

Caring for the Caregivers

NURSES ASSOCIATION OF BOTSWANA
in collaboration with
Dr. Sandra L. Bertman

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Caring for the Caregivers

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A special thank you goes to the working group of participants:

| | |
|---------------------------|---|
| Geetha FeringaRN, MEd | Executive Secretary Nurses Association of Botswana |
| Mabel K. M. Magowe | RN, CM, MSc President NAB, Lecturer and HIV/AIDS Education Co-ordinator University of Botswana |
| Thokgamo Boitshwarelo | RN, RM, FNP, MN Senior Lecturer, IHS, Francistown |
| Tilly Ngulube | RN, RM, CHN Principal Registered Nurse Gaborone City Council |
| Dimakatso S. Toitso | RN, RM, MSN Senior Nursing Officer, S/Phikwe Government Hospital |
| Harriet S. Kopi | Certificate Administration Infectious Disease Care Clinic Community Liasion Medical Adherence Counsellor Chairperson COCEPWA support Group Public speaker, PLWHA |
| S. H. Msimanga Ramatebele | RN, CM, PGDCE, MSN Mental Health Counsellor University of Botswana |
| Grace Karugaba | UNV (Psycho-social Support Specialist) MOH – AIDS/STD UNIT |
| Godirileone Matlhogojane | RN SRN in Princess Marina Hospital Paediatric Medical Ward |
| Matshediso Ramosweu | Tebelopele Voluntary Counselling and Testing Centre |

"The views expressed in this publication, however, do not necessarily reflect those of USAID."

Caring for the Caregivers

Introduction



Jesus wept.

John, 11:35

The AIDS pandemic challenges the knowledge and skills of caregivers. In some wards in health facilities, between 50-75% of beds are now occupied by patients with HIV/AIDS related diseases, whose life span has been greatly reduced. Nurses and other health professionals whose work used to be oriented towards cure, are now increasingly focused on caring for the dying. Though AIDS treatment can alleviate suffering, if “cure” had been one’s goal, caring for the dying, dead and bereaved leads to heightened senses of inadequacy, helplessness and grief.

**“self-care is crucial to survival
and turning away or ignoring it only
perpetrates the distress...”**

Most nurses in Botswana, due to HIV/AIDS have experienced multiple losses, whether professionally or in their private lives. Failure to adequately acknowledge and express feelings of sadness, anger, and frustration may result in bereavement overload, leading to burnout resulting, perhaps, in nurses leaving the profession. Health care professionals need to realize that self-care is crucial to survival and turning away or ignoring it only perpetrates the distress. They need to mourn as their clients are doing, both individually and as part of a larger group. They need to learn stress management techniques and to develop personal support systems, where they can share feelings away from the care giving setting. Institutions can provide opportunities for staff to come together for mutual support. They need to explore their own beliefs about suffering and personal history of loss and how it influences their response to those entrusted to their care.

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Purpose

The aim of the modules in this manual is to enable health workers to assist themselves and their clients who are coping with grief and loss, prior to and following dying and death, especially as it relates to HIV/AIDS, other terminal illnesses and human suffering.

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Background

In July 2001, in light of the HIV/AIDS epidemic, the Embassy of the United States of America, through their Public Affairs section, organized two half-day workshops on "Understanding Grief and Loss: Caring for the Caregivers". U.S. Speaker, Dr. Sandra Bertman, Research Professor of Palliative Care and Humanities in Medicine, Boston College Graduate School of Social Work, was invited as the speaker. Dr. Bertman has extensive experience in developing curricula for US medical and nursing schools to help health care professionals understand the psychology of loss, emotional pain and grief. The workshops were co-organized by the Nurses Association of Botswana (NAB) and the Counseling Section of the AIDS/STD Unit (ASU) in the Ministry of Health (MoH).

One of the suggestions following the workshops was to develop an in-service course on grief and loss counseling, using materials and images specific to Botswana. The Nurses Association of Botswana also acutely felt the need to do something for nurses and other health care workers to address the change in the focus of nursing. The US Embassy through the US Ambassador's Initiative on HIV/AIDS followed through on these suggestions by funding a project, conducted by the NAB to develop a manual with artwork on caring for the caregivers, focussing on grief and loss.

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Self-introduction:

MY FOUR MAJOR INTERESTS EXERCISE

OBJECTIVE

To discover one-self by becoming aware of the four major interests that make up his or her world.

MATERIALS

Paper, pencil and crayons.

PROCEDURE

- The trainees will be seated in-groups of four but will be working individually.
- In silence, each one thinks of four major interests that make his or her world and draws a symbol of each of them in the space provided. For example, if farming is of major importance in his/her life, s/he may draw a hoe or a cow or a goat. If making money is his/her major concern, s/he may draw a Pula coin.
- Each colours the symbols to suggest how s/he feels about the area of his/her life. Although farming may be one of his/her major interest, s/he may not be available for the farm at the moment so he might use grey to colour the hoe, cow or goat. If s/he gets an increase in pay, s/he might colour the Pula coin orange.
- Then each participant picks a colour to represent his/her outlook on life right now and fills in the background. If s/he is pessimistic about life at the moment, s/he may want to use blue; if s/he is hopeful, s/he may use bright yellow. Whatever s/he does, it is best to be honest – even if it hurts.
- Each participant then spends two minutes presenting to the big group the four major interests that make up their work world. Explain the importance of keeping the interchange of the session confidential – within the group.

Source:
AIDS/STD Unit. (2001). HIV/AIDS Counsellor Training Guide.
Gaborone, Ministry of Health.

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The four major interests / values that make up my world.

| | |
|---|---|
| 1 | 2 |
| 3 | 4 |

PROCESSING

Cognitive

- Was it easy to decide on the four major interests that make up your world?
- Which symbols of life's interest are very remarkable? Funny? Creative? Practical?
- Did you find others whose major interests are like yours?

Affective

- How did you feel as you selected four major interests that comprise your world?
- What feelings did you have as you listened to others discuss the symbols that represent their life's interest?
- Did you feel that some soft spot in your heart has been touched by this exercise? Would you like to share those feelings?

Source:
AIDS/STD Unit. (2001). HIV/AIDS Counsellor Training Guide.
Gaborone, Ministry of Health.

Counselling Skills and Caregiving

Introduction

*He sets the time for finding and the time for losing,
the time for saving and the time for throwing away,
the time for tearing and the time for mending,
the time for silence and the time for talk.*

Ecclesiastes 3: 6-7



“A problem discussed is a problem half solved”



Counseling is a one to one (or one to many) relationship between a counselor (the expert) and the client with a problem or concern.

Communication skills are extremely important for developing relationships, interacting with clients, and persons losing relatives and friends in life. These skills are special skills, peculiar to helping, but also extensions of the kinds of skills all of us need in our everyday lives. This is particularly true in the present era of HIV/AIDS, where a lot of people, including care providers, lose relatives and friends on almost a daily basis, and need ways of coping with this horrendous grief and loss. In general, counseling skills can assist in coping with the dying and bereaved people, help relatives and colleagues and handle other people's emotional release.

Counselling Skills and Caregiving

Purpose

The aim of this unit is to assist caregivers to develop skills in counseling in order to help themselves and others in caring for HIV/AIDS and other dying patients.

Objectives

At the end of this unit the caregiver should be able to:

- Discuss general principles of counseling.
- Apply specific techniques that promote counseling.
- Discuss the importance of counseling in the dying persons and their significant others.

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Counselling Skills and Caregiving

Pretest

Instructions: Tick whether an item is True T or False F
(Answers can be found at the end of this unit).

- Avoid specific questions about fears, guilt or remorse until patients or clients voice such concerns directly.
- Humor with the dying and bereaved is thoughtless and inappropriate.
- Setting short-term attainable goals are good interventions for patients and family members prior to and after a death.
- Bereavement counseling is a preventive rather than a curative activity.
- Asking patients/clients if they have suicidal thoughts is dangerous and might even put the idea into their heads.
- Periodic feelings of helplessness, grief and fear are signals to choose a new career.
- If a patient or client's morality differs from mine, I have a right to refuse care.
- The ending of counseling is often another form of bereavement.
- Touching or hugging patients is inappropriate.
- It is unprofessional to cry in front of a patient or family.

