Indira Gandhi
National Open University
School of Social Work

MSW-016
Fields of Counselling

Block

2

HEALTH CARE

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BLOCK INTRODUCTION

The block titled "Health Care" consists of five units which highlights the importance of counselling in health care setting. It is being reported that in health care setting, anxiety and fear can be caused by lack of information or clarity about what is happening or going to happen and its implications. This block provides adequate understanding of counselling in health counselling with special emphasis on hospitals, palliative care and hospice care and other important areas such as mental health counselling, HIV/AIDS/STD counselling, counselling for caregivers and counselling for the terminally ill.

Unit 1 is about "Counselling in Health Care Settings". The unit helps the learner to understand the responsibilities of the hospital counsellor, role of hospital administration and the scope of counselling in hospitals. It also helps you to know the standards for counselling based on various principles. This unit attempts to provide an understanding of palliative care and the principles and services of palliative care. It focuses on pain management and suffering in palliative care. It also discusses on hospice care, hospice services and the role of the hospice counsellor. The unit will familiarize the learner with some of the areas for special focus in palliative care and hospice care.

Unit 2 "Mental Health and Counselling" describes the concept of mental health, definition and scope of mental health. It throws light on the view of mental health in India. The unit provides the conceptual map of the variables that have impact on mental health status. It discusses the different mental health practice models. The unit stresses the importance of mental health and counselling as an important tool in enhancing the mental health of an individual, and finally elaborates the types of counselling.

Unit 3 "HIV/AIDS/STD Counselling" focuses on different aspects such as the history and basic information about HIV/AIDS which are necessary for counsellors. It also talks about the stages of HIV infection, diagnosing and tests for HIV/AIDS. The unit explains the mode of transmission of HIV and importance of risk assessment and counselling HIV/AIDS client. It also provides the essential principles in HIV/AIDS counselling, role of the counsellor in pre-test counselling and post-test counselling. The unit further explains the treatment for HIV/AIDS and also discusses the legal and ethical issues related to HIV/AIDS. Finally the unit briefs about STDs and the strategies adopted by the government to control STDs.

Unit 4 is about "Counselling for Caregiver". The unit introduces the term care giver, meaning of care giving and the major types of care givers. It provides the characteristic features of care giving and the effects/challenges of care giving. The unit focuses on specific health effects of care giving stress and discusses the importance of counselling to care givers which helps in minimizing their problems. It also explains various types of care-giving interventions. The unit highlights on the emerging trends, family as caregivers, role of caregivers, role of caregivers in different settings, role of social workers and finally concludes giving few self tips for the care giver.

Unit 5 "Counselling for the Terminally Ill" discusses the needs of the terminally ill. It gives an idea about how to recognize and manage depression and anxiety in the terminally ill. The unit talks about grief and bereavement and the importance of grief and bereavement counselling. It also explains about dysfunctional grieving and grief therapy. The unit discusses the importance of working with terminally ill children, addressing care giver issues and finally highlights on the self care of the counsellor.

UNIT 1 COUNSELLING IN HEALTH CARE SETTING

Structure

1.0 OBJECTIVES

By the end of this unit, you should be able to:

- understand the responsibilities of the hospital counsellor, role of hospital administration and the scope of counselling in hospitals;
- know the Standards for Counselling based on 4 principles;
- understand palliative care, the principles and services of palliative care;
- understand pain management and total suffering in palliative care;
- distinguish between hospice care and palliative care;
- understand hospice care, hospice services and the role of the hospice counsellor;
- be familiar with some of the areas for focus in palliative care and hospice care.

1.1 INTRODUCTION

Counselling in health care settings can be very different from any other counselling milieu. A new entrant to this field is required to acquaint himself with new procedures, processes, practices and systems. He will need to face various circumstances in a range of health care settings, with confidence, compassion and professionalism.

Counselling is not a profession that offers instant solutions to problems or quick fixes, and there are many things it cannot do; it cannot provide a cure for disease, but what it can accomplish is to help people see their situation differently and offer them hope. It can help someone to clarify his or her life situation, see what options are available, and decide a future course of action.

Particularly in health care settings, anxiety and fear can be caused by lack of information or clarity about what is happening or going to happen and its implications. Someone who is suffering from chronic illness and inadequately informed about his condition may be too apprehensive to take appropriate action. The ultimate goal of counselling is to liberate the person being counselled to live more fully, and this happens through appropriate action. The counselling process must be aimed at empowering the patient or client to become confident enough to choose a line of action and follow through on it.

The health care environment whether it is hospital, primary care, specialist or community

setting, influences the counsellor's role and as well as the therapeutic process. A common characteristic of the health professions is that the professional develops close and personal bonds with his client. The counsellor needs to be professionally qualified and well-informed in his field, and to understand how his work fits in with the work of others in the caring team; importantly, the counsellor should also be aware of how the physical, emotional, social and spiritual distress of his patients or clients influences him on a personal level as well as in discharging his professional responsibilities.

1.2 COUNSELLING IN HOSPITALS

Counselling services are a significant part of the health care system, and these services need to be incorporated into the health care delivery system. Every patient in need should have access to counselling services.

In today's health services, more and more efficiency is being demanded of all health workers. In addition to his professional expertise and skills the counsellor can offer his patient the precious resource of private uninterrupted time. In medical care today there is an innate tendency to let a chasm or gap develop between purely clinical or technical care, and psychological care. Counsellors in hospitals and other medical settings may let health workers go on with the responsibilities requiring detachment, whilst the counsellors provide the listening and response needed by the patient.

Certain basic facilities, infrastructure and systems need to be in place for counselling in hospitals to effectively meet the needs of patients and clients and the objectives and mission of the hospital administration. These are discussed below.

Facilities Required for Hospital based Counselling & the Role of Hospital Administration

Hospital management should ensure that there is adequate space for counselling, well lit and ventilated with minimal distractions, where privacy can be maintained. The rooms should have the following:

- Table(s) and Chairs.
- Secure cupboards for locking up equipment and confidential records.
- Filing cabinet.

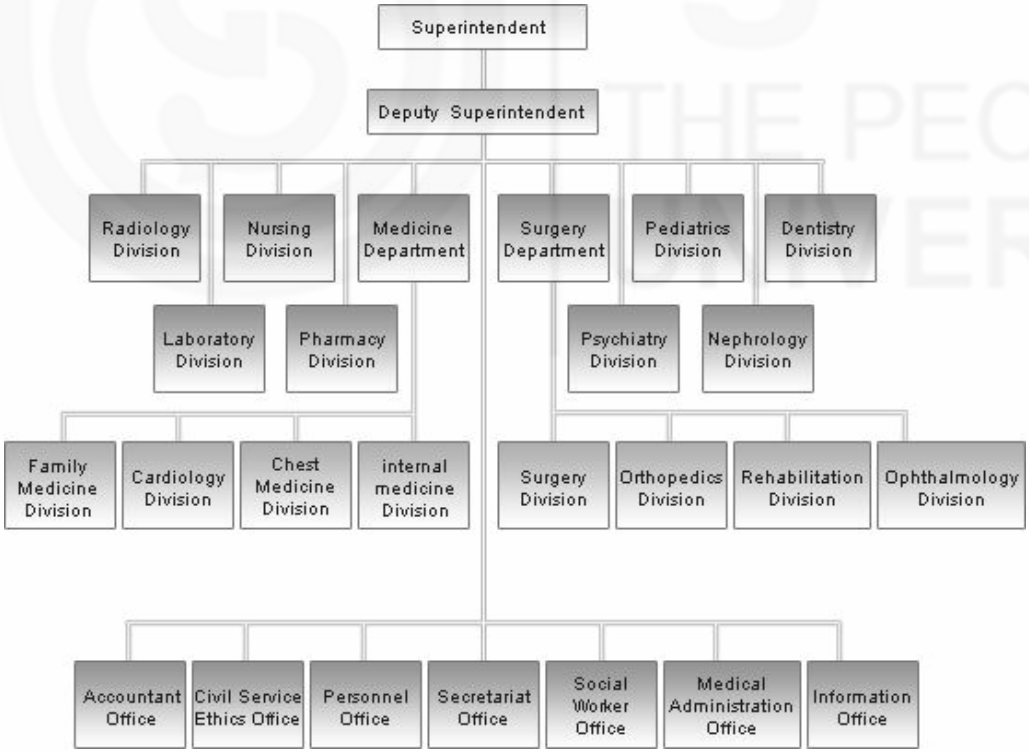
The hospital administration should provide for:

- On-the-job training of the counsellor.
- Sensitization on counselling for the rest of the hospital staff.
- Logistical support for the counsellor.
- Liaison with GOs and NGOs and other social support systems in the community for continuity of care.
- Updates on the latest developments in the field of counselling to the counsellor.
- An annual budget for the counselling service.
- Setting up a clear referral system from or to the community.
- Conducting regular performance appraisals and proper monitoring.
- Including the counsellor in a hospital committee.

Responsibilities of a Hospital based Counsellor

1. To provide counselling services to clients/patients in need in the hospital setting.
2. To follow a time-table for counselling and regular follow up of clients/patients.
3. To adhere to professional ethics when providing counselling services.
4. To keep all information on the client/patient confidential.
5. To develop a system of documentation and reporting that is regularly updated and reported to hospital management.
6. To collaborate with other counsellors and professionals in the hospital and work as a team.
7. To sensitize the hospital community on counselling and to promote counselling in the hospital.
8. To develop a networking and referral system in collaboration with hospital management.
9. To provide on the job training on counselling to counselling trainees and other professionals.
10. To set time for supervision for both peer group and vertical supervision.
11. To be a resource person for the hospital and teaching institutions attached to the hospital.
12. To carry out any other job related to counselling that may be given by hospital management.

The counsellor may report to the Medical Superintendent or Deputy Superintendent and may be attached to the Social Work Department or office of the hospital.



Hospital Organization Chart

Source: http://www.flvh.gov.tw/english/web/01about/04organization_1.htm Accessed 01.12.10

The Scope of Hospital Counselling Services

Specific types of counselling may be required depending on the particular need of the client or patient – supportive counselling, risk reduction counselling, bereavement or grief counselling, informative counselling, educational counselling (e.g. tutoring trainees), pre and post delivery counselling, crisis counselling, post-trauma counselling, counselling in spiritual distress, genetic counselling, pre and post test counselling (e.g. for HIV/AIDS) or rehabilitation counselling.

The counsellor may need to work with HIV/AIDS patients, the terminally ill, the bereaved, those in crisis (e.g. rape or abuse), substance abusers, parents of seriously ill children (e.g. neonatal intensive care counselling), those with psychological problems (e.g. depression, anxiety), pre and post surgical patients, those with disfigurement, infertile patients, orphans, those with hereditary diseases, Alzheimer's patients and their families, cancer patients, those with heart disease, high risk groups, those with spinal cord injury or paralysis, parents of children with special needs, psychiatric patients and their families, those recovering from Post Traumatic Stress Disorders, those with renal failure, patients being treated for STD's, pregnant women, or health workers and hospital employees.

The counsellor may meet the patient or client in hospital wards – either medical or surgical wards, out patient clinics, antenatal clinics, HIV testing centres or other health care centres, or at patients' homes.

Referral System

The hospital counsellor should know the procedure for referring a patient or client for further help. A clear referral system should be followed, for which a clear and simple referral form should be designed and made available at the hospital. The counsellor may refer a client for laboratory investigations, psychiatric help, legal advice (e.g. in the case of rape), to a relevant NGO or community support, or to a home based care provider for follow up. On all occasions, care should be taken to maintain the confidentiality of the client. Within the hospital, a client can be referred to the counsellor from any unit of the hospital.

Standards for Counselling

Standards for Counselling are based on the following principles:

1. Competence.
2. Confidentiality.
3. Responsibility.
4. Accountability.

The purpose of these standards is to provide the counsellor with a framework within which to work in accordance with the code of professional ethics. Within the hospital setting these standards of counselling should be applied in the following ways:

Competence

The counsellor must be aware of the expectations, needs and concerns of the type of client he/she is working with, e.g. AIDS patients, the bereaved, adolescents, the terminally ill etc. The counsellor must also have accurate and up to date information on issues affecting these clients, e.g. end-of-life issues in the case of the terminally ill.

The counsellor must be well trained and qualified to do his job – he should have completed

a basic course in counselling training and should systematically seek avenues for enhancing his professional competence, skills and self awareness. The counsellor must know the limits to competence and seek appropriate help wherever needed, through referral or supervision.

Confidentiality

The counsellor must never reveal information about the client to anyone without securing his/her consent, except when there is intention to commit suicide/crime or cause serious harm to another person. The client should be made aware that the counsellor will not keep confidential any information that will harm him/her or another person. When it is deemed necessary for the counsellor to break confidentiality (for the betterment of the client) he should use his discretion as to what and how much to reveal, and to whom.

The counselling environment should facilitate and ensure confidentiality of the counselling process; the room set aside for counselling should be well ventilated, calm and offer privacy, and also be clean, adequately furnished with a secure place where records can be stored and locked. The counsellor must also devise a recording system that does not violate confidentiality, e.g. using a code number on files instead of clients' names.

Responsibility

The counsellor must uphold professional ethics at every stage of the counselling process; recognize the value and dignity of clients irrespective of status, age, race, sexual orientation, beliefs, etc.

The counsellor must maintain a professional relationship with the client. If the counselling relationship becomes emotionally unmanageable or otherwise difficult to handle, he should immediately refer the client and seek advice from his supervisor; he must promote and facilitate the self development of clients, be dependable, reliable and faithful, and be committed, attentive and resourceful in meeting the needs of his clients in the hospital setting. The counsellor must also be mindful of his position as a representative of the hospital, be a part of the system and be true to the vision of the hospital.

Accountability

The counsellor is accountable to his client and should facilitate growth and change without causing detriment to the client and undermining his or her individuality; the counsellor should encourage clients to improve their life skills while respecting their uniqueness as individuals.

The counsellor is also accountable to stakeholders like the hospital administration, sponsors, etc. A major issue in accountability is showing "results", or the counsellor's work being linked to outcome. This can be very complex, as often the desired outcome of counselling may occur outside the location where counselling is done, may differ from one client to another, or may happen without the client even being aware of it (e.g. subtle attitudinal or behavioral changes). It may also involve a sequence of steps where it may not be easy to show progress toward the long term goals of the counselling process. So it becomes important to develop a complete program evaluation plan by experts familiar with both counselling theory and program evaluation.

Documentation of the counsellor's work is an important aspect of maintaining accountability. The counsellor should show not only that he can provide services that meet both professional standards and the requirements of the counselling program, but should offer evidence that he is actually providing such services.

Documentation and Record Keeping

The counsellor has to meticulously keep records of his work while ensuring that they are stored securely under lock and key to protect confidentiality. The following records may be maintained:

a) A registration card for every client/patient.

b) A summary of counselling sessions for each client.

c) A list of presented problems in coded form.

d) A register book for clients' names and their code numbers.

e) A directory for his/her referrals.

f) A diary of Supervision.

The simplest method of recording is by using a card file with index cards, keeping confidentiality in mind. The drawback of this is not being able to write detailed notes, so the counsellor may need to keep a notebook or a ring binder for this purpose.

A better alternative is to have a computerized system of recording using a computer database, which is also a secure way of storing confidential information (by using a password). A separate form can be kept for the client's personal details and other forms for each counselling session. Then the various forms can be linked together to review the client's progress – this is called a relational database. All the forms for a particular client are linked together by a unique number allocated to each client.

Client's name: Kumar, Anil
Address:
Date of referral:
Referred by:
Referred from:
Client No.1221
Date of counselling session:
Notes about the session:
Client No. 1221

Two forms in a relational database program for recording counselling sessions

The counsellor may want to record in the "sessions" form details about:

- The clients' feelings.
- The support system of the client.
- Points discussed during the session.
- The counsellor's own feelings during the session.
- Short term aims.
- Long term aims.
- Summary of the session.
- Agreed time and date of the next session.

Check Your Progress I

Note : Use the space given below for your answers.

1. What are the principles to be followed for standard counselling?

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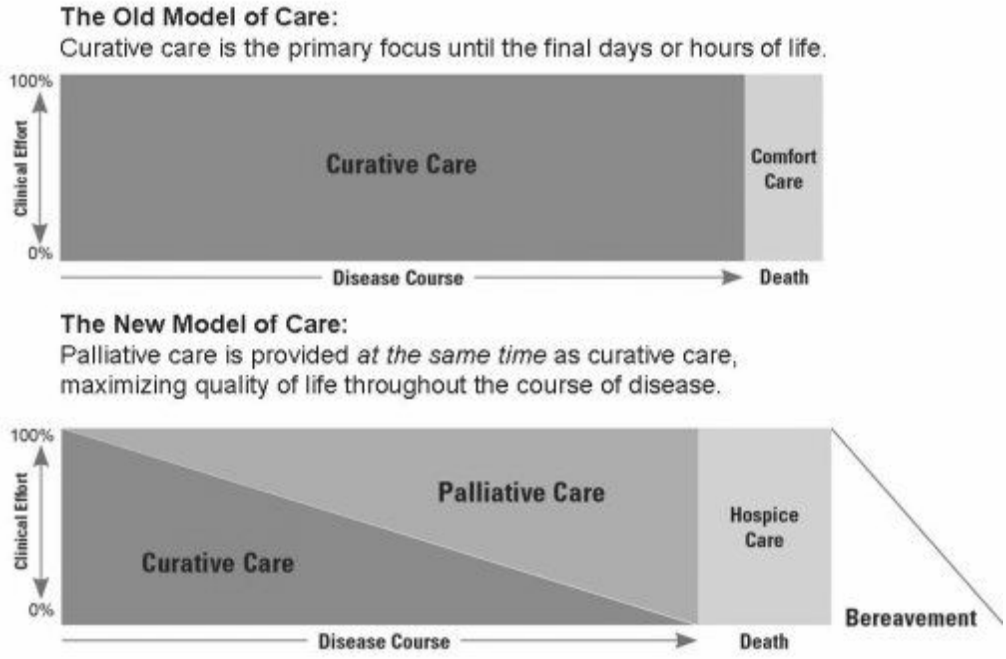
1.3 PALLIATIVE CARE

Palliative care (from Latin *palliare,* to cloak) refers to any type of therapeutic care or treatment that is focused on controlling the severity of disease symptoms, rather than trying to arrest, delay, or reverse progression of the disease itself or provide a cure. The goal is to prevent and alleviate suffering (physical, mental and spiritual) and to enhance quality of life for people facing grave, complex illness. Non-hospice palliative care can be distinguished from hospice care as it is not dependent on prognosis and is offered along with curative and all other appropriate forms of medical treatment.

A World Health Organization statement (2008) describes palliative care as ***"an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."***

The term "palliative care" is increasingly used in connection with diseases other than cancer such as chronic, progressive pulmonary disorders, renal disease, chronic heart failure, HIV/AIDS, and progressive neurological conditions. Palliative care has been helpful in situations of all kinds, from the elderly to children. The rapidly growing field of pediatric palliative care has undoubtedly revealed the necessity for services tailored specifically for children with serious illness. Parents whose children have been diagnosed with cancer or other terminal or chronic illnesses find it especially helpful because they can find a package of total care with palliative care.

Although the concept of palliative care is not recent, most physicians have traditionally concentrated their professional skills on trying to cure patients. Treatments for the alleviation of symptoms were viewed as hazardous and seen as inviting addiction and other unwanted side effects.



Source: http://www.thechristhospital.com/PalliativeCare Accessed 01.12.10

Non-hospice palliative care is suitable for anyone with a serious, complex illness, whether they are expected to recuperate completely, to live with chronic disease for an extended period of time, or to experience disease progression. In contrast, although hospice care is also palliative, the term hospice applies to care administered towards the end of life.

Palliative care

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible;
- offers a support system to help the family cope;
- uses a team approach to address the needs of patients and their families;
- will enhance quality of life;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy.

Palliative Care Services

One of the exceptional things about palliative care services is that the attention and care is not restricted just to the patient - the palliative care team also provides support and guidance for the family members and friends of those with serious, complex illness that may be chronic or terminal. In the case of end of life care, this assistance goes on for some time after the patient passes away, in the form of bereavement counselling, rehabilitation, and so on. They will be guided through various practical matters such as

the processes of preparing for the funeral, handling powers of attorney, sending notices to family members, as well as dealing with grief.

Frequently, grief begins as soon as the patient enters into palliative care, so the team will want to assist the family as well with anything they may require. The process of death can sometimes be long and painful, and palliative care specialists can help the family to emotionally and practically cope by serving as guides and mentors.

Palliative care, which is also sometimes called comfort care, subscribes to the view that it is not only the dying who suffer, but also the living. They desire to ensure that all patients are given the maximum in quality care and that they understand their options for treatment and can get whatever they need to be comfortable and pain free.

