problems need to be identified.
- *Short-term vulnerability factors:* For example, current difficulties in relationships and lack of social support, work or health-related problems, drug and alcohol misuse, or exacerbation of psychological symptoms.

- Precipitating factors are usually stressors experienced in the few days immediately prior to self-harm. Again relationship problems, financial worry, anniversaries, deaths or other losses can act as precipitators to the act of self-harm.

Check Your Progress Exercise 5

Note: a) Read the following question carefully and answer in the space provided.

b) Check your answer with that provided at the end of this Unit.

1. On the basis of the above three factors (long-term/short-term vulnerability and precipitating factors), make a formulation of the illustrative case.

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14.6.2 Treatment

A crisis intervention model is often most appropriate, when initiating treatment. At the end of the interview, the assessor should be able to plan what action is to be taken collaboratively with the patient. This may involve treating any underlying mental illness or substance abuse appropriately, counselling, improving lifestyle, helping patient to develop coping skills to resolve stressful situations.

Useful Tips when Dealing with a Case of Self-Harm

- Understand that self-harming behaviour is an attempt to maintain a certain amount of control which in and of itself is a way of self-soothing
- Let the person know that you care about him/ her and are available to listen
- Encourage expressions of emotions including anger
- Don't make judgemental comments or order the person to stop the self-harming behaviour – people who feel worthless and powerless are even more likely to self-injure

Management of persons who engage in deliberate self-harm should focus on three major areas:

- Immediate medical management of self-harming behaviour
- Management of underlying psychopathology (medications and psychosocial therapies)
- Measures to prevent the recurrence of self-harming behaviour

Support, and especially company, should be mobilized, especially in the short term. A significant aspect of such intervention is the elimination of the patient's access to potentially lethal means of suicide. Other health strategies that may

prove important are telephone helplines, and more global social support measures. The patient may be given a “crisis-card”, which carries advice about seeking help in the event of future suicidal feelings. Self-help booklets may also be helpful in reducing repeat attempts in those without a borderline personality disorder.

Some of the **specific psycho-therapeutic modalities** that have been used with the individuals who self harm are:

Problem-solving therapy: Problem solving therapy is a brief treatment aimed at helping the patient to acquire basic problem solving skills, by taking him through a series of steps:

- Identification of personal problems;
- Constructing a problem list which clarifies and prioritizes them;
- Reviewing possible solutions for a target problem;
- Implementing the chosen solution;
- Reappraising the problem; and
- Reiterating the process.

The therapy also includes training in problem-solving skills for the future. It usually involves about six sessions lasting one hour, with some reading materials and work to be undertaken between sessions. Problem solving therapy has been shown to be an effective treatment for self-harm and mood and social adjustment.

Dialectical Behaviour Therapy (DBT): This treatment was introduced to primarily help those who engage in chronic and repetitive self-harm, particularly when they have associated borderline personality characteristics. This treatment is intensive, involving a year of individual treatment, group sessions, social skill training, and access to crisis contact. Treatment studies indicate that DBT is effective in reducing some of the features associated with patients with borderline personality disorder, particularly self-harming behaviour.

Family therapy: Family therapy has been found to be especially useful for adolescents and young adults who self-harm. It has been found that many adolescents who self-harm have family problems. Moreover, when an adolescent or young adult engages in self-harm, it can be a very distressing event for the family members. They may be confused about their role or be feeling guilty about the child’s act. It is important to establish an alliance with family members (without taking sides) by empathizing with their situation and giving them a reflective listening.

The main aim of family therapy is to help the adolescent and her/his family to resolve the difficulties that led to self-harm. Family therapy is focussed on improving communication and problem-solving within the family. It can also help to restore the equilibrium of the family system if it had been negatively affected by the episode of self-harm. Finally, family therapy may help in prevention of further episodes of self-harm.

Certain key issues may need to be addressed in family therapy:

- ***Privacy:*** Parents of individuals who harm themselves often fear that their child may self-harm behind closed doors. The youngster demands privacy

by stating, “I am independent, leave me alone,” while at another level he may be testing whether the parents are able to understand the unsaid, “I hurt and I need your help.” These conflicting messages need to be dealt in family therapy sessions wherein the competing tension within each conflict can be taken up in discussions. The issue of parent-child boundaries must be continually addressed and appropriate roles must be clearly defined and reinforced.

- ***Suicide and serious harm:*** A clear contract for ensuring that the adolescent does not intend and will not seriously harm him/her self may be made (a written and signed “No suicide contract”). It often has the conditions for immediate hospitalization spelled out. Parents also need continuous support in setting limits to unacceptable behaviours (saying “No” firmly but without harshness) despite their worries of sparking a self-harm episode.
- ***Balancing needs and desires:*** Families often need help on where to draw a line between freedom and firm limits. The role of the therapist is to facilitate understanding between family members as to their needs and desires and also to negotiate some practical compromises between competing interests. Helping families acquire strategies for communicating and negotiating even in the midst of charged emotional encounters also models to the adolescent the need to use problem-solving strategies and directly address tough issues rather than acting them out.
- ***Cutting and blame:*** Often the adolescent who indulges in self-harm attributes it to external stressors, which is very often the parents and their behaviour, “My parents just don’t understand me; they think I am still a kid and can’t make any decisions”. On the other side, parents may take this to heart and assume that they, solely, are responsible for their child’s dysfunctional behaviour. Thus, the goal in therapy is to place the blame squarely to where it belongs. If it’s the adolescent’s mistake, then it’s the therapist skills that would come handy in making him/her accept the mistake without losing face. One way of achieving it is to make the parents talk about their “faults” when they were adolescents. Also, the adolescent should be appreciated for honestly accepting their role in their behaviour and the parents can be quieted in their critical, judgmental and “I told you so” attitude.