Attributes of a counselor / Core conditions in counseling

Most therapists concur that the following qualities are pre-requisites to a counseling relationship (Jourard 1971).

- Empathy, warmth, respect
- Unconditional positive regard
- Genuineness and congruence
- Self disclosure
- Confidentiality

Empathy (*walk a mile in my shoes*)

Empathy implies the ability to feel and describe the thoughts and feelings of others. It is entering the client's internal frame of reference, perceiving the client's world from their point of view, but not without feeling completely as the client. Empathy also means sensing the client's private world, *as if* it were your own, without ever losing the *as if* quality – once this quality is lost, this is no longer empathy.

Warmth

Warmth is caring and the accepting of an individual. It is showing genuine concern for another's well being. Warmth is primarily communicated through such things as a smile, a touch, or a hug, but tone of voice or physical setting might also convey warmth. These behaviors for the most part do not include words – they are non-verbal communication. It is important to note that these non-verbal messages are received by others and given meaning just as words are, and their impact can be as strong as that of verbal messages.

Respect

Respect is the belief in the innate capability of the individual. It is an expectation that people will and can solve their own problems and difficulties. It is the communication of the counselor's belief that the client is a person of worth and value with potential for positive growth and change. Respect is often communicated by what the counselor does not say. In other words, by not offering to intervene for someone, one is communicating a belief in the individual's ability *to do* for her or him self.

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Unconditional positive regard

This is the total acceptance of the client as they are without any judgement by the counselor. If the client has been involved in some crime, he deserves to be accepted as an individual in need of help from the professional, in order to facilitate the success of the counseling relationship. If clients feel that they are not accepted as they are, they will not open up to the counselor. This compromises the success of the counseling relationship.

Genuineness and congruence

This means that the counselor is real and being her or him self. It implies honesty, and candor with oneself, without pretences or putting up a professional façade. Counselors should accept their feelings as well as limitations in the counseling process.

Self-disclosure

Self-disclosure is a process by which the counselor communicates personally relevant information about self to the client. Counselor self-disclosure leads to increased client self-disclosure, and the client self-disclosure is a desirable element in the counseling relationship. "No man can come to himself except as an outcome of disclosing himself to another" (Jourard, 1971). Honest self-disclosure allows for a client to see that others who have concerns or difficulties can cope and overcome those difficulties, (*you are not alone*).

Confidentiality

Trust is an integral part of the counseling relationship, especially because of the stigma surrounding HIV. Confidentiality is essential. If clients feel that the information they have given will not be kept confidentially, then they will not open up. Confidentiality can be shared, by disclosing the diagnosis to the caregivers and family members, who are directly involved in the patient's care and well being. Information belonging to other clients should not be in view of other people, since this indicates the other client's confidentiality is not being protected.

"Shared Confidentiality". This principle is applied to those who need to know in order for appropriate health and social welfare care to be provided (AIDS/STD Unit, 1998, p. 14).

Counseling skills

Counseling skills are different from personality traits and can be learned. The use of the following attributes is essential:

- **Attending behaviors.**
- **Restatement and rephrasing.**
- **Listening for feelings.**
- **Use of questions.**
- **Constructive feedback.**

(The following is an excerpt from the Baylor HIV Nursing Curriculum).

Attending behaviors:

These are non-verbal and sub-verbal behaviors that indicate the counselor is listening attentively to the patient. These include looking at the person, nodding to indicate one is following the conversation, verbal cues such as "uh, huh, leaning forward and mirroring emotion by reaction to what the person is saying. For example one might smile in response to something that is said. Voice tone is also very important to convey concern and warmth to the patient. Cultural factors affect the appropriate use of touch, eye contact, and space between people. As an initial step, the counselor can subtly mirror the actions of the patient, smiling when he or she smiles, leaning forward as the patient does, or looking down as the patient looks down.

Restatement and rephrasing:

Restatement is repeating back to the person the content of what they said, using the same words. For example if the patient says: "I want to go back to school," one could say: "You want to go back to school". Rephrasing is restating what the person said in different words. If the patient says: "I don't know what to do. My family wants me to go back to school and I don't know if I can handle it all," the counselor might restate it as: "You are not sure about going back to school, whether you can do it." Both of these techniques can help the person to continue to tell the story and to feel he or she is being heard.

Counselling Skills and Caregiving

Listening for feelings:

Effective counselors listen for feelings to identify the emotion the person might be experiencing, based on something the patient says or does. This is usually done in tentative terms, since only the patient can confirm if the counselor's reflection is correct. Sometimes saying the feeling aloud will cause the person to reevaluate whether that is how he or she is really feeling. Using the previous example, the counselor might say: "It sounds like you are feeling confused about whether to go back to school, and maybe a little overwhelmed".

Use of questions:

Questions are often used to clarify thoughts, feelings or presuppositions the counselor has about something the patient has said. The answers to questions are used to lead the patient to discuss and consider his or her situation and possible solutions. Open-ended questions are often used to allow the person to articulate beliefs and thoughts. An example of an open-ended question is: "How did you feel when you heard the test result?" Closed-ended questions are often used to direct a conversation to obtain specific information. An example of a closed-ended question is: "Do you know anyone who has HIV?" Both open-ended and closed-ended questions are useful in various points of the counseling interaction. Clarification of questions or statements may be used to elaborate on something the patient previously said or implied. For example, the nurse may ask: "What did you mean when you said you didn't know how much longer you could continue to live with your family?"

Constructive feedback:

It is often useful for the counselor to be able to express an observation or reaction to something the patient is saying. Providing feedback in a constructive way will help the patient to reflect upon his words or actions. Both positive and negative feedback needs to be expressed in a way that is helpful, specific and not accusatory. For example, statements like: "You never listen," or "You make me happy", are vague and do not provide information to which the client can respond. Constructive feedback statements are in the form of "I" statements that describe the specific emotional reaction to a specific behavior for a specific reason. The format for such responses is: "I feel (specific feeling) when you (specific behavior) because (specific reason)." For example: "I feel worried when you miss your prenatal appointments because prenatal care will improve you and your baby's health." Using this method of providing feedback can minimize hurtful or accusatory statements that often result in defensive responses.

Stages of the counseling relationship

There are generally five stages in the counseling relationship:

- **Connecting.**
- **Discussing the current problem and history of the problem.**
- **Helping the client to develop skills and find solutions.**
- **Planning to implement and evaluate solutions.**
- **Terminating the counseling relationship.**

Connecting:

Connecting with the patient requires listening to the patient to understand his or her worldview and concerns. Greeting the patient warmly and encouraging him or her to tell his or her story can allow the patient to start where he or she is and help the listener to know the patient's preconceptions and previous experiences. Using the previously discussed listening skills can help to form a bond with the patient. In addition, connection often occurs by discussing common experiences, such as the weather or family.

Discussing the current problem and history of the problem:

Once a beginning level of rapport has been developed, the counselor can discuss the problem the patient wants to address. For example: perhaps the parent is having difficulty getting a child to take his HIV medications. The counselor will use the listening skills discussed earlier to help the parent by first having the parent describe what is happening prior to taking the medication, what efforts have been made, when the problem seemed to begin, and what seems to make the situation worse or better. The patient should describe the problematic situation in detail, describing the sequence of events and interactions, frequency and efforts, and previous attempts to change.

Skill-building and finding solutions:

Once the problem has been defined, solutions can begin to be uncovered. The patient should be encouraged to think about similar situations and how he or she solved a previous problem. By looking at these previous situations, the patient can discover that he or she has experienced a similar situation before and can use skills he or she already possesses to solve new problems. Other solutions can be found by looking at how others have responded to similar situations. Some patients will benefit from learning new skills, for example learning how to use a condom properly, learning how to break large tasks into smaller ones, or learning how to progressively relax the body to cope more effectively with stress or pain. Some problems are very complicated and not easily solved. For example, it is often difficult to negotiate condom use with a spouse after the patient has received HIV-positive results. In these

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situations, it is important for the counselor to convey empathy to the patient and not suggest "simple solutions". The counselor should encourage the patient to continue to seek effective methods of coping. The counselor should also be present with the patient as he or she considers these difficult situations. By helping the patient discover the solution, the counselor can ensure that the patient is committed to implementing that solution.