Palliative care can be held in a hospice, in a hospital, or even at home. Families can choose the services they will require to meet their particular needs. Some of the palliative care services include:

- Nursing
- Physiotherapy
- Individual & Group Therapy
- Social Services
- Nutrition Advice
- Consulting
- Spiritual Guidance & Support
- Hospital Equipment Loans (such as bedding and other medical equipment for the home)
- Communication between Patient and Doctor
- Day Care for Children
- Pastoral Care & Ministry
- Legal assistance
- Bereavement Support

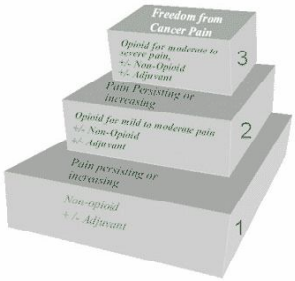
Fundamental Principles of Palliative Care in intensive care units

Chart 4 : Fundamental principles of palliative care in intensive care units
Accept death as natural end-of-life process
Always give priority to the patient's best interest
Reject futility: diagnostic and therapeutic
Do not shorten life nor prolong the process of dying
Warrant the quality of life and of death
Relieve pain and other associated symptoms
Heed the clinical, psychological, social, spiritual aspects of patients and relatives
Respect the patient's autonomy and of the legal representatives
Assess the cost-benefit of each medical attitude taken
Encourage interdisciplinarity as an assistential practice

Source: http://www.scielo.br Accessed 01.12.10

Pain Management in Palliative Care

Pain management is one of the critical elements of palliative care to ensure that the patient is comfortable and does not suffer pain unnecessarily. WHO has developed a three-step "ladder" for pain relief:



WHO's Pain Relief Ladder

Source: http://www.who.int/cancer/palliative/painladder/en/ Accessed 01.12.10

If pain occurs, drugs should be orally administered without delay, in the following order: nonopioids (aspirin and paracetamol); then, as necessary, mild opioids (codeine); then strong opioids such as morphine, until the patient is free of pain. To calm fears and anxiety, additional drugs – "adjuvants" – should be used.

To maintain freedom from pain, drugs should be given "by the clock", that is every 3-6 hours, rather than "on demand". This three-step approach of administering the right drug in the right dose at the right time is inexpensive and 80-90% effective. Surgical intervention on appropriate nerves may provide further pain relief if drugs are not wholly effective.

Addressing "Total Pain"

Establishing a safe way for the individual to address his or her physical and psychological distress, is an important aspect in providing effective palliative care; this distress at many levels is also referred to as *total pain*, a concept first introduced by Dame Cicely Saunders who pioneered palliative care in the 1950's. In her words: *"The whole experience for a patient includes anxiety, depression, and fear; concern for the family who will become bereaved; and often a need to find some meaning in the situation, some deeper reality in which to trust."*

Dealing with total pain begins with treating physical symptoms such as pain, nausea and breathlessness. Palliative care teams have become very adept at prescribing drugs for physical symptoms, and have dispelled some of the apprehensions and misconceptions surrounding the use of opioids such as morphine to manage extreme pain, and also shown how drugs such as morphine can be used safely while maintaining a patient's full faculties and function. However, when a patient shows a physiological symptom, there are often psychological, social, or spiritual symptoms as well. These are often interconnected – for example, a patient's pain threshold may vary according to his levels of stress and mental well being.

The interdisciplinary team, which often includes a social worker or a counsellor, can play a part in assisting the patient and family to address and cope with all these symptoms simultaneously, rather than relying just on medical or pharmacological interventions. The typical concerns of a patient in palliative care are pain, loss of control, worries about the future, loss of independence, worries about their family, and feeling like a burden. Needs vary from individual to individual - some patients will want to talk about emotional or spiritual concerns while some will not. It is important to take an individualized approach - to look at each patient and their family members separately to assess their need for this kind of support. Depriving an individual and their support system of an opportunity to explore psychological or spiritual concerns is as equally damaging as forcing them to confront and deal with issues they either do not have or choose not to deal with.

1.4 HOSPICE CARE

Hospice care is a specialized type of palliative care normally provided during the last few months of a person's life. It can be distinguished from palliative care, since unlike hospice care those with a life-limiting disease may receive palliative care in the *early stages* of their illness, to ease pain and other physical symptoms and to support them in coping with how the illness impacts their daily living and family. The goals of both palliative care and hospice care are to relieve suffering, which may be physical, emotional or spiritual, and to improve quality of life.

Hospice care upholds the dignity of terminally ill persons, empowering them to live their last weeks and months as they choose and assisting them to die with peace and dignity. It focuses on the needs of both the patient and the family, helping to create environments that promote emotional support and spiritual healing. Hospice care neither prolongs nor hastens the dying process.

The philosophy of hospice care is that just as with any other stage of life, the end of life is a significant phase, very much as important and meaningful as those that came before, and hence, it is worthy of putting in a great deal of attention and effort to make that period as comfortable, pain-free and dignified as possible. Compassionate, family-centred care can assist patients to live the final days of their lives in much the same way that they lived previous stages – cared for, supported and surrounded by those that they hold dear.

Hospice Services

Hospice services are quite individualized – the unique needs of each family largely determine the specific services provided by hospice teams. Some families request only companionship and possibly assistance with personal hygiene, while other patients and their loved ones may require more intensive services. Hospice team members are trained and prepared to offer psychological counselling, spiritual guidance, pain management, and symptom control. The team may attend to practical needs such as insurance coverage, transportation, and assistance with bathing in addition to addressing emotional and spiritual needs such as caregiver stress, grief, and fear of dying.

Care plans are customized to address the changing needs of each patient, with fine-tuning of services made throughout the period of care through a series of consultations with family members. Hospice care continues with the patient's family even after the death has taken place, with bereavement care available for about a year to help loved ones through the grieving process.

Some people misguidedly perceive hospice care as being services for those who have "given up," but there is a real distinction between accepting that death is imminent and simply giving up hope. In addition, if a patient's health condition unexpectedly gets better, they can discontinue hospice care, and return to it if required at a later time.

Hospice care is available 24 hours a day, seven days a week. Care is provided by an interdisciplinary team including the physician, psychologist, nurse, social worker, chaplain, pharmacist, nursing assistant, volunteers, nutritionist, and physical therapist. Care may be provided in a person's home, nursing home, hospital, or independent facility devoted to end-of-life care.

The Hospice Counsellor

A hospice thus provides medical, emotional, and spiritual support to patients with life-

threatening conditions and their loved ones as they face end-of-life issues. The hospice counsellor belongs to that team of providers whose purpose is to guide the terminally-ill patient through his last moments of life with dignity and comfort. Counsellors in a hospice setting could be either professionals or trained volunteers.

Hospice volunteers go through intensive preparation and comprehensive training before they are assigned to individual cases, helping them to deal with not only their duties, but also to manage their own emotional response as they form bonds with and then prepare to lose patients.

Unlike other settings, the hospice counsellor has to frequently grapple with complex and emotional issues related to death and dying, grief and loss, and finding hope and meaning in the midst of pain and suffering. Levels of stress can be high among hospice team members; a hospice counsellor will see patients waste away before their eyes, and witness not only the ravages of disease but also the heavy emotional toll it takes on both patients and their families. For the most part, hospice patients are elderly, but children and teenagers also are afflicted with untreatable illnesses.

Hospice staff and volunteers must accept that their patients in due course will die. A hospice counsellor requires the right combination of empathy, compassion, inner strength, the ability to maintain a certain level of professional detachment, as well as training to be successful in this role in the long run. In this context, it would be helpful for the counsellor to enhance his professional skills with a special focus on grief and bereavement counselling.

The hospice counsellor needs to recognize the role of being a good listener. People sometimes do not know whom to turn to while coping with intensely personal and often very painful feelings about their own impending deaths, or the deaths of loved ones.

The hospice patient and his family may want to talk about the fear of dying, guilt or denial regarding the patient's health condition, or unresolved conflicts within the family circle. After the death of the patient, the counsellor will continue to support and stand by the bereaved family by letting them talk, directing them toward community services, and assuring them that their emotions are normal.

Hospice care is thus more of a philosophy or approach to care rather than a place. Hospice care is holistic: it addresses the needs of the whole person rather than just treating the disease.

Check Your Progress II

Note : Use the space given below for your answers.

1. What are some of the major palliative care services?

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2. Define hospice care.

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1.5 AREAS FOR FOCUS IN PALLIATIVE CARE AND HOSPICE CARE

Maintaining Hope after Bad News

There are several areas that can be focused on even if the patient (and his family) needs long term care or no longer has the option of seeking a cure. It is important that they still feel a certain sense of control over their lives, and have something to hope for.

One of the main impediments to negotiating goals of care in case of grave illness and poor prognosis is the matter of hope (the feeling that what is desired and wished for will happen) Unfortunately, this false sense of hope may sidetrack the patient and family from seeking and finding final meaning and value, and closing their lives together. At a point when people most need a sense of connection and closeness, the conspiracy of a falsehood may end up driving them apart.

The counsellor can assist the patient and family in identifying their own goals for palliative or hospice care, and ensuring that they are realistic. This will shift the focus of their hope: to not be in pain, to die peacefully, to know my family will be ok, etc. Patients and their families may experience some feelings of hopelessness. This is to be expected and part of the normal course of grieving and reaching a stage of acceptance. They may also express anger. This is also a normal emotional reaction.

It is important for the counsellor to be aware of the culture of the patient and family – the chief decision maker in the family, whether they prefer to talk about "bad news" directly and openly or otherwise. Some cultures prefer that medical information, particularly that of a life-threatening prognosis, be given to the family and not the patient. The counsellor should decide which communications should be made only to the patient, or only to the family or both.

In some cases cultural generalizations may not be relevant to particular individuals; as such it may be a helpful approach to find out from the patient in the early phase of the relationship how he or she would like information to be dealt with and who should be making decisions, preferably in the context of a family meeting so that everyone can hear the same information.

Understanding Prognosis Helps to Cope and Plan

Prognosis is important to patients and families for a number of reasons - most importantly, an understanding of what might happen helps them to cope, respond, and plan for their future. In the absence of sound, clear information about what the future is likely to bring, patients and families may opt for treatments they would otherwise turn down, and miss significant opportunities for growth and life closure.

Questions that can be used to elicit patients' values and goals for medical care at the end of life, to help them prioritize, and to express their emotions:

- What are you expecting?
- What do you most want to accomplish?
- What is most important in your life right now?
- What are you hoping for?
- What do you hope to avoid?
- What do you think will happen?
- What are you afraid of will happen?
- What do you expect the end to be like?

Examples of patient values and preferences:

- No matter what happens, I want to stay at home, no more hospitals.
- I'm worried what all of this will cost my family.
- What I fear most is pain.
- I would like to be alert and aware as long as possible.
- If I live to see my daughter married, I'll die happy.
- When death comes, I want my family around me.
- I don't want my wife to have to quit her job to take care of me.
- My wish is never to be hooked up to machines.
- It's important to me to live as long as possible, and to go out fighting.
- It is important to me to try everything there, to cure my child.
- I don't want my child hooked up to machines.

Questions to Assess Unresolved Issues at the End of Life

- Is there something that you would like to do before you get too sick?
- Many people have old differences they would like to settle before they die. Do you?
- Many people have places or people they would like to visit. Do you?
- Some have a piece of work they would like to finish. Do you?
- In what ways has this illness affected you emotionally?
- Are you doing things that you enjoy?
- How has your mood been lately?
- How have you been coping with all of this?
- How have you handled stress in your life?

- Are you concerned about being a burden to others?
- Do you feel in control of your life right now?
- Have you thought about taking your child on one more trip before she dies?

Fears and Concerns about Death and Dying

Patients frequently will be thinking about death and dying, with questions such as:

- How will I die?
- Where will I die (home, nursing home, ICU, hospice etc.)?
- What do I need to do (estate planning, life review, advance care planning etc.)?
- How will my child die? Where will my child die?

The counsellor may encourage and give permission for people to talk about these issues weighing on their minds, by broaching the subject in a general way by saying: "Many people in your situation think about dying. Is that something you are thinking about?"

Changes and Losses

As patients confront these questions, they also have to cope with significant changes and losses. In their private world, they will be likely to have the following concerns:

- Who will care for the people I love that depend on me?
- Who will care for me?
- Will I be a burden?
- Will they still love/respect me?
- What about my job?

Parents of a dying child will be thinking:

- How can I go on without my child?
- How can I let my child die?

Loss of Control

People face, or fear, loss of control in various areas:

- Loss of control over the body, including the ability to feed, bath, and toilet oneself, is without doubt a common concern.
- Independent people suddenly and unexpectedly face dependence .
- These losses of control are associated in many people's minds with indignity and shame.
- Plans are thwarted by the illness.

Social Assessment of Patient & Family

Illness influences the social circumstances of life, and conversely, social conditions impact illness. The specialty of social work should be suitably incorporated into the treatment team to assist the patient, family, and physician.

The following areas of a person's social environment are relevant to the evaluation of suffering in the social dimension:

- Family and family dynamics.
- Community support available to the patient.
- Financial resources available to the patient.

Spiritual Assessment

Relevance of the Spiritual Life to Social Assessment:

- Each person has a spiritual or transcendent dimension to his/her life.
- Physicians frequently hesitate to inquire into this universal facet of human experience, yet studies suggest patients welcome the inquiry.
- Spiritual life means different things to different people – for some it is in terms of religious feeling, and for others in terms of personal meaning in a larger context.

Individuals who report a strong spiritual life often also report:

- A greater sense of purpose.
- A greater sense of having come to terms with dying.
- Better communication.
- Better relationships.

It is important to take into account the possibility that patients can experience significant spiritual growth and gain meaningful fulfilment during their last stage of life.

While assessing the patient, it is relevant to know:

- How spiritual this patient has tended to be in the past?
- How inclined toward spiritual life he or she now is?
- Whether there are religious rituals that are important to the patient.

Rituals

Ask if the patient wishes to have special prayers, declarations, rituals or last actions. Someone should be sure that special prayers or actions and last prayers or declarations are carried out as the patient and family would like them to be.

Spiritual Suffering and Spiritual Crises

Many aspects of advanced illness are not normally perceived to be fundamentally spiritual. Yet the pursuit of meaning and purpose in life is a spiritual quest. Perceived loss of connection to a community or to a way of life may challenge the sense of meaning and purpose. Feelings of guilt or unworthiness may be manifestations of spiritual suffering.

If these features of spiritual suffering are not acknowledged and recognized, a suitable plan for relief cannot be put in place. Other aspects of advanced illness may be more conventionally viewed as spiritual. For example, patients may:

- Question their faith.

- Express a desire for forgiveness and reconciliation.
- Feel abandoned by God.

Approaches to Spiritual Assessment

Suspect spiritual pain in a patient who is facing a life-threatening illness, and establish a favourable atmosphere that encourages discussion of spiritual issues. Show interest and ask specific questions, such as:

- Are you a spiritual person?
- What role does religion play in your life?
- Have you thought about what will happen after you die?
- What are the things that matter most to you?
- How have you tried to make sense of what's happening to you?
- If you were to die suddenly, are there important things you feel would be left undone?
- As you look back on your life, what has given your life the most meaning?
- What are some of the things that give you a sense of hope?

Listen for broader meanings in patients' descriptions of their situation and how they are feeling. The counsellor should be aware of their own beliefs and biases towards religion and the spiritual dimension.

Check Your Progress III

Note : Use the space given below for your answers.

1. Define spiritual suffering.

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1.6 LET US SUM UP

This unit has discussed on counselling in health Counselling, in Health giving and special emphasis on hospitals, palliative care and hospice care. The need for counselling in each setting, the areas to be focused and the process and the role and functions of counsellors in each setting has been discussed in detail. The difference between palliative and hospice care has been highlighted. The functions and ethical responsibilities of the counsellor in each setting is being discussed.

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UNIT 2 MENTAL HEALTH AND COUNSELLING

Structure

2.0 OBJECTIVES

By the end of this unit, you should be able to:

- understand the concept of mental health;
- different mental health practice models; and
- importance of counselling in mental health.

2.1 INTRODUCTION

The World Health Organization (WHO) constitution defines health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. However, WHO, in the first thirty years (1948 – 1978), focused largely on specific illness (tuberculosis, malaria) and not so much on 'health' (William, 1988: 7-23). The Alma Ata conference in 1978, (WHO, 1978) is a landmark in the development of the concept of health. The conference viewed health as an individual's responsibility rather than a service to be delivered to individuals (William, 1988: 185). The concept of primary health care (PHC) is revolutionary both in terms of conceptual clarity and details included for achieving the goal.

The International Mental Health Movement

The World Federation for Mental Health, a non-governmental organisation, was founded in 1948, in the wake of World War II. 'Mental Health and World Citizenship' was the theme of their first international conference. "The ultimate goal of mental health" the conference declaration enjoined, "is to help [people] live with their [fellows] in the

world." By conceiving mental health in social terms, the World Federation linked the mental health of individuals to the well-being of communities and nations. Brody (1987) translates the "ability to live with one's fellows" as the capacity to empathise, to relate, and to collaborate with one another.

2.2 MENTAL HEALTH: DEFINITIONAL CONCEPTS AND SCOPE

The United Nations' definition of health necessarily includes mental health. It recognizes health as

A state of well-being encompassing not only psychological and physical, but social and spiritual dimensions….Other dimensions of mental health are more obviously rooted in social context. They reflect development opportunities:…..to be born with an intact central nervous system to a loving and competent family;

…… for growth-enhancing early developmental and stimulating experiences;

……. And later, for education, jobs, information and freedom from violence, discrimination, and unjust treatment (Brody, 1987:3).

In the absence of such an encouraging environment, people are vulnerable to mental illness, whatever one's culture may call it.

The concept, of mental illness, varies considerably. Western attitudes that dominate the world mental health scene lay more emphasis on pathology and curing and ignore prevention. This medical model has a negative approach and has reinforced existing stigmas. Professional Bangladeshi women, recognizing the importance of correcting such a perspective, chose to define mental health as "more than the absence of disease. It implies a feeling of well-being and an ability to function in full capacity, physically, intellectually, and emotionally" (Huq et al., 1985:48). Without such a positive approach, many countries in Asia and Africa, among others, deny the presence of mental illness, even in the face of aberrant behaviour. The taboo is so strong that some cultures even deny the concept altogether, incorporating no word for mental illness in their vocabulary. To do so would be life-threatening, for a person labeled similarly is ostracized from both the family and society. Even after the death of the person, the family itself continues to be shunned, so deep is the stigmatic scar (Wetzel. 1987).

Further, the Alma Ata Recommendation includes *promotion of mental health* as one of the eight components of PHC. This shift in emphasis from illness to health is important, as the term 'mental' connotes illness rather than well-being. This article traces the evolution of concepts of mental illness and mental health, categorization of mental health issues, recent developments in the prevention of mental and psychological disorders, current approaches to mental health programme development, and concludes by outlining the future of mental health care with special reference to India.

Scope of Mental Health

The scope and importance of mental health has been known to range from the care of the ill to the promotion of mental health by professionals. One of the earliest Indian psychiatrists to clearly outline the board scope was Dr.Govindaswamy. In as early as 1948, he stated:

The field of mental health includes three sets of objectives. One of these has to do with

mentally ill persons. For them the objective is the restoration of health. A second has to do with those people who are mentally healthy but who may become ill if they are not protected from conditions that are conducive to mental illness, which however are not the same for every individual. The objective for those persons is prevention. The third objective has to do with the upgrading of mental health of normal persons, quite apart from any question of disease or infirmity. This is positive mental health. It consists in the protection and development at all levels, of human society of secure, affectionate and satisfying human relationships and in the reduction of hostile tensions in persons and group (Govindaswamy 1970).