Pharmacological and clinical management: Antidepressants have a proven role when depression or anxiety is detected but are unlikely to have a role in cases where mood disorder has been carefully excluded. Psychiatric admission remains a valuable option when risk is high and/or serious mental health problems cannot be otherwise resolved. Regular follow up reduces the subsequent rate of deliberate self-harm.

Useful tips that can be given to patients for stopping self-harm

- Writing about how you are feeling.
- Doing relaxation exercise.
- Distraction (doing some pleasurable activity).
- Going for a run, brisk walk, dancing, any form of exercise.

- Talk to a friend or your therapist — have a list nearby of people you can ring.
- Find meaningful activities to do (e.g. voluntary work).
- Do not keep extra medicines/pills or pesticides in the house.
- Do not keep sharp objects (e.g. knife, blade etc.) near you.

Check Your Progress Exercise 6

Note: a) Read the following question carefully and answer in the space provided.

b) Check your answer with that provided at the end of this Unit.

1. List some of the therapist's characteristics when dealing with a patient with history of self-harm.

.....

14.7 REFERRAL

Risk of subsequent suicide is particularly high in those with high unresolved suicidal intent, depressive disorder, chronic alcohol and drug misuse, social isolation, and current physical illness.

The most common psychiatric condition associated with suicide or serious suicide attempts is depression, and also rates of depression are substantial after self-harm. Depression is a strong predictor of further self-harm. Suicidal thoughts and behaviour are state related in depression; and resolution of the depression will almost invariably alleviate thoughts of suicide. Personality disorders, alcohol and substance abuse, anxiety disorders, and schizophrenia are also frequently associated with suicidal behaviour. About 20% of those who attempt self-harm repeat it multiple times. This group is much more likely to include individuals with persistently maladaptive ways of coping, typically in the form of unhelpful personality traits. Chronic alcohol and drug problems are a strong risk factor for self-harm and eventual suicide. Current intoxication at the time of self-harm may indicate an impulsive (disinhibited) attempt, but its link with chronic alcohol problems should be explored and taken seriously.

Physical illness can be very distressing, especially when progressive or unpredictable. In a large multi-centered transnational study, 50% of people had a physical illness at the time of the attempt for which they had sought help. Frequently, physical illness is a risk factor for complete suicide without a previously detected attempt. Isolation is a risk factor for suicide and particularly for self-harm. The majority of suicides in the elderly involve those who are single or widowed.

Frequent repeaters, those with alcohol and substance use problems, those with physical or mental illness, and those who are isolated also require input from specialist mental health professionals. It is also recommended that adolescents and elderly people warrant a mandatory specialist assessment. Patients with one or more of these risk factors should be offered enhanced care that may include inpatient or outpatient follow up care, a list of local support resources, and, where possible, self help material.

14.8 LET US SUM UP

Self-harm is more common than it is usually believed. It is usually defined as an expression of personal distress. An individual episode of self-harm might be an attempt to end life. Self-harm may be more common in young females but it may occur in any age group and in both genders. Various ways of harming self are used, with cutting and self-poisoning being the most common. The nature and meaning of self-harm vary greatly from person to person. In addition, the reason a person harms him or herself may be different on each occasion, and should not be presumed to be the same. Many people self-harm as a way of coping or escaping from a painful situation. Many biological, familial, social and psychological factors have implicated in self-harm. Management includes immediate medical management of injury and then long-term help to deal with underlying issues. While dealing with individuals with self-harming behaviours, it is essential for the counsellor to maintain an empathic and non-judgemental approach in both assessment as well as treatment; and adopt evidence-based and longer-term strategies to help individuals with self-harm problems.

14.9 GLOSSARY

- Empathy** : The capacity to recognize or understand another's state of mind or emotions.
- Predisposing factors** : Genetic, attitudinal, personality, and environmental factors that are associated with health, or lack of it, in a person.
- Precipitating factors** : Factors associated with the definitive onset of a disease, illness, accident, behavioural response, or course of action.
- Self-Harm** : An acute non-fatal act of self-harm carried out deliberately in the form of an acute episode of behaviour by an individual with variable motivation.

14.10 ANSWERS TO CHECK YOUR PROGRESS EXERCISES

Check Your Progress Exercise 1

1. (v) Suicide

Check Your Progress Exercise 2

1. Yes. A person who indulges in self-harm once (whatever be the reason) has a very high probability that he/she may do it again.

Check Your Progress Exercise 3

Dealing with Deliberate Self-Harm

1. Option (vi) - Mental Retardation. Self-injury that has not been carried out without an understanding of its nature and consequences, as in the case of mental retardation, is not considered self-harm.

Check Your Progress Exercise 4

1. Option (i) - As a counsellor, you should never ignore such signs. It is important to approach the patient in an empathic and non-judgemental manner and enquire about the injury marks. It is also important not to talk to family members before talking to the patient.

Check Your Progress Exercise 5

1. Long-term vulnerability factors: Depression in mother, conflictual family environment, dysfunctional personality variable, like, poor frustration-tolerance

Short-term vulnerability factors: Break-up with girl-friend, difficulties in office, symptoms of depression

Precipitating factors: Distressing thoughts about suicide and his girl-friend, lack of sleep

Check Your Progress Exercise 6

1. Therapist should be empathic, non-judgmental, good listener, and be able to deal with counter-transference issues.

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