Planning to implement and evaluate solutions:

Once the patient has developed some possible solutions and has acquired the skills to implement them, the counselor should help the patient to plan how she or he will start the change process. The counselor should help the patient to determine how to evaluate progress with short and long-term goals. A time frame should be established for re-evaluating and determining the effectiveness of the proposed changes.

Terminating the counseling relationship:

Throughout the counseling process the patient and or family should have learned more about self, death, dying, grief and loss and feel as though she or he has grown and gained experience towards greater self reliance. Things should have become clearer and the client should have gained in self-confidence. When the client has achieved what was wanted from the experience and shows signs of being ready to end the relationship, the counseling relationship may be terminated. Normally this is a mutual decision. (Patterson and Eisenberg, 1982). 'Doors' are left open, so that the client/patient can come back with any similar or different problem in the future.

Counseling, dying, grief and loss

In the context of grief counseling, our attention is focused on helping bereaved persons being aware of their pain, to experience it and by working through the pain to pass ultimately through the grief.

During a period of loss, families / individuals may experience a wide range of emotions such as shock, anger, disbelief, depression, hopelessness and helplessness. The range of emotions is broad and not all persons experience every emotion or experience in the same sequence. It is important for the family members to maintain communication with each other and attempt to share their feelings with each other and with other members of their support systems, e.g. priest, friends, neighbours, care givers, etc. Counseling can be of major importance during this period.

Source: Careers and Counselling Centre: Leaflet on Grief and Bereavement Counselling, University of Botswana.

Conclusion

Counselors are knowledgeable about theories of personality and psychotherapy and they have learnt the dynamics of human behavior. However it is important to note that while these skills are essential, they are not themselves sufficient for establishing and maintaining effective relationships. The most powerful determinants of a therapeutic encounter are the human qualities and experiences the counselor him or herself brings to every session. If counselors hope to promote growth and change in their clients, they must be willing to do so in their own lives. The most powerful source of influencing clients in a positive direction is the counselor's living example of who they are, and how willing they are to continually struggle to live up to their potential.

Counselling Skills and Caregiving

For further reading

AIDS/STD Unit. (2001). HIV/AIDS Counselor Training Guide. Gaborone, Ministry of Health.

Confidentiality, In:

AIDS/STD Unit (1998). Botswana National Policy on HIV/AIDS (revised version). Ministry of Health. Gaborone, Associated Printers.

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WHO. (2000). Fact sheets on HIV/AIDS for Nurses and Midwives in Botswana. Gaborone, Tiger Design and Graphics.

Careers and Counselling Centre: Leaflet on Grief and Bereavement Counselling, University of Botswana.

Learning Activities

SELF ASSESSMENT CHECKLIST

Purpose:

To find out whether you are a potential good counsellor?

Instructions:

Each participant to reflect on the questions below, then discuss in a plenary session.

Questions:

1. Why did you decide to be a counsellor?
2. How do you feel about being a counsellor?
3. With what emotions are you comfortable?
4. What are your expectations of clients?
5. Can you accept people as they are, and not want to change them?
6. Can you keep people's secrets without wanting to talk about them yourself?
7. Can you let go of wanting to solve everyone's problem?
8. Can you use your experience of life without pushing it at people?
9. To what degree can you be flexible, accepting and gentle?

Source: AIDS/STD Unit (2001). HIV/AIDS Counsellor Training Guide. Gaborone, Ministry of Health.

Counselling Exercise

Purpose:

To identify the core conditions in counselling.

Instructions:

Simulate a counselling session for about 10 minutes. Allow members of the group to pick the core conditions in counselling and discuss them.

Role Play:

A woman, aged 24, comes into your office (dressed all in black) and starts sobbing before she can say anything to the counsellor. The counsellor offers her a seat, some facial tissue, a glass of water and sits down next to the client, holds her hand and says nothing to her at that moment. A few moments later (sobs are dying down), the counsellor tells the client that when she feels better, she can relate to the counsellor what is hurting or (I realize you are wearing black clothes.....) do you want to talk about this?

The client relates that she lost her husband a month ago from some severe headache. She then decided to take an HIV test for which she tested positive in the past week (sobs again). She does not want her in laws / parents to know about her status as yet. The client is however concerned about her children's (aged 4 and 2) future if she suddenly would die too.

Counselling skills and caregiving

Pretest key

1. F
2. F
3. T
4. T
5. F
6. F
7. F
8. T
9. F
10. F

Introduction

*Someone who is always thinking about happiness is a fool.
A wise person thinks about death.*

Ecclesiastics, 7:4



“Death is not putting out the light, it is extinguishing the lamp because dawn has come”

TAGORE

Death rates have increased dramatically in recent years mostly because of the HIV/AIDS epidemic. Caregivers are therefore more often confronted with a number of deaths in their work environments. Most of us have less experience with preparation for coping with the deaths, consequently, most of us are uncomfortable when confronted with dying individuals and we are also apprehensive about our own death.

Pre-occupation with death, and particularly with the circumstances surrounding it, is a concern to almost everybody. People generally hope for a dignified death with little suffering and a dignified funeral. Most people in Botswana spend a lot of time, money, etc. for the funeral, while at the same time it produces more stress.

Death and Dying

As people confront life-threatening illness, they may start by hoping that nothing is wrong, that the diagnosis is not true. As they realize the full meaning of the illness, most patients will hope for cure and long life. As the patient realizes that the illness will take his/her life, most will shift to hope for the absence of suffering and a good death. No matter how prepared for death we think we are and no matter how anxious we are for its occurrence the moment of death is an awesome event, capable of eliciting unexpected strong feelings (Bertman, 1991). These important hours often leave lasting memories for families as well as for us. In hospital settings making room for private visits, religious and cultural observance, and communication are critical. Managed well, these last hours can lead to smooth passage and healthy grief and bereavement.

Purpose

The aim of this unit is to help caregivers work out their own feelings about death and dying, and to develop strategies, which enable them to be a source of support to themselves, the dying patient and their families.

Objectives

At the end of this unit the caregiver should be able to:

- Demonstrate understanding of the dying process and its impact on the patient, caregiver and family.
- Demonstrate understanding of the elements of end of life care.
- Apply principles of palliative care to alleviate symptoms of pain and suffering.
- Acknowledge the need for the client to explore and express desires (*e.g. drafting a will, funeral programme, convey regret, find peace, etc.*) and the impact it has on the care giving.
- Demonstrate skills in caring for the dead.

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Death and Dying

Pretest

Instructions: Tick whether an item is True T or False F
(Answers can be found at the end of this unit).

- Physical pain is almost always the most important contributor to suffering.
- When patients ask "why me" they want answers from us.
- Hope and terminal illness are mutually exclusive.
- Terminally ill patients can easily identify one overall unifying meaning for their lives.
- Health care professionals must keep patients and family members focused on positive memories.
- Some people are helped by viewing the body after death.
- Palliative medicine is inappropriate for the newly diagnosed patient.
- "How many patients like me have you followed through to death" is an inappropriate question to ask your physician.
- Some people find comfort in reading, reminiscing, saying prayers or singing to the dying.
- Touch does not help reduce pain in dying patients.

The dying process

“Cecilia was clearly almost dead but her soul refused to vacate the body. She was hanging on when no recovery was possible. What was needed was her mother to release her from her heart, to tell her that it was all right, that she could go. To reassure her that her [own] daughter would be taken care of.”

Rubbing her daughter’s body with ancestral soil, Cecilia’s mother tells her to sleep and let the pain end. She promises to take care of her daughter, assures her it is all right to join the ancestors and watch over her daughter from there.

“Just as the old woman finished bathing Cecilia, she raised her hand, dipped it in the water and ran it over her sleeping daughter. For weeks she had not been able to move a finger. As realisation spread from face to face, calm came over Cecilia’s own face. It softened, and with her hand on the thin, fragile foot of her daughter, she died”.

Dow, 2000, pp. 177-178.