The Indian View of Mental Health

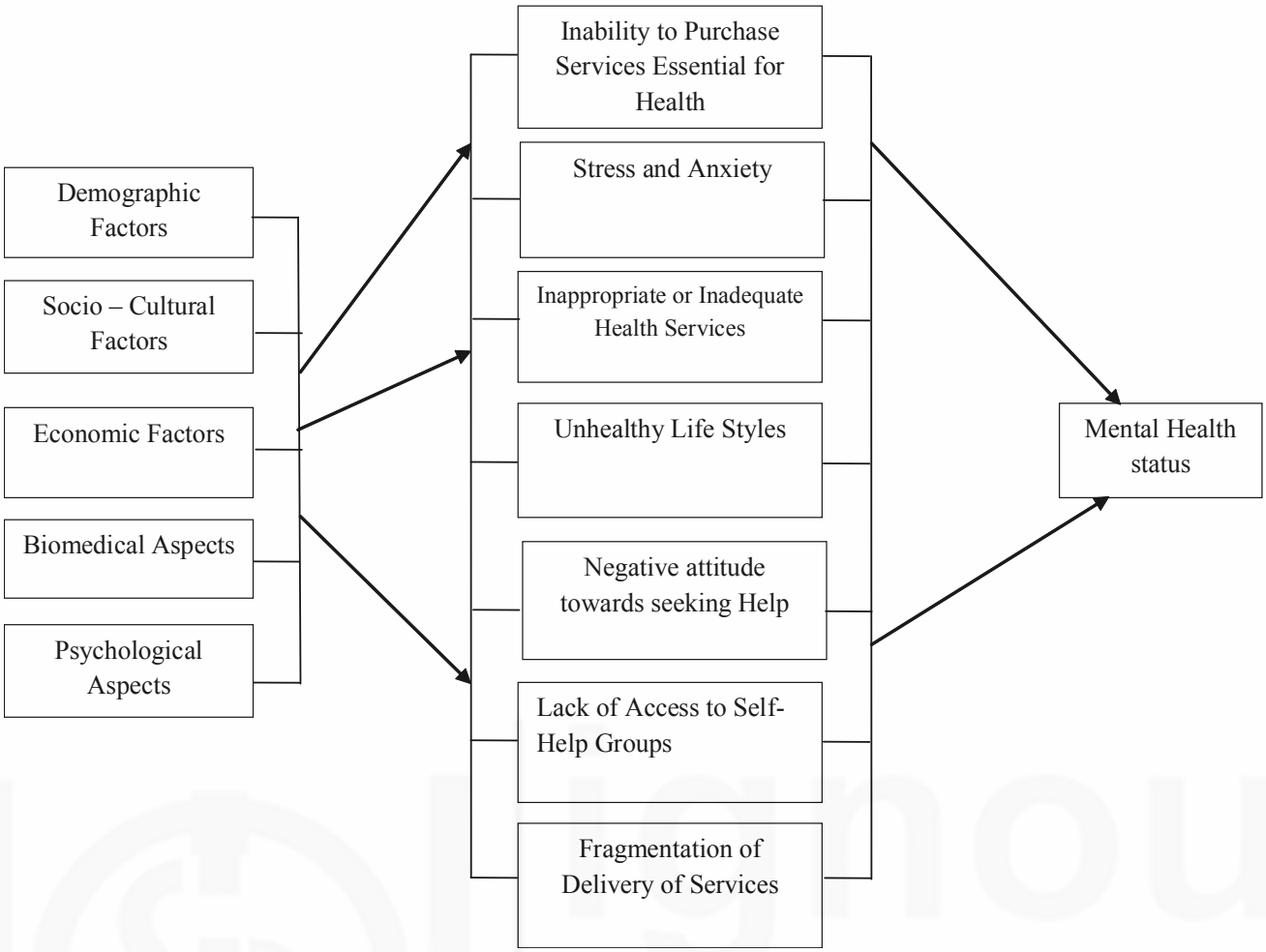
Before reviewing the development of the 'modern' concepts, it would be appropriate to consider the Indian concept of the mental health. Indian psychiatrists have described how mental health has been an important part of Indian philosophy and social thought. Wig (1990) has summarized this as follows:

Indian culture has always attached great significance to spiritual life. The term spiritual is, of course not identical with the term mental, but both recognize the value of inner mental life and experiences. In India, the term health is usually not confined to physical state: in any Indian definition of health there is always reference to mental harmony and potential for spiritual growth. The present day term mental health is European in concept and origin. There is no exact equivalent of the term mind in Indian languages, because the differentiation of 'body' and 'mind' has never been important in Indian philosophy, as it has been in modern European thought. Thus when we speak of 'mental health' especially positive mental health, not merely the absence of mental disorder, the average Indian will always perceive in it an underlying reference to spiritual development. Understood in this way 'mental health' is very important for him, is something to which he attaches great value; he is willing to spend time and resources in pursuit of it. This holistic approach to health is general and mental health in particular to a large extent, reflects the current concept of mental health.

2.3 CONCEPTUAL MAPPING

There are many factors that individually and collectively influence the mental health status of individuals. It may be useful to draw a conceptual map of the variables that have an impact upon mental health status. It is important to note that these variables do not act in isolation. They often interact and work conjointly to produce unanticipated or, at times, undesired outcomes. The feedback loops must be examined carefully and critically. Analysis of these variables, singly and in combination, may yield new insights about ways in which we may intervene intelligently and critically. Empirical research along these lines also helps us to create comprehensive and accurate data bases on which strategic planning can be based.

Illustrative is a conceptual map which follows:



Prevention

Internationally, there are at least 400 million people who are mentally ill or have a neurological disorder. Not only does this make the individual's life extremely difficult, but it is a huge burden for the individual's family and community. Many of these disorders could have been prevented or, at least, they can be effectively treated. However, in many countries including developed countries, people with these diseases receive very little assistance and effective methods of prevention are not employed (Sartorious, 1991)

Primary prevention approaches attempt to reduce the incidence of emotional distress by improving mental health rather than by solely responding to problems or crises. Prevention approaches involve an examination of the harmful environmental influences that have a negative impact on individual's mental health, as well as conditions that positively contribute to an individual's mental health (Smith, 1984). Prevention and treatment are often interlinked. For instance, a counselling programme for mentally ill mothers significantly reduce behaviour problems of their school children between the ages of eight and twelve. This is an example of how treatment for one population can translate into prevention for another (Miller, 1984).

2.4 MENTAL HEALTH PRACTICE MODELS

Just as definitions of mental health and mental illness are influenced by Western society throughout Asia, Africa and Latin America, so too is the scientific knowledge, whether theory or empirical research, upon which most of the world's mental health policies are based. Transferability of models of intervention to what are usually totally different social and cultural systems has been uncritically assumed.

Psychoanalytic Model

Over most of the past six decades, Freudian psychoanalytic theory, initially developed in the Viennese society of the Victorian era, held sway in psychiatric circles around the globe. While the early work of Sigmund Freud has been and continues to be in dynamic evolution, much of the world uses dated texts which have been rejected by many in the West today. Psychoanalytic treatment is based upon the principle of psychic determinism. Each psychic event is thought to be determined by proceeding events. The theory of the unconscious which stipulates that unconscious mental processes cause confused and non-objective reactions to life is also a fundamental principle. Critics of psychoanalytic theorists fault them for concentrating on intrapsychic conflicts when often the environment is more likely to be the cause of the problem. Freudians maintain, in defense of their paradigm, that their focus is psychological because desires and prohibitions are internalized in maturity. They argue that regardless of their external origin, they become part of one's psychic structure. While the reasoning holds merit, the problems perpetuated by ignoring social causality may offset the rationale.

Object Relations Theory: one of the more recent psychoanalytic models, holds that development is a continuous process that persists despite early affronts to the psyche. It is concerned with separation (from the mother) and individuation, a development phase parallel with separation that represents the process of forming and specialising the individual personality. While a more hopeful theory than its predecessor, it has been criticized by cross-culture advocates for its inattention to the importance of connectedness, a prevalent norm throughout the world. Instead, the concept of autonomy is the ultimate measure of mental health. Clearly, while the balance may be different from culture to culture, regard must be given to both concepts if people are to develop fully (Wetzel, 1992).

Biochemical Model

Contemporary Western models increasingly reflect the avant-garde wing of the psychiatric establishment which espouses biological/genetic determinism in understanding human behaviour. Biochemical theories hold that mental illness is caused by an imbalance of the chemicals in the brain. The person thus is viewed as a 'faulty machine', assuming a medical model similar to the diagnosis and treatment of physical disorders. It is unclear whether the chemical imbalance is the result of heredity (gene transmission) or abnormalities in brain chemistry that predispose a person to life stress vulnerability. The grounds upon which criticism of this model are based, range from the epistemological, ideological and political, as well as moral and ethical. Two responses have predominated over the years, both of which hold true of physical illness as well. The first stresses the lack of conceptual clarity and implications that may be harmful to the patient, in contrast to more sociological methods. The second response provides sociological criticism. It is pointed out that diagnosis and treatment are based upon judgments and social demand that may be biased, and which always have political consequences which tend to preserve the status quo (Goldstein, 1979; Lin, 1984).

Family Treatment Models

Paradigms of family therapy have become commonplace over the past decade. Most models are concerned with the systems concept of reciprocity wherein everyone involved in a problem plays a part in its continuance by reinforcing the behaviour of the other. The model is being criticized for overlooking power differentials, on the one hand, and perpetuating hierarchical power, on the other (Walters et al., 1988). Nonetheless, the importance of the family environment across culture should not be overlooked. Familial supportiveness has been found to be highly therapeutic, while unsupportive, controlling

family environment increases vulnerability to depression (Wetzel, 1984/1991). Other diagnoses, such as schizophrenia and substance abuse, are equally responsive to family treatment. Openness to family counselling, however, differs markedly throughout the world. Those cultures, largely Asian, that regard family matters as sacrosanct, their problems considered private business not to be shared, are not generally amenable to outside intervention unless they become acculturated to different customs.

Educational Programme Models

Educational programming is an alternative to counselling that can be used when working with families and communities. Many people who have difficulty accepting the notion of mental illness can readily accept the concept of education as a respected, stigma-free method of self or community improvement. Psycho-education is a popular model that teaches and includes families as part of the therapeutic milieu. It is often used, for instance, when a family member is schizophrenic.

Other models include non-stigmatising therapeutic Psychosocial Programming which creatively provides culture appropriate activities designed to enhance the development of connectedness, independence, positive action and positive perception. These qualities are catalysts to well-being. Their negative dimensions, however, are not only barriers to mental health, but increase vulnerability to mental illness. Thus, overdependence, alienation, negative actions and perceptions, whether emanating from the sufferer or the environment, are also to be countered through constructive programming (Wetzel, 1984/ 1991).

Finally, it would be remiss/negligent not to include in a discussion of concepts and trends in mental health the concept of 'conscientisation' developed by Paulo Friere (1973/1981; 1970/1982). Friere is the Brazilian educator, who, many believe has done more to influence progressive global education and the prevention of mental illness among the oppressed than any other person in the twenty-first century. The key element in the model is the raising of consciousness, a necessary precursor to social action and social change, both essential aspects of the prevention of mental illness and promotion of mental health. Called the pedagogy of the oppressed, the method requires a non-hierarchical dialogical relationship between the educator and the learner who learn and act together about their social reality. Popular in the seventies during the women's movement in the United States, the model has been adopted by women in recent years throughout the developing nations.

Cognitive Behavioural theories: Eastern Influences

Cognitive-behavioural theories can be readily adapted across cultures. Positive external reinforcement, the bedrock of behavioural theory, is combined with personal cognitions, positive internal reinforcers. The model holds that what people 'tell themselves' alters behaviour as much, if not more, than the external environment. Of course, what one 'tell oneself' are usually internalized external messages, so it is important that oppressive communication is eliminated.Research has documented the efficacy of the Cognitive-Behavioural Model, increasingly incorporating affirmation and visualization and powerful positive reinforcers. Thus, methods that were originally considered to be relevant to esoteric/mysterious Eastern spiritual disciplines, have been incorporated successfully into mainstream Western ideology, a welcome reversal (Wetzel, 1984/1991).

2.5 MENTAL HEALTH AND COUNSELLING

Counselling is an important tool in enhancing the mental health of an individual. It is effective in preventing the illness condition and promoting the positive mental health/

well being of a person. It is a positive human interaction, a helpful process, an act, an exercise, a deliberate effort and a plan. It can be dubbed as an art, as well as a simple science. It is a problem solving process. It is a cure to many personal and interpersonal problems. It is a very cost effective way of preventing the ill consequences. The process of counselling invariably leads towards the personal growth of a client. Counselling is a long term development process.

Definition:

"Counselling can be termed as a deliberate effort to create and maintain an environment, in which the client(s) can be empowered, deliberated, helped upon or given consultation by the counselor, in order to solve the problem, on their own and by their own means. This environment can be artificially created and maintained for, as long as, the client requires or counselor deems fit."

"Counselling is a science as well as an art, in which a purposeful conversation takes place between two people."

"Counselling is a problem –solving process."

Counselling provides the warm and permissive climate within which an individual or members of a group can solve problems with the assistance of a trained and experienced person.

Glanz, E.C.

Check Your Progress I

Note : Use the space given below for your answers.

1. Define counselling.

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2.6 TYPES OF COUNSELLING

Directive Counselling: Directive counselling is the process of hearing a person's emotional problem, deciding with him what he should do, and then telling and motivating him to do it. Directive counselling mostly accomplishes the counselling function of advice, but it may also reassure, communicate, give emotional release and to a minor extent clarify thinking. Reorientations are seldom achieved in directive counselling.

In directive counselling the counselor should first be a good listener and he should understand the problem of the client then the client should experience some emotional release. As the result of his emotional release plus ideas which the counselor imparts, the client may also clarify his thinking.

Non-directive Counselling: Non-directive or client centered counselling is the process of skillfully listening to a person and encouraging him to explain his emotional problems, understand them and determine courses of action**.** It focuses on the counselee rather than on counselor as judge and advisor hence it is "client-centered". Non-directive

counselors do not use advice and reassurance, but they do accomplish the above mentioned counselling functions. Communication occurs, but it is primarily upward to management through the counselor. Emotional release takes place, even more effectively than with directive counselling and clarified thinking tends to follow. The unique advantage of non-directive counselling is its ability to cause the client's reorientation. It stresses changing the person, instead of dealing only with the immediate problem in the usual manner of directive counselling.

The client comes for help and the counselor attempts to build a permissive relationship which encourages the client to talk freely. (These first two steps are the same with directive counselling.) At the point the non-directive counselor usually attempts to define the counselling relationship by explaining that he cannot tell the client how to solve his problem but that he may be able to help the client then explains his feelings. And the counselor encourages their expression, shows interest in them, and accepts them without blame or praise. Eventually the negative feelings are drained away giving the client a chance to express tentatively a positive feeling or two, a fact which marks the beginning of the client's emotional growth. The counselor encourages these positive feelings and accepts them without blame or praise, just as he did with the negative feelings. If all goes well, the client should at this point begin to get some insight into his problems and to develop alternative solutions to it. As he continues to grow, he is able to choose a course of positive action and see his way clear to try it. He then feels a decreasing need for help and recognizes that the counselling relationship should end.

Counselling in Relation to Mental Health

Counselling could be more appropriately concerned with hygiology- the study of the problems of normal people and the prevention of the incidence of serious emotional difficulties, than with the psycho-pathology of behaviour. According to Coleman (1973, 1976), the estimated incidence of major maladaptive behaviour patterns from the available statistics in the USA for the years 1970 and 1975 is as follows:

Maladaptive behaviour pattern	Estimated Number of Cases in 1970	1975
1. Neurotics	10,000,000	20,000,000
2. Chronic high blood pressure patterns	20,000,000	20,000,000
3. psychotics	2,000,000	3,000,000
4. Psychopathic or anti-social personalities	4,000,000	5,000,000
5. Alcoholics	9,000,000	12,000,000
6. Drug addicts	1,000,000	2,000,000
7. Emotionally disturbed persons	5,500,000	6,000,000
8. Attempted suicidal cases	200,000	200,000
9. Involvement in crimes	1,500,000	1,000,000
10. College withdrawals	1,000,000	1,000,000
11. Mentally retarded persons	6,000,000	6,500,000

The number of persons who are reported to have one kind of maladjustment or another has been on the increase from year to year.

The figures presented above speak for themselves. There is a compelling need to do something very tangible and effective to check the increase in the incidence of mental

illness. The necessary statistics for India are not available and it can be safely assumed that the incidence may be of the same order as in the USA, if not more. Community health programmes and counselling services have to be resorted to in order to provide the necessary help.

In keeping the view of healthy development of an individual, it also serves in different ways.

2.7 COUNSELLING AS A TRUE HUMAN ENCOUNTER

Counselling is truly a human encounter. It is not merely a chance meeting or a planned meeting with another human individual where we hold our own masks and recognize only the mask in the other. Encounter is differentiated from meeting since the former goes beyond the latter and the 'we experience' which emerges in encounter has a deeper meaning and is pervaded by a much more genuine humanity and affection than is usually the case in routine meetings which fill our daily lives often marked by indifference. Human encounters are the core of counselling and the basis of change and growth. Adrian Van Kaam speaks of human encounter thus:

An authentic human encounter always implies that I am, at least for some moments, totally present to a person, that I am fully with him. In a true encounter, I participate in the personal existence of another for whom I really care. To participate means literally to take part in. Thus encounter entails that I share the life of the other, the existence of the other, his way of being in the world.

In this context of encounter in which counselling takes place we find that it is a two-way collaborative process. Counselors provide stimulation to the clients and the clients take advantage of the stimulation provided and help themselves for more effective ways of living. If only counselors were to strive hard without the clients co-operating and taking their share of responsibility, counselling will be a one-way traffic that will sabotage the effectiveness of the very process of counselling. Since it is a collaborative concern, both the counselors and the clients contribute ***greatly*** their share in the human encounter that facilitates growth and change. It becomes clear when we analyze the direction that emerges in counselling. When a counselor counsels a client, no one will able to predict beforehand what direction the counselling will take since it is not entirely with the counselor or with the counselee that the direction rests. The human encounter which is deeply caring brings about a direction that has been fathered by the counselor and the counselee and hence it is rightly a human encounter which is collaborative.

We see this collaborative human encounter as a process of inter-stimulation. Since no encounter is a neutral type of meeting nor is it a one-way traffic the interaction between the counselor and the counselee is bound to be inter-stimulating. What could be the implication of counselling being a process of inter-stimulation? It simply indicates that a counselor by his attending involves the client and this is the first stimulation. Because the client is involved she begins to explore and express her concern s which impels the counselor to understand the client and to respond to her internal frame of reference and this is the second stimulation in the counselling interview; thus mutually reinforcing each other's effort the counselling glides on. But for the mutual stimulation, the counselling would get stuck midway. We come across certain counselors who are not able to provide stimulation by appropriate probing and hence lack the knack to reframe the mind of the client. At times the clients are so dull and unresponding that the counselors do not get the minimal level of stimulation to maintain their effort which is shown in one way or other as reluctance to counsel particular types of counselees.

In a truly human, caring, collaborative and inter-stimulating encounter the counselor gets involved in the personal life of another human being who needs the counselor in a very special way in some phase of her life and development. Often we do not fully realize the therapeutic effect of presence. For a child the presence of the mother is comforting, for a lover the presence of the beloved is pleasurable, for a friend the presence of her friend is reassuring, for a person in bereavement the presence of her colleagues is consoling and thus we can go on enumerating the effect of mere presence to human life enhancement. That is why Rabindranath Tagore sings of the beauty of mere presence in an ecstatic vein in Gitanjali. He begs the Lord to grant him the indulgence of sitting for a moment by His side. This presence in order to be totally present to the client involves by its very nature breaking through one's unconscious self-preoccupation and leaving behind one's self-centered world of daily involvement. If you are only a few minutes with the client let the client enjoy your total presence.

The reasons that compel us to accept counselling as a human encounter simultaneously impress upon us that counselling is a living, organic process. The living organism adapts itself to the constantly changing environmental forces and in the same way both the counselor and the counselee keep themselves adjusting not only to each other but to every new emergence of insights in their exploring, understanding and acting the three main phases of counselling.

Counselling is an interpersonal process by which one facilitates growth or change in another by adopting certain attitudes and employing certain skills appropriate to the context.

The word 'interpersonal' denotes a relationship between two human individuals. According to the existential philosophy I create a world of my own and you create yours. We are indeed worlds apart unless we decide to enter into the realm of the other and let the other enter into ours. Here we need to give more emphasis to the quality of the relationship. Not every type of relationship is conducive for counselling. By the quality of relationship I mean a whole lot of nuances that uphold human relationship and more specifically a non-possessive warmth born of genuineness and nourished by sensitiveness to the thoughts and feelings of the client. The word 'process' indicates movement, a forward thrust, a flowing. It is opposed to anything fixed, definite, immutable and un-negotiable. The Greek philosopher Heraclitus said that the world is in a flux and as an example he said that we can never set foot in the same river twice for when we step into the river for the second time the river that flowed when we stepped into it for the first time has already gone away. For him the symbol of change is fire which keeps changing constantly. Counselling is like a fire that keeps constantly transforming. The changes and turns that are being taken with every step in the counselling interview is incredibly in a flux and therefore it is more apt to speak of the interaction, as a process than anything else.

The word 'facilitates' puts the whole picture of counselling in the context of equality, of collaborative partnership suffused with a tremendous respect for the awesome person of the other. In some centers of counselling, counselors scrupulously avoid using the word 'helping' so that trainees do not get the impression even unconsciously of giving something to the client. Harvey Jackins has termed his method of counselling as 'Reevaluation Co-Counselling.' By the word 'co-counselling' he means to respect the dignity of the other and also negates the idea of one-up-and-one-down status between the counselor and the counselee. Facilitation can be understood more in terms of stimulation, an invitation which a client can accept or decline. Though we think of

collaboration and equality among the counselor and the counselee we should not forget that counselling is unilateral in the sense that the focus of attention is on the problem of the counselee and not on that of the counselor. Even though it is unilateral it is not helping a helpless person but it is seriously stimulating the client to be awake and asserting, to be brave and possessing to be active and actualizing, to be courageous and non-abusing and to be tender and forgiving. The idea of facilitation leaves the responsibility to change with the client herself. Self-help and personal responsibility of the client can be triggered off only by facilitation and not by helping.

The words 'growth' and 'change' refer to the goal of counselling. It is with this goal in the view that one enters into a counselling interview. Whichever school of thought one may follow, one aims at the clients' managing their lives more effectively and solving their problems and developing opportunities. The word 'growth' underscores the idea of clients' becoming more effective self-helpers. The word 'change' refers to the ability to problem solving and ability to develop opportunities. The clients either have unsolved problems or do not live effectively as they would like to live or both together. Counselling is not for nothing, neither is it for the sake of structuring time. It is with the idea of change that counselling is undertaken. In short, the two words refer to the problems of living which are developmental tasks that people face at different stages of their life span like getting married, forming a family, having children and getting old and the problems connected with the transitions that accompany every stage and the individual tasks like becoming what they want to become.

The word "attitudes" refers to one's mental orientation. It is a learned and more or less generalized affective tendency. It is out of our attitudes that our feelings and behaviors proceed. If my attitude towards you is positive, my feelings towards you will be one of sympathy and love and conversely if my attitude towards you is negative I feel angry and behave aggressively. A caring relationship of warmth should be buttressed by a network of attitudes which are interrelated. For example respect is an attitude. Because I am deeply convinced of your worth, individuality and potentiality and value you as a person with rights, I avoid giving advice or manipulating you. Hence a counselor is bound to have certain attitudes which are either positive or negative. But for a warm human encounter we need positive attitudes to permeate the whole relationship. More than the skills what is more appreciated by the clients is the positive attitude the counselor adopts.

The word "skills" means expertness, practiced ability or facility in an action or doing something. Counselling is not an aimless wandering for which one does not need skills. Skills are means or tools to achieve the goals. Since we have definite set of goals in counselling, it presupposes that some skills specific to the field in question are a must. The skills are to be selective and related to the tasks in hand. By employing the appropriate skills we avoid wasting time and we move in a focused way.

Finally we land on the word "context". Skills are to be exercised in certain settings. Take for example self-disclosure which in itself is a skill. This skill can be exercised at a later stage of the counselling process when the counselor judges that his self-disclosure will definitely enhance the decision making process of the client. If not used prudently this very exercise of the skill of self disclosure will be counter productive.

Check Your Progress II

Note : Please use the space given below for your answers.

1. What do you understand by client centered counselling?

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2.8 COUNSELLING AS A HELPING RELATIONSHIP

Counselling is in its essence a 'helping relationship'. All of us seek to satisfy our personal needs. More often than not, in trying to gratify our needs, we find ourselves in conflicting situations in which our interests clash with those of others. But through the process of socialization in childhood, and later through education, we learn to moderate our desires such that there is no open clash. We may learn to suppress a few desires and inhibit other needs so long as our happiness is not endangered. In addition to human suffering caused by physical handicaps and clash of interests, a major source of suffering is to be found in one's own personality.

Often a sense of personal inadequacy and inferiority leads to lack of self-confidence, withdrawal and lack of desire for achievement. Even if the individual has the desire or motivation, he is hindered by subjective and environmental factors. The psychological conflicts, namely those of goals, values, interests and the like, cause an ebbing of human enthusiasm and zest for life. The counsellor alleviates this suffering by establishing a helping relationship. In the words of Rogers a helping relationship is one "in which one of the participants intends that there should come about, in one or both parties, more appreciation of, more expression of, more functional use of the latent inner resources of the individual." The commonly observed relationships such as those between the teacher and pupil, husband and wife, mother and child, counselor and counselee, could all be considered helping relationships.

A helping relationship is characterized by certain essential features. According to Shertzer and Stone (1968), the helping relationship:

1. Is meaningful because it is personal and intimate.
2. Is affective in nature involving mild to strong emotional relationships.
3. Involves the integrity of the helper and the helped and is sustained voluntarily.
4. Involves the mutual consent of the counselor and the counselee either explicitly stated or implicitly to be inferred.
5. Takes place because the individual in need of help is aware of his own limitations and inadequacies.
6. Involves confidence reposed in the helper.
7. Is often achieved and maintained through communication and interaction; it involves give and take, that is, it is not a one-way process.
8. Involves a certain amount of 'structure'. The situation is either vaguely or clearly defined.

9. Is marked by the desire for change in the existing condition of the client, that is, it is concerned with the improvement of the client.

While most human relationships may involve the rendering or receiving of help, over the years, importance has come to be attached to providing help effectively and efficiently. In other words, helping has become professional in nature. According to McCully (1966), "a helping profession is defined as one which, based upon its specialized knowledge, applies an intellectual techniques to the existential affairs of others toward the end of enabling them to cope more effectively with the dilemmas and paradoxes that characterize the human condition." In short a helping profession involves specialized knowledge, trained skills and the desire to provide comfort to others.

2.9 COUNSELLING AS A SOLUTION TO HUMAN PROBLEMS

Counselling aims at helping the clients understand and accept themselves "as they are", such that they are able to work towards realizing their potential. Often this requires modification of attitudes, outlook and behavior. The nature of the counselling process depends on the setting or the situation. The counselor accepts his clients and has unconditional regard for their personality or self or self-worth. Naturally, counselling involves the feelings of clients. It is often because the feelings run strong that the counselling function becomes a highly delicate and specialized function. In addition to the concern for the feelings of the clients, counselling has a cognitive dimension through which a behavioral change (conation) is sought to be achieved. The client is received without any reservations and he is helped to state his problems and explore the possible solutions. The counselor does not try to solve the client's problems or make choices that could reduce his emotional conflicts. Instead through counselling the client is helped to discover for himself his strengths and weaknesses. It is generally recognized that the individual has the ability to resolve one's own problems. What is supposed to prevent the individual from making suitable choices is a lack of proper or adequate self-understanding and understanding of the environment. The counselor aims at making the client act independently in a mature and responsible manner and with full understanding of the consequences. This is what meant by personality development. A child or an adolescent is not able to act independently. He is not prepared to face the consequences of his actions. Hence, he is considered immature. A mature person, on the other hand, is expected to function efficiently, make desirable adjustments when he has the necessary understanding of his capacities and liabilities as well as the environmental conditions - physical, social and cultural - in terms which he has to act. Counselling aims at helping individuals reach a stage or state of self-autonomy through self-understanding, self-direction and self-motivation. Such an individual suffers from the minimum of inhibitions, conflicts and anxieties. He is a 'fully-functioning person'.

Check Your Progress III

Note : Please use the space given below for your answers.

1. What are the main characteristics of a helping relationship?

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2.10 LET US SUM UP

Mental health cannot be confined to a simple concept or a single aspect of behaviour. Mental health is not merely the absence of mental disorder. Mental health is the well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community. This means mental health highlights emotional well-being, the capacity to live a full and creative life, and the flexibility to deal with life's inevitable challenges. Mental health is a positive state, in which one is responsible, displays self-awareness, is self directive, is reasonably worry free and care cope with usual daily tensions.

Counselling is in its essence a 'helping relationship'. In this concern counselling could be more appropriate addressing the problems of normal people and the prevention of the incidence of serious emotional difficulties, than with the psycho-pathology of behaviour. Counselling aims at helping individuals reach a stage or state of self-autonomy through self-understanding, self-direction and self-motivation. Such an individual suffers from the minimum of inhibitions, conflicts and anxieties. Such individuals function well in society, are accepted within a group and are generally satisfied with their lives.

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UNIT 3 HIV / AIDS /STD COUNSELLING

Structure

3.1 OBJECTIVES

The focus of this unit will be on different aspects of HIV/AIDS prevalence in the country. Also many of us at some stage have cared for someone who was ill. But for caring and understanding for someone with HIV/AIDS was more physically demanding as well as mentally more exhausting. A lot of strength and will power is required to manage the situation. This is because of the sensitive nature and the acceptance of human beings about the disease. The unit will help you to gain some ideas regarding the basics of counselling in this area. After studying this unit you will be able to understand:

- Differences between HIV / AIDS/STD;
- Different aspects in HIV/AIDS counselling and its importance in individual's life;
- Impact of being tested HIV positive;
- Treatment modalities available; and
- The socio-legal issues prevailing in the field.

3.2 INTRODUCTION

Scale of the AIDS crisis now outstrips even the worst case sceneries of a decade ago. Dozens of countries are already in the grip of serious HIV /AIDS epidemics and many more are on the brink.

3.3 HISTORY/COUNSELLING

In 1981, AIDS was recognized as a definite clinical entity. In 1983, French scientist Dr. Luke Montagnier and his colleagues and almost simultaneously, Dr. Robert Galle along

with his colleagues in United Status, isolated the viruses causing AIDS. The virus was named as Human Immuno deficiency Virus, HIV meaning a virus capable of destroying the human body's immunity.

In 1984, a diagnostic test to detect the presence of antibodies against HIV, based on the principle of Enzyme Linked Immunosorbant Assay (ELISA) was developed. Dr. Montagnier's group found that the HIV test could not detect the presence of antibodies against HIV in some AIDS patients from West Africa. They isolated this virus and since this virus was slightly different than the one discovered earlier, it was named as HIV -2 and the first one HIV -1

BASIC INFORMATION ABOUT HIV/AIDS FOR COUNSELLORS

What is HIV?

HIV stands for Human Immuno deficiency Virus. HIV is the virus that causes AIDS. A person infected with HIV is medically known as an HIV positive person. Only a blood test can establish one's HIV status. However, this does not mean that the person is suffering from AIDS.

What is AIDS?

AIDS stands for Acquired Immuno Deficiency Syndrome i.e., AIDS is a set of sign and symptoms which result from the destruction of the body's defense mechanisms by Human Immuno Deficiency Virus (HIV)

A - Acquired (not born with)

I - Immuno (body's defense systems)

D - Deficiency (not working properly)

S - Syndrome (a group of signs and symptoms)

From this explanation itself we are clear that AIDS is not a single disease, but a syndrome – a cluster of symptoms which result from the destruction of the body's defenses by the HIV.

In healthy individuals, infections are kept away by a variety of defenders in the body, which constitute its immune systems. The immune systems are at work, recognizing foreign bodies (e.g. Bacteria, virus, microorganism) and fighting them. It does this with an array of cells and by producing specific chemicals called antibodies which neutralize the foreign bodies. Each disease stimulates the production of antibodies specific to it. The detection of these antibodies is therefore, used to determine past or present infection.

As HIV damages the immune system itself, the antibiotics detected in the blood of the HIV carrier are unable to fight the virus, which may be present in large numbers in the body. Therefore, the body cannot be protected against other infections, some of which become the direct causes of death. These infections are called "opportunistic infections"

Immune Systems

Human body is protected from the attacks of various infectious agents by the immune systems. CD4 lymphocytes or helper cells are the co-coordinators of the cell mediated immunity, and their counts are considered a reliable measure of health status in the HIV infected persons. There is another category of cells known as CD8 lymphocytes also known as suppressor cells. CD4/CD8 ratio is one of the markers used for assessing the stage of the HIV decease

CD 4 Counts

It is important to discuss this with the patient, because

- HIV attacks CD_4 lymphocytes
- Lower CD_4 Counts signify advanced HIV decease with increase in opportunistic infections
- CD_4 counts increase with treatment.

3.4 STAGES OF HIV INFECTION

It starts when an individual becomes infected with the virus. HIV infection causes a progressive impairment of both the immune and nervous system. As the disease progresses this impairment worsens, it begins to show itself as symptoms. Subsequently these are various increasingly serious stages in the life cycle of HIV infection.

a) **Acute Seroconversion Illness**

After acquiring the infection within 3-8 weeks, some people may develop an acute illness with symptoms such as fever, rash, joint and muscle pain, swollen lymph glands, diarrheaand sore throat. Symptoms may be mild which will eventually disappear completely. This self-limitingcondition is known as an acute seroconversion illness.

The 6–12 week times between infection and seroconversion is called "Windowperiod". At this time the person is already infected but the blood test will not indicate presence of HIV. This is because the blood test only indicates presence of antibodies and not HIV itself and formation of the antibodies takes 6-12 weeks.

b) **Asymptomatic Infection**

The person, who is infected with HIV, may remain asymptomatic and feel and appear healthy for years. During this period, the person remains infectious(i.e. able to transmit virus to others and as the virus continues to replicate, it causes progressive damage to both the immune and nervous systems. Some individuals will have persistently enlarged lymph nodes during this phase.

c) **Early Symptomatic Illness**

The symptoms and signs during this phase are sometimes referred to as the AIDS related complex .The symptoms include complaints such as oral thrush, diarrhea, weight loss, loss of energy etc., individuals feel chronically ill during this stage of HIV infections.

d) **Late Symptomatic Illness (AIDS)**

Individuals will have episodes of AIDS specific opportunistic disease such as:

- Pneumocystic Carinui Pnuemonia
- Recurrent Shingles (herpes zoster)
- Oro – Pharyngeal Candiasis (Oral thrush)
- Chronic Herpes Simplex

- Kaposis Sarcoma
- Cryptococcal Meningitis

In addition to the above, there will be significant weight loss and both neurological and neuro-psychiatric syndromes may be present. Patients in this stage will eventually enter a terminal phase and die.

Along with this, in India Tuberculosis (TB) is another disease that can take advantage of a weakened immune system and develop in a patient.

3.5 DIAGNOSING AND TESTS FOR HIV/AIDS

There is an active debate in the country on the issues of mandatory testing of people suspected of carrying HIV infection. The HIV testing policy adopted is found to be appropriate for different types of testing done under the programme. At present people are tested for:-

(a) Screening in blood banks,

(b) Epidemiological surveys, and

(c) Confirmatory testing for clinical management and voluntary testing.

Following laboratory tests helps to detect presence of HIV infection in an individual

* Detection of

a) Specific Antibodies

b) Specific Antigens

c) Detection of Viral Nuclear Acid

a) ***Detection of specific antibodies***

I SCREENING TESTS

II SUPPLEMENTARY TESTS

I **SCREENING TESTS:** These tests are performed to screen the units of donated blood and blood products for surveillance and diagnostic purposes .These tests include standard ELISA for HIV – 1 and HIV – 2

- **ELISA:** - HIV antibodies in the test serum are detected using an antibody sandwich capture technique. Some of the more recent ELISA has the capacity to detect both HIV antibodies and HIV antigen.
- **Rapid Test**: - Are most appropriate for smaller health institutions where only a few samples are processed each day.
- **Dot Blot Assays / Comb Test**: Can discriminate between HIV-1/ HIV -2.
- **Agglutination Assay:-** In these assays, gelatin particles are coated with HIV specific antigens. On adding serum from HIV positive patient, there is agglutinations

II **SUPPLEMENTARY TESTS:** These Tests are performed to confirm the HIV infection status of a person who is asymptomatic and has a history of high risk behavior, or who is positive on a screening test.

- **Western Blot tests:** In addition to detecting the presence of antibodies, the Western B lot test can also differentiate and confirm presence of various types of antibodies produced in response to different HIV antigens such as viral envelops, core and reverse transcriptions antigens. It is considered as confirmatory test for HIV.

- **Line Immunoassay:** Technically it is similar to western blot test, the advantage of this test is that, it can detect both HIV- 1 and HIV -2 simultaneously.

b) ***Detection of Specific Antigens***

P 24 Antigen Assay: -It is useful in diagnosing HIV infection during window period and in babies less than 18 months of age.

c) ***Detection of Viral Nucleic Acid***

Polymerase chain Reaction (PCR):- PCR has high sensitivity and allows detection within 48 hours of acquiring the HIV infection. It detects the genetic material of HIV itself.

Check Your Progress I

Note : Use the space given below for your answers.

1. Distinguish between HIV and AIDS.

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3.6 TRANSMISSION OF HIV

Detailed epidemiological studies throughout the world have documented only three modes of transmission. Sexual, parenteral, and perinatal.HIV has been isolated from the body fluids of infected persons including saliva and tears. However only blood, sexual fluids and breast milk have been implicated in transmission.

I. **Sexual Transmission**

The virus can be transmitted from infected person to his or her partner. Due to the high rate of sexual transmission of the virus, sexual behavior is the prime focus for interrupting transmission

II. **Parenteral Transmission**

Parenteral Transmission occurs through the transmission of infected blood or blood products, or the use of contaminated needles, syringes or others skin–piercing instruments. Recipients of a single unit of HIV infected blood have 100% of probability of becoming infected. Organ transplantation and artificial insemination from HIV infected donors also carry a significant risk of transmission.

a) Transmission through contaminated needles and syringes is a particularly serious problem among injecting drug users, and where needles and syringes are not sterilized before reuse. An explosive HIV epidemic has been reported due to this among the intravenous drug users in the north – eastern states of India.

b) Instruments used to pierce the skin, such as acupuncture or tattoo needless, ear piercing needless and beauty care instruments such as scissors and forceps, if not disinfected, may also transmit the infection.

c) A comparatively rare and accidental mode of parenteral transmission of HIV is the needle stick injuries in the Health care workers.

III. **Perinatal Transmission : - (Mother to Child Transmission)**

Transmission of HIV from an infected woman to his infant may occur before, during and shortly after birth. An HIV – infected pregnant woman may transmit the infection to her child during pregnancy across placenta during child birth or through breast –feeding.

3.7 RISK ASSESSMENT AND COUNSELLING FOR HIV/AIDS CLIENT

Counselling programs can identify and promote change for low risk behavior and, provide emotional and psychological support to people with HIV infection, their families and friends.

Why HIV counselling is unique in several respects:

It mainly affects the young, i.e., productive age.

- HIV is transmitted through behaviors which are personal, private taboo and stigmatized.
- Not only there are untimely deaths, but the death and morbidity toll affects economic and social systems.
- There is still no vaccine or cure.

Role of social worker

Social workers may help by assisting clients to identity their own coping skills to enhance them by encouraging clients to take actions for self and by enabling them to reintegrate themselves into their family and community life.

HIV /AIDS counselling has two general objectives:-

i) To prevent HIV infection and its transmission to other people,

ii) To provide psychosocial support to those already infected /affected.

In order to prevent HIV infection, the chief features of counselling that come to the forefront are risk–assessment, risk–reduction and pre-test and post–test counselling. Supportive counselling and crises counselling are the main approaches used when providing support to HIV /AIDS infected persons and their families.

Considering the two categories mentioned above, one can clearly assume that counselling would be recommended for the following cases:

- Those being tested for HIV (Pre–testing & post-testing)
- Those seeking help because of past or current risk behavior
- Persons already identified/ diagnosed as having AIDS or being infected with HIV and their families or significant partners.

For HIV /AIDS counselling in addition to technical knowledge about HIV infection, the counselor must also build his/her self-knowledge in understanding counselling principles and values and information about formal and informal resources**. Many counselors have to learn to understand their own feelings in order to be able to work with HIV/AIDS cases**. Self-knowledge is particularly important when counselling people of different backgrounds or working with resistant and seemingly ungrateful clients.

Essential Principles in HIV/AIDS Counselling

1) **Unconditional positive regard and non-condemning attitude:**

   Unconditional positive regard relates to treating a person as special within the relationship, thus building the clients self-worth and feeling of being cared for. Non condemning attitude means, that the counselor must not express disapproval of the person, must not impose blame related to causes and effects of the problems of infection.

2) **Trust and Confidentiality**:

   The counselling relationship must be built on the understanding that whatever is discussed will remain a private issue until the client decides otherwise,

3) **Empathy and controlled emotional involvement:**

   A counselor demonstrates empathy by listening attentively to what client says, what client does not say and what feelings the client express verbally and non-verbally.

4) **Time Management:**

   Time shall be given at every stage to build rapport, to clarify issues to externalize feelings, to internalize implications, to make decision and to implement behavioral change.

In Summary counselling as a process can:

a) Ensure passing–on of correct information.

b) Provide support at times of crisis.

c) Encourage change when needed.

d) Help clients focus and identify for themselves their immediate and long term needs.

e) Propose realistic action suitably adapted to different clients and circumstances.

f) Assist clients to accept and act on information on health and well-being and

g) Help clients to be well-informed and to appreciate the technical, social, ethical and legal implication of HIV testing.

Role of the Counsellor

The HIV /AIDS counselor performs several roles depending on the nature of the counselling required:-

1) ***Health Educator and referral-source role*****:** Helping the client learn new information or social skills, at the same time the counselor also recognizes the

need to refer the clients to other social service agencies and institutions for alleviation of distress and achievement of life tasks.

2) ***Advocacy role*****: -**This role involves securing or protecting an existing right or entitlement for clients.

3) ***Therapeutic a clinical Role****:* The main focus is on allowing clients to explore and express their feelings, gain insight into their inner motivations and behavior patterns and working towards positive self-growth and effective adjustments in their relationships.

PRE-TEST COUNSELLING

Counselling before the test should provide individuals who are considering being or being recommended to be tested with the information on the technical aspects of screening and on the possible personal, medical, social, psychological, and legal implications of being found either HIV positive or HIV negatives. This information should be given in a manner that is easy to understand and shall be up-to-date.

A decision to be tested should be an informed decision. Informed consent emphasizes awareness of the possible implications of a test result.

Issues covered in Pre –Test counselling: Pre–test counselling is done in addition to giving preventive information and is centered on two main topics.

(1) The person's history and risk of being or having been exposed to HIV.