As a person enters the final stage of the dying process, two dynamics are at work, which are closely inter-related and inter-dependent. Physically, the body begins the final process of shutting down, which will end when all the physical systems cease to function. Usually this is an orderly and undramatic progressive series of physical changes which are not medical emergencies requiring invasive interventions. These physical changes are a normal, natural way in which the body prepares itself, and the most appropriate kinds of responses are comfort-enhancing measures.

The other dynamic of the dying process is at work emotionally and spiritually and is a different kind of process. The “spirit” of the dying person begins the final process of release from the body, its immediate environment, and all attachments. This release also tends to follow its own priorities, which may include the resolution of whatever is unfinished of a practical nature and the reception of permission to “let go” from family and friend. These “events” are the normal, natural way in which the spirit prepares to move from this existence. The most appropriate kinds of responses to the emotional and spiritual changes are those which support and encourage this release.

When a person’s body is ready and wanting to stop, but the person is still unresolved or unreconciled over some important issue or with some significant relationship, he or she may tend to hold on in order to finish whatever needs finishing.

Death and Dying

On the other hand, when a person is emotionally and spiritually resolved and ready for this release, but their body has not completed its final physical process, the person will continue to live until the physical shut down is completed.

The experience we call death occurs when the body completes its natural process of shutting down, and when the "spirit" completes its natural process of reconciling and finishing. These two processes need to happen in a way appropriate and unique to the values, beliefs and lifestyle of the dying person. Each person is unique and needs to do things in his or her own way. This uniqueness also applies to the dying process. This is not the time to try to change your loved one or your client's styles, but



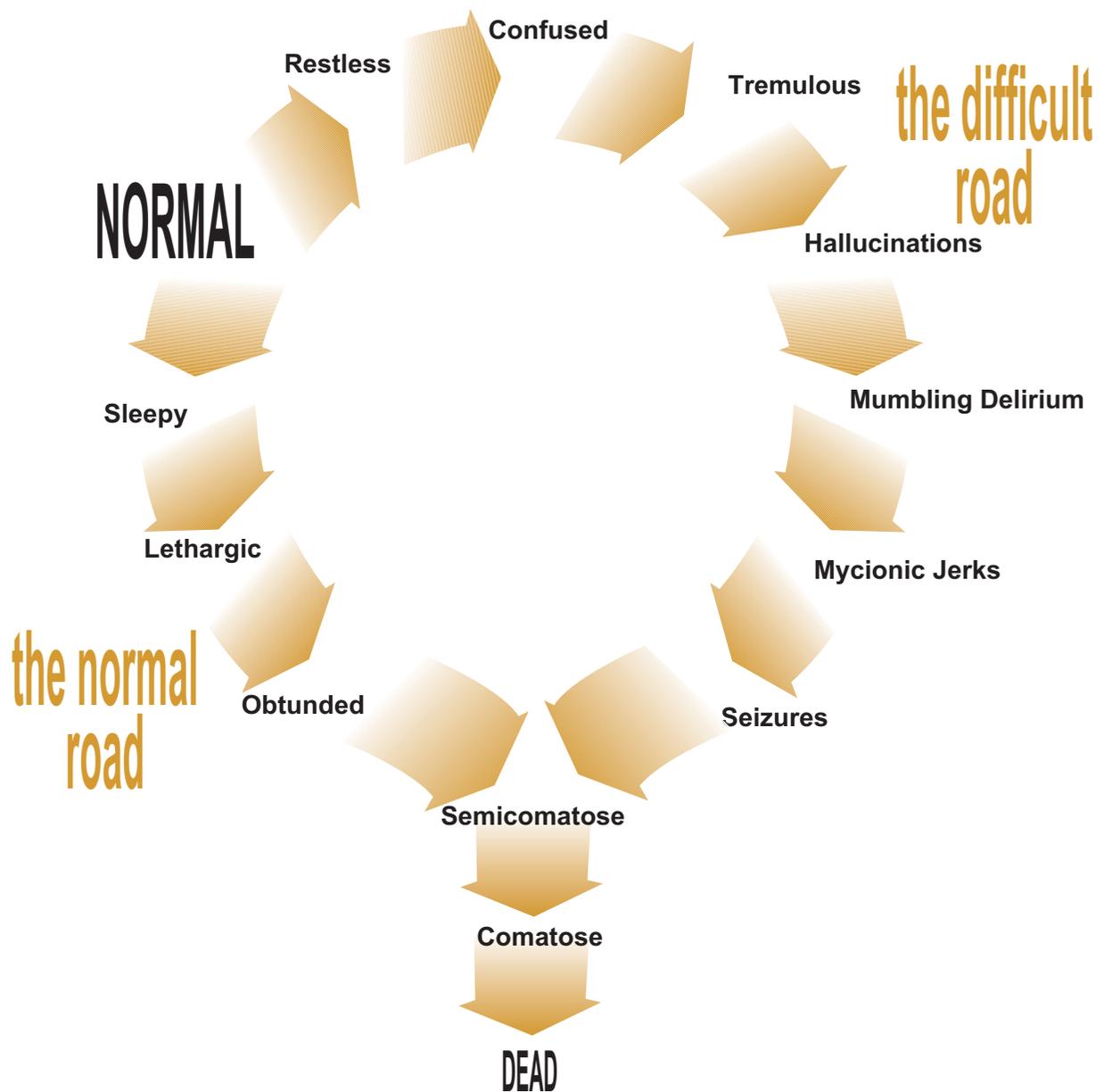
the time to offer full acceptance, support and comfort. The concept of "goodbye" achieves closure and makes final release possible. Saying goodbye may be as simple as saying "I love you", "I am sorry" or "Thank you". In many cultures, tears are a normal and natural part of saying goodbye. Tears do not need to be hidden from your loved one or apologized for, they express your love and help you to let go (Bertman, 2001).

**"May those from under our feet
Breathe the warmth of community into us,
so that the peace we seek
mounts our bodies and sits
on the chairs of our hearts,
sprinkling love and joy around us all".**

(Kounbaterzie Dabire)

Roads to Death

The usual road to death involves decreasing ability to communicate. Patients sleep most if not all of the time. Time spent preparing families is likely to be worthwhile. Advise family members and caregivers to talk to patients as if they were conscious, and express feelings of love, or just support and comfort by being present.



Source: A Comprehensive Guide for the Care of Persons with HIV Disease. (1995).
Toronto: Mount Sinai Hospital and Casey House Hospice Inc. PP. 118-120.

Death and Dying

Signs and symptoms of dying

- Weakness / fatigue
- Decrease in appetite / food intake
- Decrease in fluid intake
- Decrease in blood perfusion
- Neurological dysfunction
- Decreasing level of consciousness
 - Terminal delirium
 - Changes in respirations
 - Loss of ability to swallow
- Pain
- Loss of ability to close eyes

The signs that death has occurred include:

- Absence of heart beat, respiration.
- Pupils fixed.
- Colour turns to a waxy pallor as blood settles.
- Body temperature drops.
- Muscles, sphincters relax
 - Release of stool/urine
 - Eyes remain open.
 - Jaw falls open.
 - Body fluids may trickle internally/externally.

(Source: The EPEC Project, 1999)

Point for discussion:

Is the person dying really fatigued, and how do we, as caregivers perceive this?

Needs and issues of the dying person

The dying person may have needs and issues, which need to be identified and addressed accordingly (Bertman, 2001, adapted from Maslow, 1968).

Needs

- **Physiological** Good symptom control (nausea, bodily comforts, medication to ease the pain)
- **Safety** A feeling of security
- **Belonging** The need to be needed
The need not to feel a burden
- **Love** Expression of affection / human touch
- **Understanding** Explanation about disease and its symptoms
Opportunity to discuss process of dying
- **Acceptance** Regardless of mood and sociability
- **Self-Esteem** Involvement in decision-making especially as physical dependency on others increases
Opportunity to give as well as receive
Life review: Bolster personal sense of self worth by knowing one's life meant something to someone
- **Comfort** Make person feel comfortable by e.g. offering a soothing touch, a cool drink, a kind word
- **Rituals** Performance of last sacraments, anointing of oils, prayer, bathing, priest visiting, etc

Issues

Fear of death

Fear is a normal reaction and can make people angry, depressed, or aggressive. Caregivers should be careful not to give false reassurances, but should encourage the person to talk about their fears. Spiritual support might also be helpful.

Loneliness and depression

Sometimes when someone is dying, people stop coming to visit because they fear death, or do not know how to react. Such isolation can lead to a sense of loneliness and depression. People should be encouraged to visit (if the dying person so wishes). In some cultures, people will also need an opportunity to discuss their feelings about being with someone who is dying.

Death and Dying

Feelings of guilt and regret

Where a person is dying due to HIV / AIDS, the patient may feel responsible for exposing his/her partner to infection, or may feel guilty for having brought shame to their family or friends. Failure to settle debts, fulfil ambitions, or attend to their responsibilities to children can all cause feelings of guilt, sorrow, and regret. A person may seek forgiveness or wish to discuss ways of resolving problems for which he/she feels responsible.

Spiritual support

This support is a very important component of care which may come either through an organized religion, or through the exploration of the patient's own spirituality, beliefs and values. The patient might have been cut off (whether by him/herself or by their community) from his/her religion. Caregivers should acknowledge spiritual needs, respect religious beliefs or lack of them), identify an appropriate person who can provide spiritual support, and discuss whether any religious observances to be performed, including funeral arrangements, in the event of death are desired.

Inheritance issues, leaving a legacy

A will helps to make clear what a person wishes to happen after his/her death. The surviving spouses and children are often left impoverished and unprovided for unless a will is made (*see section on Leaving Legacies, p 34*).

Care Givers Policy Implication:

- Develop standard documentation in nursing care plan that the "will" has been discussed with the dying patient.

Reactions of the patient to dying

The following are stages a patient may go through when dying, but it may not necessarily be in the same order. Alternatively, some stages may occur simultaneously (Kubler Ross, 1969).

Stage of Denial: *(No, Not me! It can't be.)*

- Period of denial allows patient to mobilize his defenses.
- Patient will exhibit withdrawal and avoidance of subject of death.
- Usually a temporary defense to be replaced in time by partial acceptance.
- Patient may talk of death and then change topic abruptly.
- Patient may be in a temporary state of shock.

Stage of Anger: *(Why me? It's not fair.)*

- Anger, rage, envy and resentment may replace denial.
- Anger may be displaced and projected into environment.
 - Anger frequently directed at hospital staff. (avoid reacting personally to this anger).
 - Try to tolerate rational and irrational anger. Patient may experience considerable relief in expressing anger.

Stage of Bargaining: *(If I can just live to see my son graduate from secondary school.)*

- Bargaining is an attempt to postpone the inevitable and to extend life.

Stage of Depression: *(Please don't bother me with medication, leave me alone.)*

- This is a stage in which the patient is preparing himself to accept the loss of everything.
- Patient may be undergoing anticipatory grief to prepare himself for the final separation; may mourn the loss of meaningful people in his life.
 - Allow the patient to express his sorrow helps make the final acceptance easier.
 - Sit with the patient.
 - Use touch therapy if appropriate.

Stage of Acceptance: *(My children, take care of yourselves, we'll meet in heaven.)*

- Patient is neither depressed nor angry about his impending death; he bows to the sentence.
- May contemplate his demise with quiet acceptance and expectation – detachment may make death easier.
- During this stage patient may be almost void of feelings – his circle of interest diminishes.

Death and Dying

- Patient will sleep and rest more- does not desire news or visitors from outside world.
- Patient may just wish someone to hold his hand – reassures him that he is not forgotten.
- Patient may reach the point where death comes as a relief.
- Family may require more support during this stage.

Source: Brunner and Suddarth, 1982, p. 857-858

Critical concepts in death and dying

- **Pain versus Suffering**
- **Cure versus Healing**
- **Hope and Meaning**
- **Leaving Legacies**

PAIN versus SUFFERING

Physical pain is always the most important contributor to suffering. If the pain is not relieved, some people might request assistance in hastening their own death.

In terminal illness, pain becomes one of the most feared outcomes, both for the patient, the family members and the caregiver who feel helpless in the face of a loved one's agony. Terminal illness is not always physically painful. In many cases it can be managed by regular human touch by a family member or a caregiver (See Simpson in Bertman, 1999).

Research issue:

- Pain relief in Home Based Care: how much is done to relief pain in HBC patients?
- Pain management / protocols during death and dying.

Effects of Pain

Pain is more than “just” hurting. Pain decreases physical, emotional, social, and spiritual well being in a variety of ways. It affects a person physically, mentally, and emotionally. When in pain, a person may:

- Be less able to function
- Feel tired and lethargic
- Lose appetite or have nausea
- Not be able to sleep, or have sleep interrupted by pain
- Experience less enjoyment and more anxiety
- Become depressed, anxious, or unable to concentrate on anything except pain
- Feel a loss of control
- Have less interaction with friends
- Be less able to enjoy family affection
- Have a change in appearance
- Feel more of a burden on family or other caregivers
- Suffer more
- Not want to communicate

Suffering

Suffering encompasses more than physical pain. Persons are unique and do not experience suffering in the same way. To be a person is to have a past, a present, an anticipated future, a private life, personal and professional roles, and a belief system. When any aspect of “personhood” is threatened, whether in the realm of social roles, group identification, relationship with self, body, family, God or transcendent sources of meaning, we are prone to suffering (Cassell, 1982)

Facing the end of life may challenge our usual sources of meaning. What would you list as the things that give you most meaning and value to your life? Think about how the prospect of disease might affect those.

Death and Dying

CURE versus HEALING

Cure is seen as the elimination of symptoms, whereas healing means to make whole, to restore the intactness of personhood (Bertman, 1999).

Women living with HIV / AIDS have given the following definitions of healing:

Healing is:

- a lifelong journey toward wholeness
- embracing what is most feared
- remembering what has been forgotten; softening what has been hardened into obstruction
- experiencing God and love
- creativity and passion and love
- learning to trust life.

| | |
|--|--|
| Hate AngEr Anxiety Physical pain Indignity Abandonment SufferinG | Is not cure Is never too late Is ALWAYS possible |
|--|--|

Healing conversations:

Many people near the end of their life want to know that they have been loved, that they will be forgiven for things they may have done wrong, and that they will leave good memories. Asking to hear stories of the person's life ("life review") reassures people that their time on earth has been worthwhile.

The dying person may also need to know that those left behind will be able to take care of themselves and wish for permission to go.

Six important conversations to complete a peaceful death:

- Please forgive me.
- I forgive you.
- I love you.
- I love you too - I will take care of the children and myself
- Thank you.
- Goodbye or "au revoir" ("See you in Heaven").

Helpful questions / assurances for end-of-life.

- What are you most afraid of?
- What are you hoping for?
- What aspects of life are most important to you?
- What have you accomplished in your life that makes you feel proud?
- How would you like to be remembered?
- Let's discuss what we can do to fulfil your wish to stay at home...to insure your property will go to the right people...to see that your children will be taken care of.
- We'll do everything we can to help you maintain your independence.
- We will concentrate on keeping you comfortable.

HOPE and MEANING



“We can hope for the best,
but we also need to plan
for the worst”

"Hope is a multi dimensional, changing life force. It is characterized by confident yet uncertain expectation, of achieving a goal. Hope is not a single act but a complex series of thoughts, feelings and actions that change often. Clients facing death, as well as their families, experience different dimensions of hope" (Potter and Perry, 1993, p. 867).

Maintaining hope is a primary task for every person with AIDS and it is one of the most difficult. Feelings of hope fluctuate daily and sources of hope differ from person to person. Maintaining hope is a daily process, not a state that is ultimately attained.

The degree of hope people feel can be affected drastically by how well they feel physically, emotionally, or spiritually that day. Hope is fostered when individuals feel powerful and in control of their lives to as great a degree as possible.

Hope is frequently associated with developing or maintaining spiritual and religious practices, finding new meaning in experiences, becoming politically active, altering one's attitude and way of thinking, maintaining significant social and family ties, and being able to help others. For many individuals, hope is also tied to medical treatments or alternative healing options.

“Always expect
hopefulness – the object
of hope changes over
time”



Maintaining hope often requires reframing and redefining what feels hopeful. Associating hope with day-to-day accomplishments and events, greatly increases the possibilities for feeling hopeful.