(2) The clients understanding of HIV/AIDS and previous experience in dealing with crisis situations

The Pre-Test Counselling should cover

- Reason for attending the counselling.
- The assessment of client's knowledge relating to HIV/AIDS.
- Discuss potential implications of a positive and negative test result.
- Obtain informed consent.
- HIV test procedure.
- Client's conceptions and misconceptions on the virus of HIV and its modes of transmission.
- Meaning of HIV positive test result and HIV negative test result.
- Access the person's ability to deal with a positive result.
- Find out who else should be informed and is likely to be supportive to the client infected positive.
- Establish a relationship as a basis for post –test counselling.
- Provide adequate preventive counselling.

During the pre-test counselling it is also important that the client be told that current testing procedures are not foolproof. Both false positive and false negative results occasionally occur, although confirmatory tests are very reliable if initial test is positive.

Post-Test Counselling

HIV testing can have three possible outcomes:

a) A negative result

b) A positive result

c) An indeterminate result.

Basic facts that has to be dealt in a post–test counselling session to help the client include:

- Integrate and understand the meaning of the test result at all levels (rationally, emotionally, behaviorally, and medically).
- Cope with the immediate reactions to the test result (from indifference to relief to denial and shock).
- develop a health plan for risk reduction
- minimize healthy coping skills and strategies
- extend help to other family members

a) *Counselling after a negative test result*

Explain the meaning of negative result. This may being a feeling of relief or anxiety but following points must be emphasized:

1) Re confirm about the "Window Period". A negative test result carries greatest certainty if at least six months have elapsed since the last possible exposure.

2) Further exposure to HIV infection can be prevented. For this risk reduction counselling has to be given by avoiding high–risk behavior.

3) Some clients have a false belief that since high risk behavior has not led to infection so far, they have a natural "immunity to HIV".This has to be taken up; otherwise incentive to change behavior will be low.

4) Other information regarding control and avoidance of HIV infection, including the development of positive health behavior, must be provided.

The procedure for a negative test result

(1) establish rapport with the client

(2) disclose the test result

(3) assess

- "Window period"
- Client should be encouraged for re testing considering the window period.
- Client should be motivated to take necessary precautions to prevent HIV infection in the future.
- Provide information on risk–reduction.
- Clients alcohol and drug abuse.
- Provide resources and referrals as needed.

b) Counselling after a positive result

The first step is to inform the client about the positive test result. Under the strict conditions of privacy and confidentiality, the clients should be given the test result. Time may be given to the client to understand and absorb the news. Acknowledge the shock of the diagnosis and provide emotional support. Encourage hope–hope that achievable solutions can be found for resulting personal and practical problems.

The procedure for disclosing positive test result is :-

1) Establish rapport with the client.
2) After gaining the complete trust of the client and then disclose the test result.
3) Give the result in a direct, neutral, non-judgment tone.
4) Wait for client's reactions before answering or continuing with the session.
5) Support the grief.
6) Establish or re–establish support networks to provide physical, emotional care during the course of the decease.
7) Sharing the result with others.
8) Handling fear hostility & feelings for having HIV infection.
9) Discussion on personal, family and social implications.
10) Discuss on personal risk reduction plan.
11) Refer if necessary for adequate immediate emotional, material and medical aid.
12) Look at plan for immediate action on behalf of the client.
13) Follow up plan.
14) Referral notes to other resources.
15) Answer the questions /doubts of the client with full respect.

The news of HIV infection is accepted or incorporated often depends on the following:

1) The person's physical health at that time.
2) How well prepared the person was for the news
3) How well supported the person is in the community/family/friends.
4) The person's pre-test personality and psychological condition.
5) The cultural and spiritual values attached to AIDS and death.

The following points need to be repeatedly emphasized:-

1) HIV infection is not AIDS: Since normal living requires the support of others, those concerned may need to be informed and also provided regular counselling to anticipate and cope with new needs.
2) A person who is HIV positive should take care of his or her general health.

3) Spouses and partners will need support &telling them that the test is positive and bringing them in for counselling to prevent transmission is a frequent counselling goal.

4) Spouses and partners must be protected against infection.

c) Counselling after an indeterminate test

A test may be indeterminate for a number of reasons: for instance, there may have insufficient time for full seroconversion to take place since the possible exposure to HIV occurred. So a repeat test is needed after several weeks. During this period he/she should abstain from any risk activities.

Follow-Up Counselling

Though HIV positive individuals have to start behavior changes, their partners /spouse also have to make an effort to accept them as a part of family and help them lead a comfortable life. To achieve these goals, follow-up counselling is essential.

Crisis Counselling

In HIV /AIDS situations multiple crises could occur. The individual usually goes through four steps of this crisis: the blow, the recoil, the withdrawals and acceptance. Reactions to fear of being HIV infected or of AIDS, in the crisis mode may include:

- Denial
- Anger
- Bargaining
- Resignation
- Acceptance
- Fatalism

Supportive Counselling

On one hand, help persons with HIV/AIDS to lead active, productive and hopeful lives to the extent possible and on the other hand counselor helps the client to maintain hope and engage in constructive life pattern. Also cope with the prospect of death, which is a salient issue.

Check Your Progress II

Note : Use the space given below for your answers.

1. What is the purpose of pre-test counselling?

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3.8 TREATMENT FOR HIV/AIDS

As regards use of antiretroviral drugs for clinical use it is recognized that these drugs are not only extremely expensive, but also result in adverse side effects and drug resistance in case of improper use. But the course of HIV infection has been altered significantly by the use of potent antiretroviral therapy and treatment for HIV–related opportunistic illnesses.

HIV treatment issues

The aim of anti-retroviral therapy is to reduce HIV viral load, prevent HIV disease progression and immunological reconstitution. Antiretroviral therapies reduce the destruction of CD4 cells, and are therefore instrumental in delaying disease progression. They have improved and lengthened the lives of thousands of patients fighting the decease.

Initiating antiretroviral therapy

The decision to commence anti-retroviral therapy is made on the basis of the risk/ benefit analysis and the patient's readiness to take treatment. The increased recognition of the risks of antiretroviral therapy in the form of long term metabolic toxicities, combined with the realization that eradication of HIV is unlikely to occur, has resulted in recommendation to delay the initiation of anti-retroviral therapy until the CD4 cell count is around 350 cells/l.

The following are indications to begin treatment with combination antiretroviral therapy:

- Symptomatic HV infection.
- Asymptomatic HIV infections with a CD4 cell count below 350 cells.
- The final decision rests with the patient and clinician in consultation.

What is resistance?

HIV is 'resistant' to some drugs and if the client keeps taking the drug, the resistant virus will multiply faster.

Viral resistance

If the patient is regularly missing doses, not following recommended doses of medicine or has started a new medication/complementary medicines which affect the metabolism of the drugs, it may result in drug resistant HIV and failure of the anti-retroviral regimen.

Cross résistance

Once the virus becomes resistant to a particular anti-retroviral medication, the virus may also exhibit resistance to other medication of the same class that have no yet been prescribed to that patient. This limits the choice of drugs.

Disease stages

The progress of the disease can be delayed with treatment if taken regularly and correctly. The predicted time for disease progression from stage III to IV is about 2 years. Survival of patients in stage is III and IV is 3.7 years & 1.7 years respectively.

When started very late in the disease process, medication may not be able to control disease progression.

Side – Effects of Drugs

Side effects are unwanted effects of a drug. Medications are prescribed for specific purpose, such as to control HIV. Anything else the drug does is a side effect.

Some common side-effects:

- Fatigue
- Depression
- Diarrhoea
- Skin problem
- Anemia
- Nausea and vomiting
- Weight loss
- Dry mouth

Role of Counsellor in Preparing the Patient for Art

Initial assessment of the patient over three to four visits before initiating ART

- To understand the challenges of taking ART
- To think about the impact the treatment will have on their lives.
- To make a commitment to long-term treatment.

For treatment-experienced patients, the counselling helps:

- To re-evaluate their commitment towards treatment
- To identify potential and actual barriers
- To address these barriers and adhere to treatment

Preparation of the Patients

The preparation process works on the principles described below. It gives patients the time to understand their disease and its severity, and to understand the need to take medications to gain health benefits. It helps the patient to make a commitment to take treatment regularly and correctly. The preparation process helps to empower patients before starting treatment.

Establishing trust between the patient and the provider.

The first step in preparing the patient is to establish trust. This is an ongoing process that is strengthened over time.

Introducing to the treatment and adherence programme.

A discussion about the ARV programme, health facility, medication availability, laboratory facilities and support services helps to familiarize the patient with the treatment programme.

Assessing the patient's health status through a detailed medical history.

Overall health physical and mental health status need to be discussed.

What patients can expect to see with treatment?

A discussion on the changes in the CD4 counts and viral load measurements with successful treatment should be included.

The important of adherence need to be emphasized

Prior to use of Anti-retroviral Drugs a discussion is needed regarding the adherence to the treatment.

Patient's beliefs and attitudes should be understood.

Social Support and Socioeconomic situation is an important part for the initial assessment.

Pre-Anti-Retroviral Therapy Adherence Counselling

In the first counselling session it is important to assess the patient's knowledge of H1V/ A1DS, clear misconceptions and educate them and, if required their families of HIV/ AIDS

Issues relating to ART that need to be addressed are:

- ART is not a cure but a-treatment that suppresses the virus and improves the immune system.
- ART does not prevent transmission of the virus, hence, behavior change and safe behaviors need to be adopted.
    - Regular clinical follow-up and laboratory investigations would be required.
    - Adherence to the medication regime is important.
    - Potential barriers to adherence need to be identified.
    - General side-effects of ART and how to manage them.
    - Other health-related (physical or mental) aspects.
- Issues related to substance use (alcohol, illicit drugs).
    - Diet and nutrition.
    - Financial difficulties.
    - Support services that may be required.
    - Answers to questions the client may have.
    - Follow-up visits need to be planned.
- Other important issues are disclosing the status to family and preparing the guardian to participate in treatment.

Follow-up counselling session

Follow up sessions at regular intervals help provide appropriate information, clarify misinformation, and re-emphasize the need to adhere to treatment.

Strategies and Tools to Enhance Adherence

a) **Counselling** b) **Pillboxes**

c) **Electronic devices** d) **Telephone reminders**

e) **Medication diaries.** f) **Buddy system**

g) **Pill Charts**

Documentation

Documentation is not only an important tool of learning, but it helps the organization\counselling service. Especially considering the impact of HIV/AIDS in the global scenario and considering it as a new social challenge for social workers documentation is an important part HIV/ AIDS counselling.

Types of records

- Reports/Assessments
- Graphic presentation /genograms
- Registers
- Case notes

3.9 LEGAL AND ETHICAL ISSUES RELATED TO HIV /AIDS

In addition to scientific research for treatments, and in the future, vaccines and a cure for HIV infection, social, political, and legal solutions are required to adequately deal with the epidemic and the social inequalities, which it highlights and reveals.

HIV testing is a complex subject involving issues related to ethics and human rights. Some of the critical issues are:

1. **Discriminations**

   In the content of HIV /AIDS, discrimination is one of the most significant human rights abuses individuals and communities face. Persons who are seen to be associated with PLHAs such as family and friends or those seen to be at risk of infection such as "vulnerable" groups are also discriminated against.

   The concept of equality. In principle, discrimination is anti-ethical to equality. Many states have expanded their interpretation of disability to include HIV status and protect PLHAs from discrimination in both the public and private sectors.

   Employment: PLHAs are often denied jobs at the time of recruitment on account of their HIV status; also some HIV + ve employees were terminated.

   Health care: PLHAs are often refused treatment and surgery, denied admission to hospitals or charged additionally for basic services. PLHAs have also been subject to mandatory pre-admission testing and consequently stigmatized by having their hospital beds tagged with "HIV–positive" or being isolated in special wards with a lower quality of care.

   Mandatory testing: In some places i.e., employment and for getting admissions in schools and colleges there is compulsory testing. Mandatory testing should extend only to blood and blood fractions, organs or for invitrofertilization or artificial insemination.

2. **Consent**

The primary reason for taking consent from a person before testing and treatment is the respect for human dignity and bodily integrity. HIV testing is unlike any other diagnostic or therapeutic test because of the peculiarity of the test, the window period and the social, financial, medical and emotional implications of a positive result. Informed consent for HIV testing accordingly requires a more stringent standard of disclosure of information, ideally coupled with appropriate counselling services to assist persons undertaking the test to cope with its outcomes.

3. **Confidentiality**

The maintenance of confidentiality of an individual's health status is one of the cornerstones of public health and rights based responses to HIV/AIDS. Disclosure of HIV–positive status has also led to gross discrimination whereby children have been expelled from school and denied their fundamental right to education.

HIV/AIDS And Human Rights

Discrimination against people living with HIV/AIDS denies their rights to access health care, information and other social and economic rights granted by the constitution to its citizens.

Government recognizes that without the protection of human rights of people, who are vulnerable and affected with HIV/AIDS, the response to HIV/AIDS epidemic will remain incomplete.

3.10 SEXUALLY TRANSMITTED DISEASES

Sexually Transmitted Diseases were earlier called VD–Venereal Diseases, and are now often referred to as STI – Sexually Transmissible Infections. STD can be transmitted through sexual contacts. STDs are serious, can be very painful and can cause a lot of damage to the body often resulting in illness, infertility, various disabilities and even death. In pregnant women, some Sexually Transmitted Diseases can infect babies in the womb or during delivery, causing disability or death.

The large prevalence of STDs in Indian population is a cause for concern as presence of STDs, facilitates transmission of HIV infection. The risk of transmission i.e. 8 to 10 times higher in case of person with STDs compared with others. As the risk behavior of persons with STDs and HIV is the same, government attaches top priority to preventive and control of STDs as a strategy for controlling the spread of HIV/AIDS in the country. The following approach will be adopted by the government for STDs control: -

i) Management of STDs through syndromic approach (management of sexual transmitted diseases based on specific symptoms and signs and not dependant on laboratory investigations). Once the STDs case management is integrated in peripheral health system, unnecessary referrals can be avoided leaving the specialized services free for management of complicated cases, operational research and supervision of sites where STDs patients are treated.

   a. It has been decided to integrate services for treatment of reproductive tract infections (RTIs) and sexually transmitted diseases (STDs) at all levels of health care. Dept. of Family Welfare and National AIDS Control Society should co-ordinate their activities. STDs clinics at district/block/First Referral Unit (FRV) level would function as referral units for treatment of STDs referred from peripheries

WHO estimate that about 330 million cases of treatable STDs exist worldwide at any time yet women may have these inspections without realizing it, some 50-80 % of STDs in women are asymptomatic or go unnoticed because they are internal. Women are much less likely than men to seek timely treatment for STDs for this reason. Stigma attached to STDs, especially for women, inaccessibility of clinics, lack of money and too many other responsibilities further prevent them from getting treatment.

The most common STDs are:

- gonorrhea
- syphilis
- Chlamydia
- herpes
- genital warts
- hepatitis –B
- chancroid
- lympho-granuloma venerum

Other commonly occurring diseases are:

- trichmoniasis
- crab lice
- scabies

Control of sexually transmitted disease is possible through early identification, accurate diagnosis, effective treatment, and careful follow up education and counselling.

Check Your Progress III

Note : Use the space given below for your answers.

1. Name any five STDs.

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3.11 LET US SUM UP

The three major blood–borne, viruses (BBV) human immunodeficiency virus (HIV), hepatitis B virus (HBV) and hepatitis C virus (HCV) are members of different virus families but share one thing in common; their major mode of transmission is via blood or bodily fluids. So as professional social worker we should focus our attention not only to HIV/AIDS prevention and counselling but the other blood borne devastating diseases human kind has even faced like HBV and HCV too.

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UNIT 4 COUNSELLING FOR CAREGIVER

Structure

4.0 OBJECTIVES

An increasing number of families are confronted with caregiving obligations; there is a corresponding needful health and social service practioners to offer emotional and psychosocial support to those providing regular care to someone with a less of autonomy at disability. However the concept of caregiver counselling is a new one and requires a deeper study.

After reading this unit, your must be able to :

- Understand the meaning of caregiving;
- Challenges of caregiving;
- The needs of caregiver counselling;
- Family as caregiver;
- Caregivers in different settings; and
- Role of social work in caregiver counselling.

4.1 INTRODUCTION AND MEANING OF CAREGIVING

The term caregiver may be new, but "giving care' as a practice has always been a part of our culture. Since time immemorial, human beings have lived together. Sharing emotions, including happiness as well as sorrow, has always been a common practice. This was the basic function of the family. All needs were met within the family. The

older members counseled the younger ones and the younger ones sought advice from the elders. (COL 2007)

In recent times, social and economic changes have brought changes in the structure of the family. More people have left their families to seek employment making extended families &Joint Family system vanished. Hence all who needs care and service at home are vulnerable. It is very difficult for even the family members to choose the role of a caregiver. So both the caregivers as well as the recipient are under stress. More and more professional caregiver is being sought for emotional, physical, financial, medical and spiritual need.

What is Caregiving?

Caregiving is an act of caring for elderly, sick or disabled individuals. It is likely a matter of time, when, not if, most people will become either the givers or receivers of care. According to Marjorie Silverman in her book "counselling with caregivers" (Lies Editions) caregiver is a term used to describe someone (usually woman) who provides regular care or support, unpaid to someone with a cognitive or physical loss of autonomy or mental health problem. But we can say that the term encompasses a wide and diverse variety of people and many do not even realize that they are caregivers.

Caregiving can be the act of providing unpaid assistance of or help of family members or relatives or friends who have physical, psychological or developmental needs. Mainly caregivers are typically family members, friends, neighbors, and relatives. Now-a-days some religious institutions are affiliated with caregiving. Also professionals like social workers, nurses, and counselors who are paid for their services can come under this category too. Another important aspect which comes under caregiving is that the daily care and support by the parents of the disabled children. This can be considered parenting. But at the same time, it may come under caregiving also. If so, those parents with grown–up adult children with disabilities are doing the dual roles of parenting and caregiving.

So many family caregivers are giving personal assistance to individuals 18 yrs or older who have a disability or chronic illness. Children under 18 and receiving assistance because of disability are often characterized under different criteria for Caregiving

4.2 MAJOR TYPES OF CAREGIVERS

Formal caregivers: can be volunteers or paid care providers as associates with a service system. The service system here stands for: Community services, Religious services, Day care centers and so on.

Informal Caregivers: are the family, friends, relatives, neighbors, who give unpaid care. They provide care due to obligations, friendship, or respect to a disabled person.

Intermittent Care: is a situation which requires occasional need of an informal caregiver at the same time they may also be a medical condition that may require expertise the informal caregivers does not possess. Most people who receive the sort of care lives in their own homes, the caregivers either visits them during the time of this need or arranges care providers for the time being, if they are staying away.

Part Time Care: Here the care receiver may not have an extensive medical condition requiring frequent attention from a caregiver. Morally the care receiver and the caregivers will be living together

Full Time Care: can be offered by informal caregivers, living with the care recipient. Many times the caregiver will be burdened by the need for full time attention results in suffering from depression, burnouts, and social isolation.

Certain other types of Caregivers

Non-Certified Aides/home helpers: may provide long term help like personal care, preparation of meals, companionship.

Licensed Practical Nurses: are qualified to perform certain skilled nursing procedure. They need to pass a qualifying exam and must work under the supervision of a physician.

Registered Nurse: had undergone extensive curriculum and may pass standardized national exam. Qualified to perform all aspects of skilled nursing care in addition to supervising other members of the health team.

Physical Therapists/Occupational Therapists/Speech Therapists: Help in rehabilitation of those with physiological impairments, deformities, physical injuries due to disease. Their priority includes helping individuals who are disabled by physical injuries or diseases to regain maximum functions with the activities of daily living.

Social Workers: They may provide family or individual counselling to manage the crisis situation. Also they help to identify the resources available in the community. Also assess and evaluate the social, emotional and environmental factors affecting the ill and disabled.

4.3 CHARACTERISTIC FEATURES OF CAREGIVING

Characteristics of caregivers

Skilled Care: is the provision of services and supplies that can be given only by or under the supervision of licensed medical personnel E.g.: monitoring of vital signs, ordering of medical tests, diagnosing medical problems, drawing blood, dressing wounds, providing counselling and therapy sessions.

Custodial Care: is the provision of services and supplies that can be given safely and reasonably by individuals who are neither skilled nor licensed medical personnel. For example help with the activities of daily living are thought to be by definition custodial care.

Characteristics of those who receive care

According to the degree of the need /assistance for care, there are generally three categories of care:

a) **Acute Care:** Acute care is often a recovery from a period of hospitalization due to an injury or serious illness. Here the individual will be completely under the supervision of a medical team comprises of nurses, physiotherapists and other professionals. The patient can be at home but requires assistance of skilled nurse. After recovery the person may partly or completely capable of managing oneself independently without the actual help from a caregiver.

b) **Chronic Care:** Certain types of disorders, accidents, disease, injuries, and infections may result in disabilities. The disabled person will recover and may adapt to take care of himself with the disability. But the support of the caregivers may be needed

for a certain larger amount of time. The care can be provided either by the formal or informal caregivers.

c) **Mental impairment developed early in life:** Those who are requiring caregivers, between the ages of 18-65, are impaired due to mental retardation, autism, Down's syndrome, mental illness and may require life time supervision. Many of them are given care under the supervision of family.