H
O
P
E

Heavenly father
Open your arms and heart
Prepare me for whatever happens
Endings are but new beginnings

Strategies to foster hope: prior to and / or after death.

- What does hope (death) mean to you?
- If death is inevitable, what would make it acceptable?
- Tell me about your hope. What kinds of things do you hope for?
- If you could identify a source of hope for yourself, what would it be?
- What things cause you to lose hope? (What might lead you to want to die?)
- What helps you to maintain your hope or makes you feel hopeful?
- What might one do to prepare for death? If death is close, what matters most?

Care givers' implications for promoting hope.

- Convey an empathetic understanding of client's worries, fears, and doubts.
- Reduce the degree to which clients become immobilized by concerns.
- Build on client and family strengths of patience and courage.
- Clarify or modify hoping persons' reality perceptions.
- Offer information about the illnesses or treatments, correct misinformation, and share the experiences of others as a basis of comparison.
- Help clients use personal and family resources in relation to hope.
- Balance levels of independence, interdependence, and dependence when planning care.
Enhance clients' self-esteem and capabilities; give praise and encouragement appropriately.
- Strengthen or foster relationships that provide hope.
- Help clients know that they are loved, cared for, and important to others.
- Attend to client's experience.
- Use clients' insights from past experiences and apply them to the present.
- Provide the opportunity to communicate about life situations that influence hope.
- Encourage discussion about desired goals, reminiscing, reviewing values, and reflecting on the meaning of suffering, life, or death.

Source: Potter and Perry, 1993, p. 873.

Developmental landmarks and taskwork for end of life.

Our role is to enable patients to discover their meaning of life through any strategy such as creating a work, doing a deed, experiencing something or someone (loving). We may do this by eliciting and sharing personal stories from patients; as well as those told in the bible, arts, film and literature.

Drawing on the work of psychologists Erik Erikson and Abraham Maslow and others, Dr Ira Byock (1996) has provided a working set of guidelines for end of life care:

Sense of completion with worldly affairs.

- Transfer of legal, fiscal and formal social responsibilities.

Sense of completion in relationships with the community.

- Closure of multiple social relationships (employment, commerce, organizational, congregational). Components include; expressions of regret, expressions of forgiveness, acceptance of gratitude and appreciation.
- Leave taking: the saying of good-bye.

Sense of meaning about one's individual life.

- Life review.
- The telling of "one's stories".
- Transmission of knowledge.

Experienced love of self.

- Self acknowledgement.
- Self forgiveness.

Experienced love of others.

- Acceptance of worthiness.

Sense of completion in relationships with family and friends.

- Reconciliation, fullness of communication and closure in each of one's important relationships. Component tasks include; expressions of regret, expressions of forgiveness and acceptance of gratitude, appreciation, expressions of affection.
- Leave taking; the saying of good-bye.

Acceptance of the finality of life - of one's existence as an individual.

- Acknowledgement of the totality of personal loss represented by one's dying and experience of personal pain and existential loss.
- Expression of the depth of personal tragedy that dying represents.
- Decathexis (emotional withdrawal) from worldly affairs and cathexis (emotional connection) with an enduring construct.
- Acceptance of dependency.

Sense of new self (person hood) beyond personal loss.

Sense about meaning of life in general.

- Achieve a sense of awe.
- Recognition of a transcendent realm.
- Developing / achieving a sense of comfort with chaos.

Surrender to the transcendent, to the unknown - "letting go".

LEAVING LEGACIES

The caregiver is sometimes confronted with situations whereby the dying person needs help in the process of drawing a will. Having knowledge of what a will should have and the requirements of a will can assist the caregiver to help the dying person in such situations. The caregiver will also be able to use such knowledge in drawing up her/his own will where need arises, while a lawyer or legal expert should be consulted whenever possible.

A will helps to make clear what a person wishes to happen after his/her death. The surviving relatives/family are often left impoverished and unprovided for, unless a will is made.

"what a will should have"

A will must be made in accordance with local law and may:

- Ensure that property, land and valuables are passed on to people that the dying person stipulates.
- Make clear who has custody of the children, and if there is no partner, appoint guardians.
- Specify trustees or executors who will ensure the will is acted upon.
- Provide instructions about funeral arrangements.

"requirements of a will"

To be valid, a will must usually be:

- Written in permanent ink or typed.
- Signed by the person and clearly dated. Signing and dating must be witnessed. (Those who benefit from the will should not be witnesses).
- Written when the person is of sound mind, and not being forced to do so by someone else.

Making a will is a practical step that in a concrete way acknowledges the possibilities of death. Experience suggests that a will be better made when people are still well. However, the task of making a will is never routine nor familiar for young people and they may need help. Opportunities should be made for the patient to consider the benefits of making a will and the implications of making a will before he becomes too ill to make his own decisions. The act of contemplating a will, or indeed writing it, may prompt some people to think more about dying and the psychological benefits of “getting one’s affairs in order” should not be overlooked.

By neglecting to make a will some patient may indirectly communicate that they prefer other people to make decisions for them about their estate and consequently about their relationships. Once a patient has been given the opportunity to consider the implications of making a will, he should be left to decide in his own time, what he wants to do. He might then feel that he wants to talk about the implications of not making a will. These are examples of questions that could be asked:

- Do you know what could happen to your wife and children if you could die without making a will?
- What ideas might your wife have if she knew that you had not made a will and all your possessions were to go automatically in to your family?
- What message would it convey to your wife if you do not make a will?

Policy implication:

- Legal considerations of customary or traditional will.
- Legal / customary considerations when there is no will.

Palliative care

Palliative care, also called comfort care, is primarily directed at providing relieve to a terminally ill person through symptom control, pain management and whole person care: attention to the physical, psychological, social and spiritual concerns. The goal is not to cure, but to provide comfort and maintain the highest possible quality of life for as long as life remains.

The World Health Organisation (WHO) defines palliative care as: “the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment”

Palliative care and pain management can make the difference between a gentle death and one in which suffering is so terrible and prolonged that assisted suicide becomes an attractive alternative.

PHILOSOPHICAL CONSIDERATIONS OF PALLIATIVE CARE

- Affirms the right of the individual and family to participate in informed discussions and make treatment choices.
- Affirms life and regards dying as a normal process.
- Neither hastens nor postpones death.
- Provides relief from pain and other distressing symptoms.
- Holistic care: integrates physical, emotional, social and spiritual aspects of care; fosters opportunities for growth.
- Offers a support system to help the dying person live as actively as possible until death.
- Provides a support system for family and significant others during patients' illness and / or bereavement.

Source: WHO, 2000. Factsheets.

PRINCIPLES OF PALLIATIVE CARE

- Provide holistic care
- Regard the family as the unit of care
- Enhance patient / family control
- Provide practical support / comfort
- Provide adequate pain relief
- Information is a right and choice
- Maintain dignity
- Facilitate access to care and information
- Ensure equal availability of service without discrimination
- Maintain ethics and confidentiality
- Prepare patient and family for impending death
- Ensure that adequate provisions are made for children
- Care provided by an interdisciplinary team
- Ensure continuity of care
- Provide bereavement support

Research issue:

- The extent to which palliative care is practiced in Botswana.
- Caregivers attitude and knowledge in the provision of palliative care in CHBC patients in Botswana.

Supportive attitudes and actions to the dying patient and family

PHYSICAL SUPPORT OF THE DYING PATIENT

Promote comfort through:

- Administer analgesics / narcotics according to a regular schedule.
- Use relaxation, guided imagery and other techniques to provide relief.
- Adjust therapies as condition of the patient changes.
- Avoid physical irritation; provide adequate skin care, bathing, lubrication, repositioning and dry, clean linen.
- Provide frequent oral care, at least every 2 - 4 hours.
- Wash eyes regularly and use artificial tears to lubricate the eyes.
- If nauseated, ask for use of anti emetics and administer before meals.
- Clean up promptly after vomiting.
- Conserve clients' energy for valued tasks.
- Provide frequent relaxation in comfortable and quiet environment.
- Pace and time nursing activities to conserve client's energy.
- Increase fluid intake and fresh vegetables to avoid constipation.
- Clean immediately when patient is incontinent.
- Protect skin from breakdown / pressure sores, reposition frequently.
- Avoid anorexia; provide small, frequent bland meals.
- Provide relief of thirst by offering frequent small sips, ice chips, lip ice, etc. and provide frequent mouth care.
- Position patient comfortably to allow for easy breathing.