4.4 EFFECTS OF CAREGIVING ON CAREGIVERS

Caregiving is very demanding and stressful. In the case of healthy spouse or a child living with the disabled person at home, caregiving can be a 24 hour 7 day week commitment. For many, the challenges of the role lead to negative feelings about the situation and the person for whom they are providing care. A survey of caregiver studies indicate that caregivers may suffer from a variety of health and emotional problems related to the stress of caregiving such as depression, anxiety, social isolations and physical symptoms (Cousine, Daires, Turnbull or Player, 2002, Millan, 2005, Toseland, & Smith 2001)

Effect of caregiving on caregivers:

- Physical Well-being
  - General health decrease
  - Increase in fatigue
  - Increase in cognitive dysfunction
  - Sleep problems
  - Limited activity
- Psychological Well-being
  - Tears
  - Depression
  - Anxiety
  - Nervousness
  - Less and ineffective coping ability
  - Family friction
- Social Well-being
  - Decreased marital satisfaction
  - Sexual problems
  - Decreased social support &interaction
  - Increased loneliness & Isolation
  - Financial worries.

Specific health effects of caregiving stress

Impact on physical health: Strain of caregiving can aggravate certain diseases; some

of them will develop even **physical injuries or illness.** Diabetes, anemia, ulcers, hypertension etc are some of them. Caregivers may sometime start dependence on **alcohol** and might develop the habit of depending on **psychotropic drugs**. **Irregular sleep** of the client will definitely affect the sleep patterns of the caregivers; and might start depending on sleep inducing drugs. **Weight gain** is another issue that has to be considered. A study shows that women caregivers have a chance of gaining weight.

Wound healing is affected by the stress of caregiving. **Immune system** will definitely be affected by stress. It will reduce the activity of natural killer cells, which usually wards off viruses. Consequently caregivers are more prone to the attack of different viruses and illnesses. Caregivers also suffer due to their tight schedule as they lack time and energy to prepare meals or to exercise. The physical stress of caregiving affect **the physical health** of the caregivers, especially when providing care for someone, who cannot transfer him/herself out of bed, walk or bathe without assistance. Caregivers have a tendency to increase their **cardiovascular condition**, which increase the risk of developing high blood pressure or heart disease.

The Emotional effects of caregiving

Caring for others is filled with many mixed and varied emotions such as feelings of love, anger, affection, sadness frustration and guilt. Caregivers often experience a higher rate of stress, anxiety and depression. Changing family role, unresolved part of family dynamics and stress brought on by the loved one's health, can strain even the best of support system and relationships.

Emotional support is when those around the caregivers say or do things that help the caregiver and offer encouragement and comfort during difficult times. The most difficult challenge that can face a caregiver is not the physical or medical issues regarding the person for whom they provide care, but the emotional and psychological impact of caregiving on them. A variety of complex emotions will always follow the caregivers as they try to adjust with the family and the care receivers.

Guilt is the most common emotion that caregivers report. The other emotions include frustration, anxiety, and anger and so on. In course of time, they will start trying to channelize the **anger** on other family members too. Sometimes the anger might be directed toward the care receivers because of past experience. But in majority of the situation, it is directed mainly towards the illness/problem, the feeling of helplessness.

Some other concepts related to caregiving

Burn Out can be best used to describe the caregivers who find themselves unable to provide the quality of care that is expected and can be characterized by depletion of energy, difficulty in concentrating and a sense of hopelessness. They are often burdened and pressed about the demands of caregiving.

Attitudes play an important role in our relationship with the care receiver and the ability to see work related stress in a new way. Caregiver has to be very healthy and powerful individually and collectively in dealing with the stress related aspects.

Behaviors: it shows an understanding of the interconnection between thinking, feeling and action. To be effective role models for those entrusted to be cared, it is necessary that caregivers need to act professionally.

Practices: To be an efficient and effective caregiver, full attention has to be given to holistic, integrative frame work which allows the caregiver to address the entire system.

Increasing awareness of emotional selves, develop healthy positive mental patterns.

Impact on social well-being: Many caregivers are also stressed by the restrictions on their social life. The caregiving process affects their family and hence, social activities. It even changes the family relationships.

Family relationship or marital relationships have been severally interrupted. Many women find it difficult to give much time for the husband and children due to the caregiver role for the parents. Also they do not have much time to spend for hobbies, leisure activities, partying, going for holidays etc.

Employment is the next area that is affected due to caregiving; a lot many has to quit their jobs to take care of a patient at home. Time off from work will be entitled by the caregivers for caregiving activities. Many switch over to part time jobs. Lack of career advancement and promotion will be the net result ending in dissatisfaction. Another factor is the financial difficulties due to the lack of full time job. A diminished social life, low self esteem and a decline in job performance are some of the other problems. If care-giving has been allowed to go on for long, the caregiver can sometimes break down and may end up needing long term care.

Check Your Progress I

Note : Use the space given below for your answers.

1. Differentiate between acute care and chronic care.

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2. What is meant by burn-out?

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4.5 WHY SEEK COUNSELLING?

Professional assistance will be sought, if caregivers are emotionally and mentally dissatisfied with some aspects of their lives**. Counselling can be considered as a major important means to minimize or to cope with these problems**.

Caregiving is a time consuming non rewarding job. For majority, caregiving may give rise to physical, emotional and psychological problem such as depression, anxiety, reduced marital disharmony etc. At one point or the other, they will definitely require the support of a professional for their well being as well as for the well being of the care receiver.

Counselling for caregiver

Counselling for Caregivers can be said to be a set of self-instructional learning materials

which offers caregivers with the required skills, knowledge, and understanding to efficiently support the healthy development of children, youth, disabled, and adults in their care. Understanding the need for counselling, when necessary, helps caregivers to maintain the quality of life.

Caregiver counselling includes

Programs that grant emotional support, information and guidance in the individuals or group setting for family members, friends, significant others, non familial caregivers or attendants who are caring for someone who has a serious illness or disability or who is elderly and increasingly unable to provide for his or her own care, and are feeling overwhelmed by their responsibilities and the effect that caregiving role has had on their lives.

Necessity of Counselling: As mentioned earlier in the unit, you are aware of the stress and strain associated with caregiving. Most of the caregivers go through periods of stress, depression, frustration and despair. These are all normal human responses and feelings toward stress.

There are two types of stress:

Primary: applies to helping the client in the day-to-day activities like toileting, managing difficult patient behavior such as wandering, agitation and so on.

Secondary: from the sources other than direct caregiving duties like financial constraints, limitation on leisure, social out going, and interpersonal issues with other family members.

Caregiving affects the life of caregiver wholly. That may have physical symptoms, mental symptoms, social symptoms and medical symptoms, all associates with the signs of burnouts and stress. Thus **stress** does not just affect one aspect of life**. It affects all the major aspects of lives.**

Caregiver who receives regular emotional support is much more apt to be able to handle difficult decisions, situations of the needs of the care receivers.

Counselling options and opportunities

Counselling for caregivers may come in different forms and shape. It depends on the individual who needs counselling.

- Some participate in *family and individual counselling.*
- Other may opt for *group counselling session.*

Other forms:

- *Respite care opportunities*
- *Caregiver support groups.*

Individual and family counselling intervention: Individual intervention gives a major impact on the caregiver's emotional health. Individual counselling for adult's children can assist them in understanding the dynamics of family as well as help them to process their feelings and caregiving experience in relation to their elderly parents.

According to Toseland &Smith (2001) the individual counselling includes several categories of topics that will benefit the caregiver. They are:

- Emotional issues surrounding illness.
- Problem solving and behavioral management skills

- Family relationship problems
- Case management skills

Group interventions: Group counselling for caregivers provides an open platform where they can share concerns, communicate, increase their social support and gain information about new resources. Psycho-educational group interventions are beneficial for both the caregivers and care receiver as well. This will help the caregivers to provide a better care. Along with the ***religious faith*** some group support interventions will be very successful for caregivers.

In some counselling strategies ***peer support*** will be highly beneficial. The idea behind this is that, it will be easy for the caregivers to relate or building rapport with the peers who had been caregivers, better than would be with professional counselling. However, one interesting study by Smith, Tobin and Toseland (1992) showed that professional counselors, did better than peer counselor at building rapport, which allowed the professional counselors to connect more with the needs of the clients.

Support group intervention: is very valuable because, the caregiver participants are allowed to unload their frustrations and share information about resources.

4.6 TYPES OF CAREGIVING INTERVENTIONS

Psycho-educational interventions: it includes a structured programme planned toward providing information about the care receiver's disease process and about the services and resources available. This system trains the caregivers to respond effectively to disease related problems. E.g. Memory and behavior problems in dementia patients. By this the knowledge, caregivers can improve their adjustment with the care receiver and the environment. These types of interventions mainly focus on educating or teaching caregivers to develop skills so that they can deal better with stress factors.

Psychotherapeutic Interventions: the main underlying factor is the therapeutic relationship between the caregiver and the trained professional. The trained professional will extend counselling to the caregivers. Most psychotherapeutic interventions with caregivers follow a cognitive-behavioral approach. Here, therapist may teach self monitoring and evaluation, challenge negative thoughts and assumptions, help caregivers develop problem solving abilities by focusing on time management, managing overload, other coping method and problem solving techniques.

Supportive Interventions: the main aim is to build a support system or network of caregivers. This can be led either by professionals or peer-led support groups. It will create a space in which they can discuss their problems, feelings regarding caregiving, helps the participants recognize that others have similar problems, and may provide an opportunity to participants to exchange ideas and strategies for coping with their difficulties. Support groups depend on group members to a great extent to provide mutual emotional support and to share information and feelings about the nature of care receiver's needs, and how to manage behavior problems.

Service Based Intervention: here caregivers are encouraged to use formal service for improving the competence of care receivers. This delays the institutionalization of care recipients. The services that can be provided under their category also include respite for caregivers and drug activity therapy for care recipients.

Other Types of counselling for caregivers: there are many types of counselling that may be used in providing care to client caregiver, which type to use will depend on the problem presented by the client. Some common types of counselling are

1. **Preventive counselling:** providing information on an individual or group basis. It is based on a specific programme.

2. **Behavioral counselling:** here the child through education and learning is helped to change to a more acceptable behavior. Here the main aim is to support the child personal growth through the process of self-understanding and self acceptances.

3. **Individual counselling:** based on one to one counselling process the client is guided by the caregiver to understand his problem and enables them to see the choices available to solve the problem.

4. **Group counselling:** is based on the belief that there are factors in the environment, culture and relationships that affect the client. It is used to introduce behavior changes in the client.

5. **Peer counselling:** chooses individuals having support of other people with similar experiences and characteristics as the client

6. **Crisis counselling:** It is given to client who is in acute distress and feels he/she can no longer cope. This is given to clients who need immediate help.

7. **Supportive counselling:** Helps the clients to develop a hope to live in; so that there is a chance to understand the client's social and home situation, which could help in the counselling of the client.

8. **Spiritual counselling:** It is provided by priests, pastors, nuns, imams and others. Here belief in supernatural being is used to help clients deal with their problems.

9. **Grief counselling:** It is helpful to client who has lost their loved ones and need support in dealing with their grief. It is also called bereavement counselling because it aims to help client's experience normal mourning.

4.7 FAMILY CAREGIVERS-THE EMERGING TRENDS

- In every society it is indicated that as people live longer and have more chronic diseases, the number of family caregivers is increasing. Additional factors that will contribute to this is advances in medicines and health care which prolong the length of life but not necessity the quality, and the rising cost of long term care.

- As there is an increase in number of families who need caregivers, with the cost of living which is shooting up day by day, many cannot afford to hire home care workers.

- The degrees of care may vary from simple tasks called *instrumental activities* of *daily living,* like help with meal preparation, paying of bills and other financial matters to more involved tasks like bathing, dressing, and toileting called a*ctivities of daily living*. The situation and times may vary from one person to another. Some may need 24 hrs services.

- Caregivers need not always live with their care receivers. Many adult children live distance apart due to many reasons. This may produce much stress from the side of the caregiver.

Family Caregiving, according to Maggi Reid., (Sept,2004)Counselling in Different Settings, E- book -Family caregiver is an adult (18 ys of age or older family member or another individual) who provides an unpaid care to an older individual (age 60 or older) or to an individual of any age with Alzheimer's disease. A grand-parent or other relative over the age of 55 who cares for a child related by blood, marriage or adoption. This caregiver must be living with the child, and identified as the primary caregiver through a legal or informal arrangement.

Caregiving for a sick relative is often a family experience and often provides a chance for siblings to co-operate and become closer under a stressful situation.

There are different types of family caregivers:

- Parents
- Adults children
- Spouses
- Family members
- Neighbors
- Friends

Importance of counselling in family caregiving

According to wellness &Prevention–(2006 -2010) all families require a giant effort to balance the needs and requirements of its members. Added to this if a grand-parent, parent or child requires constant care and support, it can only disrupt the family routine and the caregivers balance. *Family counselling* minimizes the caregiver's sense of responsibility for meeting everyone's needs. It gives every family member a chance to ventilate their own feelings.

Impact of diagnosis on the family

The impact of a problem on the family will never lie with the primary caregiver alone. Discomfort about the disease, disappointment, anxiety, shame, guilt etc are some of the common feelings family members and caregivers report.

The children of the caregivers are the most affected lot. They may not open up or show their feelings, because they did not want to burden the caregiver. But these hidden emotions will produce adverse reactions on the child .By counselling, the family can move ahead and work harmoniously as a group. The power struggles and the conflicts regarding the wealth etc. between the siblings can be lowered.

Family counselling is very successful in helping both the care receivers and their adult caregivers understand the change in the relations. With the increasing dependency of the care receivers and how caregivers can adjust to that change. There may be family dysfunction which will certainly affect the caregiving relationship. In these situations family counselling assist the family unit to work through these issues and focus should be to help both the caregiver and receiver to find that place where both can communicate and experience the new level in their relationship (Myress,1988)

Experienced caregiver specialists offer the caregiver practical advice and emotional support. They can provide information about chronic condition and diseases and help identity resources, services and support options in the community & among family members. Also a counselor can help the caregiver to cope more effectively with the emotional demands or even depression that can result from caregiving. They can help

the caregiver works through feelings of grief and losses, problems, solve difficult relationships or situations, and work through any stress anger and guilt related to caregiving.

Implications for counsellors

Good coping skills and management strategies are indicative of lower levels of burden, so it is necessary that counselors should be knowledgeable about counselling theories that help to strengthen skills in their caregiving clients. Also the counselors must be knowledgeable in the special area needed by the caregivers about their issues. Because caregiving is a family issue, it is important that the values, cultures of each family should be taken into consideration.

At many times, due to too much involvement in the role, many caregivers will begin to lose their identity as a child, spouse and will consider the identity of the caregiver alone. At this movement the caregiver will be ready to accept help. So the counsellors should be able to identify the situation and to be ready to work on their issues.

No professional will be attentive to the caregiver when treating the care receiver, even the family physicians, dentists etc. But majority of the caregivers are apt to be clinically depressed and needs to be screened for depression, because they might not volunteer out information about themselves.

Another important aspect is counselor should be aware of the resources that can be utilized for the caregiver from the community.

Benefits of caregiving

Not all caregivers are stressed. It all depends on how the caregiver perceives the situation and on individual's coping skills. A successful caregiver is the one who maintains a balance between providing the necessary care and encouraging the care receiver to be independent as possible.

Check Your Progress II

Note : Use the space given below for your answers.

1. Write short notes on

   i) Behaviour counselling

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   ii) Group counselling

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4.8 ROLE OF CAREGIVERS IN DIFFERENT SETTINGS

Caregivers of Dementia patients

Family members play a vital role in adjusting with the behavioral health care of the patients with dementia. Medical Practitioners depend on the family members for the assessment and prescribing medicines to the patients with dementia. For this, caregivers should make observations to furnish information about the day to day activities, their capacities, their behavior etc. Because memory loss and language impairment will always be there. Caregivers can rely on gestures, facial impressions etc for communication. Appropriate understanding of the illness and behavioral disturbances, is necessary for the caregiver to manage, assess and to minims the agitation.

Dementia patients will have a decline in functional activities due to impairment in cognition. First the problem starts with instrumental activities of daily living, then the next phase basic activities of daily living will be affected. Only when the caregiver is educated about these facts, they can foster the remaining abilities. In the past two decades, the role of informed caregiver in providing care to older person has increased

Caregivers for children

Other than parents, caregivers are the adults who can have an impact on child's development and behavior, because they are the adults who are around the child most often. In a joint family or extended family system grand-parents can be the second most persons who can influence the behavior and development of the child. The parents can often check with the caregivers the method of discipline they are employing when they hire a caregiver and can also discuss with him/her about the strategies they prefer to use and not to use to discipline the child. Parents should consult with the caregiver, how they prefer to encourage and reward the child

A child who has been **diagnosed with behavior disorder** will need to meet an expert in medical profession and should follow a treatment plan whether it be behavior management, counselling,etc and, the caregiver should be given full instruction on how to follow the plan .

Coping with cancer

A lot many issues are connected with the caregiving for cancer. The different types of cancer patients and caregivers to cope with the situation, the treatment procedures, its side effects, issues, grief, financial commitments, employment issues etc. It is very beneficial for the caregiver to consult an oncology dietician regarding **nutrition**. As for cancer patients, to regain health and to support treatment procedures like chemotherapy and radiation it plays a major role. After chemotherapy majority of the patients have nausea, diarrhea etc., the coping lies in the hands of the caregiver. A lot of knowledge as well as information regarding the **side effects** of the treatment like hair loss, fatigue, nausea, pain, developing of infections etc. should be known to the caregivers as well. As the treatment for oncology requires huge commitment financial position of the patient as well as the caregiver is very important.

Oncology **social workers** are available to help those affected by cancer to cope with their concerns. The services they provide will include support, individual and family and group counselling sessions. Also they work as a communicator between the

caregivers, medical professionals. They educate and provide referrals to community resources also.

Caring for HIV/AIDS Patients

Caring for someone with HIV/AIDS was more physically demanding as well as emotionally draining. At the same time the support one receives from outside will be very limited, when compared to other illness or situation, because of the nature of the diseases. In many societies, the extended family has traditionally acted as the main source of support, sometimes aided by NGOS, Government and other religions institutions. **Poverty** is a major factor in the transmission of HIV but to epidemic itself contributes to the poverty. Another important matter regarding this is HIV/AIDS **affects women** in three ways–as individuals, as mothers and caregivers.

The affected individuals may experiences emotions and feelings of shock, denial depression, guilt etc. Many will be isolated and cannot disclose the result. Treatment procedures may be ignorant to so many. The caregivers often find it difficult to approach for resources and medical help, resulting in burnouts & depressions.

Children who are HIV positive need to have their immune system boosted up from getting opportunistic infections. But they may hardly receive any care. The caregivers themselves will be sick or poor or unaware of the resources available.

Prevention can stop many illnesses. So awareness and education about the risk of HIV /AIDS will **prevent the spread of infection** to a great deal.

The social workers as a caregiver:-Social workers can identify, strengthen, and support existing positive community resources. Pre and post-test counselling services can be provided – Motivating the positive people to take up Zidovudine and for adherence to the treatment schedule can be monitored well by the social workers. Can organize youth &children's group for awareness, prevention and education of HIV/AIDS. Support net work and providing bereavement counselling are the next steps that can be taken up by a social worker. Social workers will also be more effective if they lobby for co–ordinate response with other sectors, such as health education and business.

Role of Staff Counselling within health service work places: This special field of counselling can be called counselling within health service work places. Major input is given to the psychological health of nurses and other health service staff, and it is aimed at both preventing and alleviating unnecessary distress and psychological ill health to staff involved in carrying intervention.

In work place counselling employer either provides service (a) *internally*-through a service located in the organization or by staff employed by the organization. (b) *Externally*- an external is contracted to provide the services.

- The services provided should be fully confidential.
- There should be clear defined lines between counselling and other functions like human resources and occupational health.
- Counselling should be undertaken voluntarily.
- Employer should be sensitive to the needs of the staff who are using the service

Features of counselling practice in work place:

a) Counselors should extent the service keeping in mind with the interests of different organizational stakeholders and of the potential for conflicts of interest between the needs of the client, the service etc.

- Most of the counselling services will be short term say about 6-8 sessions.
- So counselors should be qualified to work within the short span of time
- Counselors need to work with an understanding of the organization culture in the client work

Support for staff exposed to traumatic incidents may include physical and verbal assault, a drug error, and suicide or homicide cases.

Here also caregiver counselling is very important. To absorb back to the stream of working environment emotional support is every much needed. Because already the paramedical and professionals working in a hospital setting will always put on the shoes of a caregiver. Added to this, group will be constantly under the stress of family life, job pressures etc. This will add to their frustration. Over above all this are the accidental traumatic incidents. So, only an expert counselor can handle this situation.

4.9 THE ROLE OF SOCIAL WORK AMONG CAREGIVERS

Social workers are integral part of carrying out the process of caregiving issues. They are the one in unique position to create, implement, and advocate policies, programmes, sentences and research in this field. Social works practices participatory approach to involve all. At the same time they may focuses on community organizing for citizen empowerment. Social works can also address the needs of diverse group. Their holistic view of person in environment provides them with skill and abilities to engage in culturally sensitive, helping relationships with marginalized group. Working directly with the vulnerable groups, they can understand the need for support. For counselling services and referral services also they play an important role too.

Specific Role of Social Workers in caregiving

1) Assessment: Collaborative determination of appropriate service for client.

2) Counselling: Focused on adjustment to caregiver issues and caregiver stress.

3) Referral: To community resources as required according the best interests of the client.

4) Advocacy: To other community resources as required according to the best interest of the client.

Social workers provide many important services to family caregivers

- Educating caregivers about aging, health and mental health.
- Counselling to help families cope with the stress of caregiving.
- Coordinating care and service.
- Linking caregivers with the resource they need.

- Helping families plan for the future.
- Leading support groups for family caregivers
- Working through conflicts and managing crises
- Communicating with other service providers and organization

Social workers help family caregivers take care of themselves

Conclusion

Caring for someone who is critically ill, old age, etc is one of the greatest expressions of love. There are few things we do in our day-to-day lives that benefit another as much. Doing too much without the support of others can create feelings of resentment that linger long after the crisis is over. Caregiving is an unspoken promise that many of us make in our relationship with our loved ones. But in today's electronic age, few people will have time, resources or ability to care for their aging or disabled loved one. At the same we must be aware of our limits, know ones resources in the community, and understand the wants and needs of the person who needs care. Caregiver counselling is comparatively a new concept which requires deeper understanding and awareness, especially among social workers.

4.10 SELF MANAGEMENT AS A CAREGIVER

Some tips to take care of oneself when he/she is a caregiver

a) *Become informed*: Understand about the illness /disability or the problem as such. Try to learn about the diagnosis and the possible treatment plans. Consult the general practitioner. Because they might be useful in getting support.

b) *Understand about the social support system*: Can always contact the care receiver's employers or insurance companies. Clarify benefits and suggestions so that better health related services can be utilized.

c) *Organize Help*: Prioritize the care receivers need. Check the possible plans from where caregiving can be utilized, including family members, community support systems, religious institutions etc.

d) *Maintain a sense of humor*: Laugh, but be sensitive. Watch a funny movie read joke books etc.

e) *Get individual help*: Caregivers may sometimes need to talk/discuss the issues with professional counselors. Sharing the emotion, concern or feelings with a counselor or social worker can help to cope with the problems.

f) *Keep up with medical check-up*: This is very important for the caregiver. Because caregiver's health is very important while giving care.

h) *Join a Support group for caregivers*: Loneliness can be lessened. Also a safe and supportive environment will be provided by them.

i) *Try to relax*: Find out time every day for relaxing or for entertainment.

j) *Maintain the boundaries*: Try to think whether one is satisfied with the role of caregiver. One can give, but there should be a limit. Straining oneself and sacrificing ones needs to give beyond one's capacity may end in frustration.

Check Your Progress III

Note : Please use the space given below for your answers.

1. Describe social worker as a caregiver.

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4.11 LET US SUM UP

In the past two decades, the character of informal caregivers in providing attention to elder persons and the association of informal caregivers to nurses, medical practitioners and social workers and other health care providers have experienced remarkable modifications as a result of industrialization and urbanization. Ever-changing demographic patterns have resulted in an increasing number of seniors who require acute and long-term care. The change in the Medicare system has lifted the obligation from institutions to individuals and families. Involvement of social workers to reduce the hassle and burn outs of caregivers by giving appropriate assistance and counselling services will bring change within the caregiving relationship itself.

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UNIT 5 COUNSELLING FOR THE TERMINALLY ILL

Structure

5.0 OBJECTIVES

By the end of this unit, you should be able to:

- Understand the needs of the terminally ill;
- Understand grief and bereavement;
- Know the 5 Stages of Grief;
- Know the 4 Tasks of Mourning;
- Know about grief and bereavement counselling;
- Know about dysfunctional grieving and grief therapy;
- Know the Six Step Protocol for Breaking Bad News;
- Understand how to work with terminally ill children; and
- Know about caregiver issues and self care.

5.1 INTRODUCTION

Among the diverse groups of individuals and settings a counsellor may need to work with, one of the most complex areas of work for counsellors is with the terminally ill. The dying have needs that are unique and complex and counsellors have limited available literature to guide them in providing service.

When confronted with a diagnosis of terminal illness, there are a range of emotions to cope with. These may include denial, shock, fear, anger, and sadness. When they are first diagnosed, many people are determined to fight and conquer their illness. While strength of will and refusing to give up easily is an admirable quality that very often influences the course of the disease and treatment, some terminally ill patients will not beat the odds. Some of the dying eventually reach a point of acceptance, while some do not. It is important to keep in mind that acceptance is not about giving up, but about finding peace. Once a patient is convinced that they have done everything in their power in the hope of beating the disease and getting their health back, accepting the inevitable can help patients to make the most of the time they have, focusing on the quality, rather than quantity of their remaining days.

One goal of counselling the terminally ill is to enhance patient understanding of the disease and its expected course and to assist the dying person to face the reality of death by educating them about the dying process. Withholding information is not usually helpful, though there are right and wrong times and also better and worse techniques for delivering bad news.

Another counselling goal is to identify the strengths and coping strategies of the client and individual family members. Most people will have had experience coping with major stresses or a crisis, and it would be helpful for the counsellor to help them recall that experience and explore how they coped. This method diverts attention from the current crisis, and encourages clients and reminds them of their previous successes. On other occasions, however, clients may require help developing new coping strategies.

The counsellor's responsibilities may also include supportive therapeutic interventions that address the client's physical, emotional, social, spiritual, and practical needs (Davies, Reimer, Brown, & Martens, 1995; Doka, 1997; Parkes et al.; Rando, 1984; Rando, 2000, cited in Daneker).

5.2 NEEDS OF THE TERMINALLY ILL

It is important for the counsellor to be aware of the various special needs of the terminally ill in order to effectively address their issues and support their families.

1. ***Physical needs:*** Clients may frequently lose strength, have increased fatigue needing more sleep and rest, and reduced appetite due to nausea, constipation and pain. Pain management is a major concern among those with advanced disease, and besides pain medication, interventions like hypnosis, biofeedback, relaxation and imagery techniques can be used to enhance the client's skills and his awareness and control of pain (Arnette, 1996; Cook & Oltjenbruns, 1998; Rando, 1984, cited in Daneker).

   Major physical changes can affect body integrity and the ability of the body to function normally (Viney, 1984 cited in Daneker). Educating the client about common physical changes (either part of the dying process or side effects of treatment) and processes preceding death and what to expect, can help alleviate anxiety and correct inaccurate perceptions about dying (Parkes et al., 1996; Rando, 1984; Rando, 2000 cited in Daneker).

   It is important for counsellors to address the loss of functional capability and increased dependence on others that happens with advanced illness – this could lead to depression and a feeling of being a burden to others as the client is no longer able to do the things he/she was once able to do.

2. ***Emotional needs:*** Coping with intense emotions such as shock, fear, guilt, anger, and grief are both a normal part of the dying process and can be minimized by sensitive intervention; thus the dying can gain much from counselling (Doka 1997; Rando 1984; Shneidman, 1978 cited in Daneker).

   Addressing *anticipatory grief* is a vital part of counselling the dying (Parkes et al., 1996; Rando, 2000; Shneidman cited in Daneker). Issues of anticipatory grief include helping clients redefine life as it presently is, supporting clients as they cope with change, facilitating communication about feelings of being a burden, encouraging the search for meaning, and allowing the client to live day-by-day (Davies et al, 1995 cited in Daneker). Open communication within the family must be developed or supported during this stressful time (Rando; Shneidman cited in Daneker).

3. ***Social needs:*** Through appropriate interventions the counsellor can facilitate the ability of friends and family to help the terminally ill to retain a social life despite physical restrictions (Davies et. al., 1995; Kubler-Ross, 1969; Rando, 1984; Shneidman, 1978 cited in Daneker). Terminally ill patients should be encouraged to cherish and enjoy the time they have left as much as possible, spending their days on their favourite activities, people, and foods, and doing what is meaningful to them. It is best to ask the patient his preferences though close family and friends may already know what types of activities he would most enjoy.

   There may be "unfinished business" that needs to be resolved - tasks such as settling old disputes, communicating with long-term friends, and asking forgiveness are all important to the dying individuals' peace of mind (Davies et al.; Rando; Shneidman).

4. ***Spiritual needs:*** There are three central spiritual aspects that counsellors can provide the terminally ill (Doka, 1993 cited in Daneker). Firstly, the counsellor can *help clients find meaning in their lives and in the illness* - being unable to find meaning in life can generate a profound spiritual pain – the dying person may feel their life has become empty or meaningless. Counsellors can, through allowing time for reflection, support the assimilation of life events and experiences to bring meaning into life by encouraging exploration of significant events and deeds performed in the individual's life.

The second spiritual aspect is *guiding clients to construct their own personal definition of a good death.* Individuals wish to die in a manner that is consistent with their self-identity. A person who has lived an independent life may experience great distress if he is deprived of all control over his own death. Counsellors can ease some of this suffering by listening and helping the terminally ill, to plan her/his manner of death, care of the body following death, the disposition of possessions after death, including organ donation if the person so wishes.

Finally Doka describes the need to *help clients transcend death*, either through belief in religion and an afterlife, or a legacy through descendants or work that remains after they are gone. Doka states that a significant spiritual need is transcendental - we look for reassurance that our life has had meaning and value, and that we have contributed something over our lifetime.

Studies have shown that those who are intrinsically religious—who do not participate in religion or prayer for any sort of secondary gain—find it easier letting go and making end-of-life decisions than those who are extrinsically religious (i.e., persons who participate in religious activity because they believe they will gain some sort of reward).

Practical needs: Counsellors can frequently help in dealing with practical problems - issues such as bequeathing possessions, settling financial affairs, creating wills and trust funds, and pre-funeral planning are all important topics for discussion, which family members may often be hesitant to mention (Rando, 1984 cited in Daneker).

5.3 MANAGING DEPRESSION AND ANXIETY IN THE TERMINALLY ILL

Depression

The medical literature indicates that the prevalence of major depression in the terminally ill ranges from 25% to 77% (cited in Fine, Robert 2001). Depression is both associated with intense suffering and a cause of intense suffering, and advanced disease increases the chance of depression. Depression is managed with psychotherapeutic intervention, cognitive approaches, and behavioural interventions.

Signs & Risk Factors*:* Identifying depression in terminally ill patients starts with a consideration of pre-existing risk factors: a past history of depression, previous suicide attempts, social stressors, a history of substance abuse, or a family history of depression. Another sign of depression in the terminally ill is pain that does not respond to treatment as expected. People cannot deal with all of the psychological and spiritual issues of dying when in pain.

Depression & Suicide: Discussing suicidal thoughts may reduce the risk of suicide. If the client has had such thoughts, the counsellor should learn how far they have progressed and how frequently they occur. By discussing suicidal thoughts, the counsellor can normalize them for the client and encourage him to bring up the subject in the future so that the issue can be dealt with early on. If a patient has tangible, specific plans—a time, place, and method—for suicide, intervention is more difficult.

Anxiety

Anxiety about the end of life is normal. Anxiety has physical, psychological, social, spiritual, and practical aspects. It can present as agitation, insomnia, restlessness, sweating, tachycardia, hyperventilation, panic disorder, worry, or tension. Management of anxiety consists of counselling and supportive therapy.

Delirium

Delirium is common as a person approaches death – physicians can consider it a reasonable indicator of when to tell the family that the patient's life is near its end. Delirium is characterized by the acute onset of a global change in cognition and awareness. It usually presents as a fluctuating level of consciousness and cognitive impairment and must be distinguished from dementia, depression, and anxiety.

5.4 GRIEF AND BEREAVEMENT

According to Webster grief is defined as ***"a keen mental suffering or distress over affliction or loss; sharp sorrow; painful regret"*** (Pickett, et al., 2005, p. 500 cited in Slate & Scott, 2009). Webster also defines bereavement as the ***"state of sorrow over the death or departure of a loved one"*** (Pickett, et al., 2005, p. 106 cited in Slate & Scott, 2009). Grief and bereavement are not interchangeable – the term bereavement is exclusively used to explain the effects that arise from the death of a loved one, whereas grief can be attributed to any kind of loss not necessarily related to

death, i.e. loss of a job, miscarriage, divorce (National Institute for Trauma and Loss in Children, U.S.A.).

In the context of terminal illness, grief is normally associated with the feelings of a bereaved person after the loss of a loved one; however the grieving process frequently starts much earlier, at the diagnosis of a terminal illness of a loved one. Talking about the loss and expressing the feelings associated with it is usually helpful and allows a person to reach a "new normal" and adjust to their new life with all its changes. Keeping feelings bottled up or denying the sadness can prolong the pain. Any loss has to be acknowledged in order to move forward.

Complicated Grief: The literature shows that around 20-33% individuals experience more complicated grief reactions (Doka, 2006) which are characterized by a disproportionate degree of intensity after a lengthy passage of time, a lack of progress towards psychical adjustment or accommodation of the loss, and the presence of maladaptive behaviours (Freud, 1917).

It is important to understand and distinguish between normal and abnormal grief (or *mourning* and *melancholia/pathological grief*) since this has a bearing on the kind of clinical work involved.

There are mediating factors that can intensify the complexity of the grief response.

These include who the person was (particularly children and spouses), the nature of the attachment e.g. ambivalent or dysfunctional, the mode of death (especially suicide, sudden or ambiguous), previous histories like a prior history of mental health issues, personality variables (especially ego strength and attachment style), social variables (in particular where there is a lack of, or no support network) and concurrent stresses (especially other recent deaths or serious economic impacts).

Grieving is an extremely private and personal experience. Each person works through the stages of grief in their own way (there is no one "right" way, but someone who finds it particularly difficult to cope with their grief may benefit from grief counselling.

Kübler-Ross & the Five Stages of Grief

Elisabeth Kübler-Ross, Swiss psychiatrist and a pioneer in Near-death studies in her landmark book "On Death and Dying"(1969) discusses five stages of grieving that people may commonly experience on receiving a diagnosis of terminal illness, though she concedes that not everyone may experience all five stages, or go through them in the same order. The grieving process is equally relevant for both patients and their loved ones.

The five stages of grieving as described by Kubler-Ross (1969) are:

1. **Denial**: For many, total disbelief is a typical initial response to the diagnosis of terminal illness.

2. **Anger**: The terminally ill often react to the feeling of being unfairly singled out by asking themselves "Why me?"

3. **Bargaining**: Hoping and praying for enough time is common - focusing on specific events that are particularly meaningful, such as a wedding or a birth in the family, can add to the enormous feeling of loss, making the terminally ill person wish for enough time to be present at a milestone event.

4. **Depression**: A deep sadness is commonly the final step prior to reaching acceptance. In a way, allowing the sadness is a form of acceptance – no longer holding out hope that there has been a misdiagnosis or that the patient will beat the odds.

5. **Acceptance**: Though not every person finds acceptance ahead of death, those who are able to come to terms with their situation may have a greater sense of peace than those who continue to fight.

Kübler-Ross believed that all terminally ill patients would experience at least two of the above stages, and that not only the dying person but also his loved ones would go through the same process.

Grieving can be an extended and complex process, with many people making progress, only to slide back and regress to a less comfortable place. For some, staying busy and diverting their attention to the needs of others may help to make their own feelings of despair seem more manageable. But they should take care not to use other activities just to avoid dealing with their feelings – this simply postpones the grieving process, rather than bypassing or avoiding it. Seeking help (professional or otherwise) from others can be beneficial for those who are having trouble managing their feelings.

Symptoms of Bereavement

- Physical discomfort & pain - tightness in the body, breathlessness, lack of energy
- Confusion, hallucinations, disbelief
- Obsession with the deceased, sleeplessness, lack of appetite

Most cultures have rituals during the funeral that let the bereaved be supported by those close to them and move automatically through the early period of their loss in a structured way. Funeral services, rituals and rites take up the early days of shock and disbelief and fill them with activity and other people. For many, decision-making becomes difficult and they can lose concentration for extended periods. Feelings of anger may be displaced and misdirected at family members, health professionals or others directly linked to the deceased person.

The bereaved person may feel an extended yearning for the person to return and an inability to accept the loss. If his relationship with the person who has died was unhappy or disturbed, the contradictory emotions can make the loss even more difficult to bear and create a burden of guilt. Professional help may help to understand and deal with the different feelings.

The four main tasks of mourning:

- To accept the reality of the loss and understand its significance
- To work through the confusing pain of grief
- To adjust to life alone – to re-draw the map of oneself
- To let go of the person and find a place for them emotionally

Grief and Bereavement Support Groups

It can be extremely helpful for those who are feeling overwhelmed by feelings of grief and despair to talk with someone who truly understands what grief feels like. Support

groups often consist of those who are or have gone through very similar experiences of loss, so the members of the group may connect and be able to offer each other a level of understanding that their loved ones may not. Though it makes a great difference to be surrounded by supportive and sympathetic friends, sometimes it is only those who have walked the same path who can truly understand what the bereaved person is going through.

Check Your Progress I

Note : Use the space given below for your answers.

1. List the basic needs of a terminally ill person.

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5.5 GRIEF AND BEREAVEMENT COUNSELLING

The literature indicates that there is a societal shift towards professional support for assistance with grief (Wolfe, 2006). Grief counselling can help terminally ill patients to reach a psychological state of peace and acceptance, and be equally helpful for their families, both before and after the death.

Sometimes, people fully comprehend the intensity of their pain only several weeks or months after experiencing a significant loss. Coming to terms with the permanence of a death and understanding the effect that it can have on daily life often takes place when survivors try to get back to their previous schedules and realize that they are unable to function as well as they used to earlier.

Grief counselling can:

- Help in understanding the mourning process, and bridge the gap between the stages of grief to a peaceful acceptance
- Help to deal with lingering areas of conflict
- Explore areas which might hamper moving on
- Help to adjust to a new sense of self
- Consider if the mourning has turned to depression/pathological grief

Qualities of a Grief/Bereavement Counsellor

Grief and Bereavement counsellors need to be emotionally stable individuals, comfortable with discussing end-of-life issues, death and dying. Grief counsellors should be genuinely interested in helping people come to terms with one of the most difficult phases in their lives. They need to be mature, professional and systematic. They must be good communicators who are sensitive to their client's distress and willing to listen. Grief counsellors are also creative problem solvers who work with clients to explore what is best for them in the grieving process.

Role and Functions of the Grief/Bereavement Counsellor

1. *Emotional Support & Coping:* The role of a **grief or bereavement counsellor** is to provide emotional support while helping the bereaved person cope with the behavioural, cognitive, emotional, physical, and spiritual reactions to death. Grief counsellors analyze client history, assess the client's present condition, and develop strategies for their client to cope and grieve in a healthy, beneficial way. They can help clients individually, or have group support sessions. They may have only a few meetings with a client, or be in constant contact for a number of years.

2. *Mediating:* The grief counsellor can mediate between the family and the medical team, and can assist the medical staff in dealing with their patient's emotional issues, as well as in managing their own responses.

3. *Practical help:* The counsellor can also help the family deal with practical issues such as funeral arrangements or household chores by providing a list of tasks to accomplish to family and friends.

4. *Supervision:* Another role of the counsellor in this setting is supervision of others, for example trainee counsellors or volunteers. The counsellor's functions may include hiring, assessing aptitude, training, and providing emotional support for volunteers (J. A. Bryers, personal communication, June 18, 2003). Counsellors also may be involved in training other professionals in the emotional, psychosocial, and spiritual needs of the dying individual and their family (Parkes et al., 1996; Shneidman, 1978, cited in Daneker).

A bereavement counsellor should be responsive and sensitive to his client, allowing him to openly express his feelings and take the lead in the healing process. Instead of having preconceived ideas or set expectations about how a person's grieving process should take place, the counsellor must respect and accept the person's feelings and listen to what they have to say. Through sensitivity, patience and compassion, the counsellor can help the person come to terms with the death, without actually trying to guide or push them through the process.

Two crucial components of grief counselling include helping the bereaved to be aware of their coping behaviour and to identify coping mechanisms that in the long term are damaging or unhealthy for the individual. Without this understanding and self awareness, the bereaved person may maintain these unhealthy methods of coping and may need more extensive treatment such as grief therapy. If the counsellor observes any signs of depression or suicidal thoughts, they will usually refer the person to a psychiatrist or a physician for more intensive care.

5.6 DYSFUNCTIONAL GRIEVING AND GRIEF THERAPY

Dysfunctional grieving is a state in which a person or group experiences prolonged unresolved grief leading to dysfunction and harmful conduct.