Source: Potter and Perry, 1993, PP 876-877.

EMOTIONAL SUPPORT OF THE DYING PATIENT

- Make sure the patient has continuing personal and caring contacts as this gives comfort and reassurance.
- Give the patient an opportunity to talk about himself, his illness and his dying.
- Allow the patient to act out his feelings without judgement.
- Be alert for behavioural changes, as this may be the way the patient is communicating something.
- Encourage the patient to retain confidence in his/her caregivers.
- Help the patient who is dying to settle affairs, plan for the future of children, parent or spouse; utilize services of priests, legal counselor, social worker etc.
- Pay attention to the patient's day to day complaints, reassure the patient and give appropriate care and treatment.

Source: Brunner and Suddarth, 1982, p. 858.

Cultural consideration/nursing implications:

In Botswana the family expects nurses to be busy during the last minutes, not to be sitting and touching

Research issue:

How do nurses deal with the increased exposure to dying and death?

SUPPORT OF THE FAMILY OF THE DYING PERSON

- Understand that the family may be undergoing anticipatory grief and may be reacting to anticipatory loss.
- Accept the feelings and attitudes of the family, such as fear, anxiety, sorrow, grief, guilt feelings, etc.
- Realize the problems faced by the family i.e. anticipatory separation of loved one, financial problems, disruption of family life, problems of communication.
- Demonstrate concern for the family by allowing them to ventilate conflicts, anger, depression or victimization by illness and reassuring them.
- Involve the family in care giving.

Source: Brunner and Suddarth, 1982, p. 859.



Suggestions for Involving the Family in the Care of a Dying Person

- Allow young children to visit a dying parent, even when the parent is unable to communicate.
- Be willing to listen to family complaints about the client's care and feelings about the client.
- Help family members learn to interact with the dying person (e.g. using attentive listening, avoiding false reassurances, conducting conversations about normal family activities or problems).
- Allow family members to help with simple care measures such as feeding, bathing, and straightening bed linen. Recognize that family members are often more successful than nursing staff in persuading the client to eat.
- When the family becomes fatigued with care activities, relieve them from their duties so that they can acquire needed rest and support.
- Refer them to resources such as Home based Care (HBC). Assist in planning a visitation schedule.
- Support the act of grieving between client and family. Provide privacy when preferred. Do not discourage open expression of grief between family and client.
- Provide information daily with regard to the client's condition. Prepare the family for sudden changes in the client's appearance and behaviour. Enroll patient in hospice care were possible.
- Communicate news of impending death when the family is together, if possible. Remember that members can provide support for one another. Convey the news in a private area and be willing to stay with the family.
- As death nears, help the family stay in communications with the dying person through short visits, caring silence, touch, and telling the client of their love.
- After death, assist the family with decision making, such as utilization of mortuary services, transportation of family members, and collection of client's belongings.

Research issue:

- The concept of hospice care in Botswana.
- Preferences for the place of dying.
- Examination of cultural influences on care of the dying.

DYING PERSON'S BILL OF RIGHTS

Nursing care of the dying person can be demanding and stressful. However helping a dying person retain dignity is one of caregivers' greatest rewards. The caregiver can share the dying person's suffering and intervene in a way that improves the quality of life. A dying client must be cared for with respect and concern. The dying person's bill of rights ensures comprehensive and compassionate care.

The Dying Person's Bill of Rights

- I have the right to be treated as a living human being until I die.
- I have the right to maintain a sense of hopefulness, however changing its focus may be.
- I have the right to be cared for by those who can maintain a sense of hopefulness, however changing this might be.
- I have the right to express my feelings and emotions about my approaching death in my own way.
- I have the right to participate in decisions concerning my care.
- I have the right to expect continuing medical and nursing attention even though "care" goals must be changed to "comfort" goals.
- I have the right not to die alone.
- I have the right to be free from pain.
- I have the right to have my questions answered honestly.
- I have the right not to be deceived.
- I have the right to have help from and for my family in accepting my death.
- I have the right to die in peace and dignity.
- I have the right to retain my individuality and not be judged for my decisions, which may be contrary to beliefs of others.
- I have the right to discuss and enlarge my religious and/or spiritual experiences, whatever these may mean to others.
- I have the right to expect that the sanctity of the human body will be respected after death.
- I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.

Source: Potter and Perry, 1993, P. 875

Policy implication:

Develop a dying person's bill of rights and add it to the Botswana Patients Charter.

Last offices

After death has occurred last offices have to be performed, i.e. providing care for the client's body after death. The caregiver may be the best person to do so. After death, the body undergoes a number of physical changes and as such it should be taken care of as soon as possible to prevent tissue damage and disfigurement.

PHYSICAL CHANGES AFTER DEATH

- Stiffening of the body (rigor mortis), developing 2-4 hours after death involves contraction of skeletal and smooth muscle).
- Reduction in body temperature with loss of skin elasticity (algor mortis).
- Purple discoloration of skin (livor mortis) in dependent areas from breakdown of red blood cells.
- Softening and liquifying of body tissues by bacterial fermentation.

Source: Potter and Perry, 1993, PP 880.

PREPARATION OF THE BODY AFTER DEATH

The caregiver prepares the body by making it look as natural and comfortable as possible.

- Remove any tubes, dressings and any other equipment, which the patient has used.
- Put the body in a supine position (normal anatomical alignment), with arms at the sides, palms down or hands across the abdomen. If hands are put across the abdomen, they should be tied with a bandage to keep them in place.
- Close eyelids by gently holding them down for a few seconds, if this doesn't work, moisten cotton wool balls and use them to hold the eyelids in place.
- Bring both lips together to close the mouth and ensure dentures are in the mouth. A rolled towel under the chin keeps the mouth closed.
- Stuff the orifices with cotton wool to avoid drainage of body fluids.
- Tie the feet together with a bandage to keep them in position.
- Dress the body in a clean gown, brush and comb the hair and then cover the body to the shoulders with clean linen.
- If the family was not involved in preparing the patient, they can be called in to view the body; the caretaker should be there to provide emotional support.
- After the family leaves, a nametag for identification purposes is attached to the body, the gown is removed and the body is completely wrapped in shroud and then transported to the mortuary. Sometimes shrouding is done at the mortuary. Instead of shrouding, the dead patient may also be dressed in normal clothing.

Adapted from: Potter and Perry 1993, P. 880

Impact of death and dying on the care provider

Death and dying can have a profound impact on the health care worker and other caregivers. Nurses working with the terminally ill may experience grief like any other person. Multiple death (as is currently occurring in the era of HIV/AIDS) may easily result in de-motivation, burnout or other psycho-emotional problems. Caregivers therefore should:

Examine own attitudes and ability to face death and dying. Acknowledge that the nurse may be the most important person at the time of death.

Monitor own feelings such as denial, fear and guilt and assess and address one's own biases and fears. Watch emotional responses to challenges of death and dying and "difficult" families.

Not withdraw from the presence of death i.e. face the reality of the dying patient and be skilled and sensitive in the art of human interaction.

Ask or watch for opportunities to demonstrate support to other health care workers.

Source: Brunner and Suddarth, 1982, P. 859.

Conclusion

All of us need to learn to think ahead to a time when we may not be healthy and able to care for ourselves. Advance care planning, making a will, selecting someone to make medical and legal decisions at a time when we feel well, lets us remain in control and make our own choices.

Just as quality of life evolves, so do desired outcomes. Many caregivers fear that talking about death will scare patients and "take away hope". A skilled caregiver helps patients and families find hope for realistic goals, which can change over time. Being able to leave good memories behind for children, being free of pain in a dry bed with family around, making peace with the Lord, or forgiving a relative may be what is needed to relieve the patient's suffering and create a peaceful death.