Defining Characteristics of Dysfunctional Grieving:

Major (One or More Must Be Present) -

- Unsuccessful adaptation to loss
- Delayed emotional reaction

- Prolonged denial, depression
- Inability to assume normal patterns of living

Minor (May Be Present) -

- Social isolation or withdrawal
- Failure to restructure life after loss
- Failure to develop new relationships/interests

Predisposing factors associated with Dysfunctional Grieving include the following (Bateman, 1999; Worden, 1991):

- A socially unacceptable or negated loss (eg, suicide, AIDS-related death)
- New feelings of dependence and neediness related to the loss
- History of depressive illness or prior complicated grief reactions
- Sudden, uncertain, or overcomplicated circumstances surrounding the loss
- A highly ambivalent, narcissistic, or dependent relationship with the deceased

Grief therapy is a term used to deal with more serious or complicated grief reactions that usually fall under four main types including exaggerated grief, chronic grief, masked grief, and delayed grief (American Society of Clinical Oncology [ASCO], n.d.a). The goal of grief therapy is to identify and resolve the conflicts which prevent the completion of mourning tasks in bereaved persons whose grief is absent, delayed, exaggerated, or chronic.

Exaggerated Grief: This applies to those with depression or anxiety that is excessive, or who exhibit other traits generally associated with normal grief behaviour in an exaggerated and dysfunctional manner, and a psychiatric disorder diagnosis could apply.

Chronic Grief: A bereaved person experiencing chronic or prolonged grief is consciously aware that he has not reached an adequate resolution of his grief, because the loss has occurred many months, sometimes years, before. Since such people are aware that there is a problem, they are generally self-referred. The therapy mostly involves identifying the tasks of mourning not yet completed and what is preventing completion, then working towards resolving the obstacles to completion.

Masked as Somatic or Behavioural Symptoms: Those experiencing masked grief are generally unaware that unresolved grief is the cause of their symptoms. The reason for this complicated grief reaction is because the grief was absent or its expression was repressed, at the time of the loss. As a result, mourning tasks were never completed and the unresolved grief later manifested as somatic or behavioural symptoms.

Delayed Grief & Absent Grief: Here the bereaved person experiences grief at a point after the death in response to another loss or a reminder of the loss. A person going through delayed grief is unable to grieve because of competing stressors e.g. having to shoulder the responsibilities of the family during the time of loss. In absent grief, as far as the bereaved is concerned, it is as if the death never occurred.

NINE WAYS TO HELP WITH GRIEF
(Worden, 1989; Rando, 1984; Cook & Dworkin, 1992; Bertman, 1991)

These guidelines help the bereaved family to gradually complete the four tasks of grieving and resolve their grief.

1. **Increase the reality of the loss.** This is especially important in the early period after the loss. Provide ways to allow the family to say goodbye at the bedside, before death when possible. The family should be encouraged to provide care for the dying person and feel that they helped and contributed as much as they possibly could. Encourage and support the family while they follow cultural and social rites and rituals associated with death and grief. Express sympathy, and allow family members talk about the deceased and their experiences grieving; encourage them to share their memories of the deceased.

2. **Allow time and place for the expression of feelings.** Provide for a quiet room with privacy that is free of distractions. Some drinking water and tissues can be made available. If culturally or socially appropriate, a sympathetic touch on the shoulder or hand is a tangible gesture of concern and support. Help the family to contact significant others. Give verbal permission to grieve or express emotions and thoughts. Listen without judgment.

3. **Normalize feelings.** This is particularly important when the bereaved experiences anger or relief at the loss, or any other emotion that may be perceived as inappropriate. Let the person know that ambivalent feelings are normal and common. It is also very important not to minimize feelings.

4. **Reality test.** Help the bereaved person understand difficult feelings in the context of the situation. E.g. Helping a person understand that feelings of relief and guilt after the death occurs in the context of being overwhelmed during the dying process due to the demands of caregiving and anticipatory grief.

5. **Help with problem solving as survivor adjusts to an environment without the deceased.** Have a helpful and practical discussion of new roles and responsibilities for the survivor. Help the bereaved to break down tasks into small steps that can be accomplished so it does not seem overwhelming. Identify sources of support in the community. Provide referral to social service, legal or financial advisors, spiritual or psychiatric support, etc.

6. **Discourage major life decisions too soon.** The bereaved will be faced with many life decisions and will need to make life changes after the loss. However, making certain major life decisions early in the grieving process (e.g. moving, marriage, pregnancy, changing jobs, etc.) may be counterproductive or detrimental. If the bereaved person is dealing with complicated grieving, or experiencing fresh, intense grief, has difficulty accepting the pain and reality of the loss, or has trouble initiating new activities without the deceased, it is too early to make any major life changes or decisions.

7. **Encourage healthy reinvestment of emotion.** The bereaved should be encouraged to take up previous roles and responsibilities and engage in new activities and relationships in their lives.

8. **Allow for individual differences.** People experience a broad range of emotions and other experiences while grieving, including differences in the time needed to grieve.

9. **Provide continued support.**

Benchmarks of Grief Resolution

- **The bereaved person is able to talk about the deceased without intense affect.**
- **The bereaved person can reinvest emotions in another.**

Questions/Statements to facilitate the counselling process:

Starting the conversation:

- I am wondering what effect this illness is having on your life generally?
- Is there anything especially on your mind today?
- Do you find the illness is creating any stresses in the family?
- I am wondering whether you see any particular meaning in this illness
- How is the illness affecting your view of the past/ the future?
- Is this conversation helpful or would you prefer to be talking about something else?

Talking about Fears:

- Are there any particular fears about what may happen?
- Do you have any concerns about home circumstances at the moment or in the future?
- Would you like to talk about how things might change over the time ahead?

Exploring physical and emotional support for the patient:

- Who would you say are the people who support you - the people you can count on?
- How are they coping?
- Are they helping with your care - how is this going?

Only one question is asked at a time.

- You seem particularly concerned about your wife (husband) today. Is there something on your mind?
- How do you think those left behind will manage?
- What would you say your wife (husband) most appreciates about you?

The latter question allows the patient or family member to explore their personal resources in terms of qualities and also encourages review of the relationship, as well as recognizing the person's relationships and how they might be impacting on the situation. It also helps in assessing the person's people resources and potential practical help as the patient becomes less independent.

Check Your Progress II

Note : Use the space given below for your answers.

1. What are some of the role and functions of a bereavement counsellor?

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5.7 WORKING WITH TERMINALLY ILL CHILDREN

Terminally ill children can be remarkably accepting and open about their impending death; they are often less afraid and can recognize and accept a poor prognosis better than their parents. Sensing their parent's pain and anxiety, they can keep their own feelings to themselves in order to protect their parents. Children can thus be encouraged to share their thoughts and feelings about their illness, about death, about their concern for their families, etc. They can be reassured that they have made a difference, that their lives count for something, and that their deaths will be significant to their loved ones. It would be comforting for them to know that their parents will cope after their deaths.

Counsellors working with dying children should understand the distinctive social needs of children to offer care that is developmentally appropriate (Stevens & Dunsmore, 1996). Play therapy, art therapy, peer support and support groups can all be helpful in allowing children with serious illness to live their lives as normally as possible (Cook & Oltjenbruns, 1998).

Communication

Children express their fears and concerns in several ways: crying, acting out, through playing and drawing, asking repeated simple questions, ignoring others, seeking information from others, and writing letters. The child or teenager can be reassured that these feelings of sadness, fear, confusion and anger are all acceptable.

A dying child has a profound emotional, physical, and spiritual impact on the family and community. It would help to lessen the fears and uncertainties associated with this process by understanding how children at different ages and developmental levels view death and dying. When discussing death, with the child, it is important to use language that the child will understand. The following points should be noted:

- Infants lack language skills; however, they do react to physical comfort. A comforting touch and holding are as important for the dying infant as the caregiver.
- For toddlers and young children, use clear language. Avoid misleading terms for death, such as "sleep" and "passed away." A young child may feel scared to go to sleep if it is associated with death.
- Young children may sometimes ask very direct questions about death. It is important to give honest and consistent responses, and if the answer is not known, to say so. From a very young age children can sense dishonesty in an answer, and if answers from different people are confusing or evade the truth.
- Teenagers may want to discuss death with a friend or someone other than a parent. Encourage communication in any manner that will help the child express his/her fears and concerns.

Some children may communicate through play or drawing. Art therapy can be particularly helpful for young children as their vocabularies are limited and they are typically less skilled and less comfortable using words. Their drawings should be explored and discussed with the child. Others may write letters to their parents or loved ones to say good-bye or to indirectly ask questions. Writing allows the older child to ask direct questions without visibly upsetting the parents. Some adults and children communicate best through writing small notes to and fro to one another.

There are two basic principles according to the latest research in counselling terminally ill children:

1) Children are aware of the seriousness of their illness and just like adults, go through grief and anxiety. Research has also shown that children can sense the emotional distancing of the adults around them and often adapt their behaviour accordingly.

2) Open communication should be encouraged. Clinical evidence shows that the child's understanding of his illness depends chiefly on his capacity to integrate and synthesize the information.

It takes time for the terminally ill child to assimilate information. Bluebond-Langner (1977) discusses five stages in children's understanding about their illness:

1. In the first stage, the child learns, after diagnosis, that s/he has a serious illness.
2. In the second stage the child learns the names of the drugs, their use and side effects.
3. In the third stage the child learns the goals of treatment and the particular procedures used to minimize side effects of medication. Now the child understands the link between each procedure and the corresponding symptom.
4. In the fourth stage the child realizes that there is a sequence of remissions and relapses during the course of the illness. The child recognizes that s/he can get ill repeatedly and that the medicines are not always effective.
5. In the fifth and final stage the child understands that the amount of medicines available is limited and when treatment becomes ineffective, death is imminent.

Bluebond-Langner (1977) has also identified five stages related to the child's changing definition of himself or herself:

1. In the first stage before diagnosis, the child perceives herself as well/not seriously ill.
2. In the second stage, the child sees herself as seriously ill, but thinks she will improve.
3. In the third stage, she realizes that she is constantly ill but still has faith she will become better.
4. In the fourth stage, the child realizes that she very ill and will not become better.
5. In the fifth stage, the child recognizes that she is dying.

Here the implications for counselling are that children need to be given the information required for them to understand what they are experiencing and they also need a protected and caring atmosphere that facilitates open communication to help their emotional well-being.

5.8 ADDRESSING CAREGIVERS ISSUES

When to Seek Help

Caregivers can sometimes become so weighed down by the demands of looking after the terminally ill loved one and taking on other responsibilities that they can no longer function well. Burnout is widespread amongst caregivers, particularly if they do not

receive much help with the every day responsibilities required to care for a terminally ill loved one.

Caregivers who are unable to calm down, sleep well, or who experience symptoms of depression that do not respond to changes in lifestyle may require professional help, both medical and psychosocial. Unlike professional caretakers, family members who are responsible for the daily care of a loved one are also coping with the additional stress of their own feelings about the imminent death.

It is easier for caregivers to manage stress when they are provided with assistance and support and encouraged to take care of themselves. The caregiver should not hesitate to seek help from other family members or close friends with everyday caretaking tasks, including providing companionship, doing household chores, running errands, providing transportation etc.

Managing Stress

The caregiver should be encouraged to eat properly, exercise regularly, and take time away for friends and hobbies to help manage the stress of taking care of a dying family member. It may also be useful to take up meditation, massage, yoga, hypnosis, guided imagery, and simple breathing techniques to help them to feel calm, centred, and more capable of handling stress.

How Caregivers can help the Patient

Voicing Preferences: Many terminally ill patients feel that they have no control or power over their lives - one of the most important things that loved ones and caregivers can do for terminally ill patients is to encourage their participation and ask for their say while taking decisions regarding their care, daily life, and even funeral arrangements; this reassures the patient and helps bring a sense of peace and acceptance.

Expressing Emotions: Difficulty in expressing emotions can impede the process of accepting a terminal diagnosis and can make grieving more painful. Everyone goes through both positive and negative emotions, but some may feel the need to stay cheerful and upbeat, though that is not what they are feeling inside. It is important that family and friends closest to a terminally ill patient persuade them to express their feelings freely as this can help terminally ill patients to work through their grief, anger or any other emotion, leading toward calm and acceptance. It is equally important for caregivers to seek support and a sympathetic ear with whom they can unburden their stress and feelings of helplessness or despair.

5.9 QUALITY OF END OF LIFE CARE

In order to ensure the quality of end of life care, it is crucial for health care professionals to be aware of their own emotional responses to this work, including their responses to its pressures and mental stresses. Those working with the seriously ill will endure many losses of their patients during the course of their carers along with the losses that they will experience in their personal lives.

The stresses of work in end of life care include:

- Awareness of loss – others' and our own
- Awareness of our own mortality

- Experience of multiple losses and accumulating grief (bereavement overload—Kastenbaum, 1969)
- Reminders of our own traumatic loss experiences contributing to re-experiencing of trauma
- Awareness of the limitations of medicine as well as our own limitations as caregivers
  - ✡ Threats to feelings of self-control, mastery, and self-esteem
  - ✡ Feeling of disillusionment with the uncomfortable, harsh realities of death
- Lack of organizational and professional support for the grief of health care professionals

Self care for the counsellor is essential to avoid distancing themselves from their own emotions or their client's and to prevent burn-out. Some counsellors perform rituals to help themselves process their grief such as lighting candles, keeping a memory journal, attending the funeral, etc. It also is helpful to see a variety of clients if possible, to provide balance in the counsellor's case load.

Working with the dying has both trials and rewards for counsellors. Many counsellors report feeling greater love of life, more gratitude for friends and family, and a more spiritual life from this rich experience.

Check Your Progress III

Note : Please use the space given below for your answers.

1. What are some of the important stresses of work in end of life care?

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5.10 LET US SUM UP

In this unit we had discussed the needs of the terminally ill, concepts of grief and bereavement and the different stages of grief. This unit also focused on grief and bereavement counselling, dysfunctional grieving and grief therapy. Having understood and analyzed these concepts you will become more clear about how to work with terminally ill children and to handle the caregiver issues and self care etc…in specific settings and contexts.

5.11 APPENDIX

Communicating Bad News - A Six Step Protocol Overview

(Adapted from *How to Break Bad News: A Guide for Health Care Professionals* by Robert Buckman)

1) Steps 1-3 involve preliminary activities that could be concluded before the session at which the counsellor actually delivers the bad news

2) Step 4, the news is delivered

3) Steps 5-6 allow the health care professional to respond to the patient's reactions and constructively plan for follow-up

STEP 1 - *Getting Started*

Plan What to Say

- Before communicating any news, plan what will be discussed
- Confirm the medical facts of the case
- Ensure that all required information is available
- If this is an unfamiliar task, rehearse what you will say
- Do not delegate the task

Create a Favourable Environment

- Ensure privacy and adequate seating
- A box of facial tissues should be handy
- For pediatric patients, have staff available to be with the child while information is conveyed to the parents, first

Time Management

- Do not fit this into a short interval between other critical tasks
- Prevent interruptions; put on hold telephone calls, messages, etc.

Find out Who the Patient Would like to be Present

The patient may wish to have family, significant others, surrogate decision-makers, or key members of the interdisciplinary team (nurse, social worker, chaplain, etc.) accompanying them for the discussion. For paediatric patients, include parents.

STEP 2 - *Finding Out What the Patient Knows*

What to Ask

- Begin the discussion by establishing the awareness of patient and family regarding the patient's health
- With this information, ascertain if the patient and family will be able to comprehend the bad news
- Questions might include:
  - ✡ *"How would you describe your medical situation?"*
  - ✡ *"Have you been worried about your illness or symptoms?"*
  - ✡ *"What do you understand about your (your child's) illness?"*
  - ✡ *"What did other doctors tell you about your condition or any procedures that you have had?"*

- *"When you first had symptom X, what did you think it might be?"*
- *"What did Doctor X tell you when he sent you here?"*
- *"Did you think something serious was going on when…?"*

When the Patient Seems Unprepared

- Sometimes a patient (or a parent if the patient is a child) will become silent and seem completely unprepared or unable to respond
- To ease the situation and stimulate discussion:
  a. Try to clarify what the patient understands about his or her medical history and recent investigations
  b. Identify absent family members or others on whom the patient relies
- Consider rescheduling the meeting for another time:
  a. If the efforts described above seem ineffective
  b. If the patient remains silent
  c. If it appears the patient requires more support

STEP 3 - *Finding Out How Much the Patient Wants to Know*

Recognizing and Supporting Patient Preferences

- Every patient has the right to:
  - Decline voluntarily to receive information
  - Designate someone to communicate on his or her behalf
- People may handle information differently based on race, ethnicity, culture, religion, socioeconomic status, age, or developmental level
- If the patient prefers not to receive critical information, establish to whom information should be given
- Possible questions include the following:
  - "If this condition turns out to be something serious, do you want to know?"
  - "Whom should I discuss these issues with?"

Advance Preparation

- Before actually delivering the bad news it is important to:
  a. Conduct an initial assessment
  b. Hold subsequent discussions to prepare the patient for critical tests
- These discussions will provide opportunities to determine:
  a. What does the patient know? (Step 2)
  b. How does the patient handle information? (Step 3)

When the Family Says "Don't Tell"

Professional Responsibility, Family Preferences, and Patient Rights

- Many times, family members will ask the health care professional not to tell the patient the diagnosis or other important information
- Rather than confronting their request with "I have to tell the patient," ask them:
  - "*Why do you feel that I shouldn't tell?"*
  - *"What are you afraid I will say?"*
- Suggest "Why don't we go to the patient together to ask how much he or she wants to know about his or her health and to what questions there might be."

When the Patient is a Child

- Parents may not want the child told about the illness
- This protective instinct is understandable, but may eventually be problematic
  - As the child experiences treatments and procedures, he or she will perceive there is a problem
  - The child may feel distrustful and misled when this happens
- To avoid this, a better initial plan is to help the parents to understand that this is likely to occur

Step 4 - *Sharing the Information*

General Guidelines for Breaking Bad News

- Deliver the information in a sensitive but straightforward manner
- Say it and pause
- Avoid delivering all of the information in a single, steady monologue
- Use simple language that is easy to understand
- Avoid technical jargon or euphemisms
- Pause frequently
- Check for understanding
- Use silence and body language as tools to facilitate the discussion
- Do not minimize the severity of the situation
- Well-intentioned efforts to "soften the blow" may lead to vagueness and confusion

Examples of How to Break Bad News

You might choose to break bad news by using language like:

- *"Mr. Narayan, I feel sorry to have to tell you this, but the growth turned out to be cancer."*
- *"I'm afraid the news is not good. The biopsy showed that you have colon cancer."*

- *"I'm afraid I have bad news. The bone marrow biopsy shows your daughter has leukemia."*

STEP 5 - *Responding to Feelings*

How do People Respond to Bad News?

Patients and families respond to bad news in a variety of ways, including affective, cognitive, and psycho-physiological responses

- Affective responses include:
  * Tears
  * Anger
  * Sadness
  * Love
  * Anxiety
  * Relief
- Cognitive responses include:
  * Denial
  * Blame
  * Guilt
  * Disbelief
  * Fear
  * Loss
  * Shame
  * Intellectualization
- Basic psycho-physiological responses include:
  * "Fight or flight"
  * Leaving the room
  * Withdrawal
- Parents may become very emotional when thinking about actually telling their child the diagnosis

15 Ways to Help Patients and Families Cope with Bad News:

1. Be prepared for a broad range of reactions, including outbursts of strong emotion
2. Give the patient and family time to react
3. Be prepared to support them through their reactions
4. Listen quietly and attentively

5. Acknowledge their emotions
6. Ask them to describe their feelings:

   "I imagine this is difficult news…"

   "You appear to be angry. Can you tell me what you are feeling?"

   "What worries you most?"

   "Is there anyone you would like for me to call?"

   "I'll help you tell your son."

   "Your Mom and Dad are sad now. They'll feel better when you get better."
7. Remind them that their responses are normal
8. Make a box of facial tissue available
9. Use nonverbal communication
10. Consider touching the patient in an appropriate, reassuring manner
11. Offer a drink of water, a cup of tea, or something else that might be soothing
12. Allow time for the patient and family to express all of their immediate feelings
13. Don't rush them
14. Remind yourself that once the emotion is "spent", most people will be able to move on
15. Remember that a shared understanding of the news and its meaning will enhance the relationship with the patient and facilitate future decision-making and planning

STEP 6 – *Planning & Follow-up*

Establish a Plan

Planning may include:

- Gathering additional information
- Helping parents to tell their child about their illness and what treatment will be like for them.
- Arranging for appropriate referrals

Assess Support

Explore probable sources of emotional and practical support, including:

- Family
- Significant others
- Friends
- Social worker
- Spiritual counsellor

- Peer support group
- Professional therapist
- Hospice
- Home health agency
- Sources of support for an ill child's siblings

Provide Reassurance

- Reassure the patient and family that they are not being abandoned
- Emphasize that the physician will be actively engaged in an ongoing plan to help and inform the patient and family how they can reach the physician
- Establish a time for a follow-up appointment

Ensure Patient Safety

In order to ensure that the patient will be safe when he or she leaves, ask:

- Is the patient able to drive home alone?
- Is the patient distraught, feeling desperate or suicidal?
- Is there someone at home to provide support?

Future Visits

- At future visits, elements of this protocol may need to be revisited
- Many patients and families require repetition of the news to gain a complete understanding of their situation

5.12 FURTHER READINGS AND REFERENCES

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