Go swa go tlaa apesiwa ke go sa sweng

Death will be enveloped by life

Go bola go tla a apesiwa ke go saboleng

Rot will be enveloped by freshness

Lerole mo leroleng

Dust to dust

Molora moloreng

Ashes to ashes

A go bakwe leina la morena

Praise the Lord

DOW, 2000

Death and Dying

For further reading

Potter, P.A. and Perry, A.G. (1993). **Fundamentals of Nursing, Concepts, Process and Practice** (3rd Ed.). Chapter 28. Mosby.

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Bertman, S.L. (1991). **Facing Death: Images, Insights, and Interventions**. Florence, USA, Taylor and Francis.

Brunner, L.S. and Suddarth, D.S. (1982). **The Lippincott Manual of Nursing Practice** (3rd Ed.). USA, Lippincott Company.

Dow, U. (2000). **Far and beyon'**. Gaborone Longman.

Learning activities

ACTIVITY 1

Show an image, a photograph, painting or magazine depiction of death and dying.

Instructions:

- Present the image to the group and elicit concerns..
- In a group discussion, identify common ideas/issues about death and dying as illustrated in the image.
- Discuss how the exercise reflects on you as caregivers.

ACTIVITY 2

Given the following guidelines, make a draft of your will.

Cover the following in your draft:

1. Inheritance of property
2. Custody of children
3. Executioners of the will
4. Instructions on funeral arrangements
5. Written in permanent ink
6. Signed and witnessed
7. Free will

Instructions:

In a plenary session, discuss your reaction to making a will.

ACTIVITY 3

Using the concept **HOPE**, write a phrase on death and dying for each letter (see page 31).

H
O
P
E

Instructions:

Present your poems to the other participants.

Death and Dying

Pretest

1. T
2. F
3. F
4. F
5. F
6. T
7. F
8. F
9. T
10. F

Introduction

*Happy are those who mourn;
God will comfort them.*

Matthew, 5 : 4



“Death ends
a life, but
not a
relationship...”



Losing a significant other to death is considered one of the most stressful events in a person's life. Even in the most uncomplicated of circumstances, the psychological tasks of grief work, present the survivor with multiple challenges. It is very important for the grieving person to understand that various kinds of feelings are to be expected. Such information usually makes the experience of grief much more manageable. Grief is not a disease. It is love not wanting to let go. It can be likened to a “blow” or a cut in which the wound gradually heals. For a while, one is acutely vulnerable, physically and emotionally. Though grief can be temporarily disabling, working through it ultimately brings strength. Parkes (1972) cited in Bertman (1991, p. 200) states that:

Grief and Loss

"Just as broken bones may knit together more strongly, so the experience of grieving can strengthen or mature those who have previously been shielded from the misfortune: "The pain of grief is just as much part of life as the joy of love; it is perhaps, the price we pay for love, the most commitment. To ignore this fact...is to put on "emotional blinders" which leave us unprepared for the losses that will inevitably occur in our own lives and unprepared to help others to cope with the losses in theirs".

Grieving is active. It is work. It requires remembering, repetitively, experiences shared with the dead person, over a long period of time, talking about, and expressing the mixed emotional ties – particularly the anger, remorse, and sadness, perhaps, even relief, until the devastating potency of the loss is neutralised. Death has a way of sealing people off, making them feel totally isolated. Part of dealing with the sense of being cut off – for both the one dying and the bereaved – is acknowledging that though a vital part of life has changed dramatically, all relationships (with friends, even with you, perhaps) have not. After sadness, anger, fear, bitterness and regret have been addressed, survivors can learn to draw solace, and support from continuing a relationship with the memories of the deceased.

The most important balm a counsellor, friend, relative or significant other can offer is presence and concern; by listening non-judgementally and by reassuring the bereaved persons that they are not losing their mind. We can further affirm that the acute pain they are experiencing is grief-in-process, and that in its present intensity, it will not last forever.

Purpose

The aim of this unit is to assist caregivers in dealing with grief and loss for their own benefit and that of others.

Objectives

At the end of this unit the caregiver should be able to:

- Understand grief and loss.
- Deal with grief and loss in self and others.
- Accept grief and loss as part of personal /professional life.
- Recognise complicated grief
- Appreciate the impact of multiple loss on the caregiver and the family.

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Pretest

Instructions: Tick whether an item is True T or False F
(Answers can be found at the end of this unit).

- Grief can be cured and drug therapy or psychotherapy are the most effective treatments.
- Periodic thoughts of not wanting to go on living, and brief visual and auditory hallucinations of the deceased are normal grief reactions to the death of a close family member.
- Rebuilding assumptions about the world and reconstructing meaning are essential components of adapting to loss.
- Frequent moves, estrangements, and geographical separation from family members can adversely affect the grieving process.
- Anxiety is not a normal feature of grief.
- Sudden, unexpected, untimely or multiple death is more likely to complicate grief.
- We are permanently changed by grief, some become crippled; others stronger and wiser.
- Time heals all wounds.
- Grieving people should be prevented from actively taking care of a dying family member.
- To accept grief and loss as part of one's professional life, the caregiver may have to distance herself and hide personal feelings.
- The grieving process is the same for everybody.

Nature of grief

Grief is a natural reaction to loss in all cultures, even in the animal kingdom. It is not an illness to be cured or a psychiatric disorder. The general consensus is that denying adequate expression or grief is detrimental. Current research findings are divided as to whether confronting the loss is necessarily a better coping style than being absorbed in activities that distract one from grief. The way a person grieves may be dictated by one's cultural background and upbringing and must be considered in the assessment. Nonetheless we believe acknowledging grief leads to healing and growth.

Cultural/Traditional Consideration

In Botswana, following loss and grief due to death of a significant other, relatives and friends assemble at the home of the bereaved daily, for prayers, discussions and support until the day of the funeral. Older people usually stay longer with the bereaved.

The bereaved will not need to carry out any duties, but are involved in the funeral arrangements. During the lie-in period (time between death and funeral) only specific persons (older male and female and/or close relatives) sit with the male or female survivor. The female survivor (widow/mother) is supposed to lie down inside the hut/house on her abdomen. She has to cover her head!

The male survivor (widower/father) may sit up inside the house, but in some cultures, may only put on one shoe. During the lie-in period only a widow can provide food and do other duties for the immediate survivors, such as assisting in bathing, etc. The bereaved are not supposed to care for themselves and are often referred to as "balwets" (patients). Only specific designated persons keep the immediate bereaved company during the lie-in period.

During this period, prayers will be held each morning and evening and announcements are made about the funeral. The bereaved are expected to attend the funeral. After the funeral everybody gathers together for food and drink. Close relatives will stay behind for a period (days to months) of time. In case of elderly, within a week a cow is slaughtered to mark the official declaration of the death (go latola).

Other rituals exist for a certain post-funeral period, such as wearing symbolic clothes, shaving of hair in females, children and close relatives may need to wear specific necklaces or small pieces of cloths, etc. Each religion or specific population group will have its own specific rituals.

Expression of grief and loss is encouraged in a quiet way; people are socialised to be strong.



Point for discussion:

Does wearing symbolic attire during and after the funeral, add to stigma surrounding HIV/AIDS?

CAUSES OF LOSS AND BEREAVEMENT

There are many ways that one can experience grief due to bereavement or loss, for example due to:

- death of someone close
- death of a spouse
- disability
- retirement
- migration
- loss of a job/employment
- separation/divorce and other
- loss of body part /organ

FACTORS WHICH INFLUENCE GRIEF AND LOSS

There are many factors which can influence grief and loss, such as:

- Professional support
- Nature and timing of death
- Length of final illness
- An outlet for the expression of grief e.g. rituals
- Bereavement overload (multiple losses)
- Nature of relationship
- Practical issues
- Availability of the extended family support, etc.
- Stigma
- Anticipatory grief

GRIEF THEORY – STAGES OF GRIEF AND LOSS



As bad as it may feel
someone else has been
there and made it
through

Most models suggest a linear progression that people follow as they work through grief. Although many people may follow such a progression, grief is individual and may be a circular process: (1) sometimes stages are omitted all together, or (2) several stages may occur at the same time.

According to Bertman (1999, p.1): *"All categorisations - stage, phase, helix-like or task based - address the following: 1) the realities of adjusting to a changed life; 2) the fact that we are meaning-making creatures; and 3) the idea of a healing trajectory. She continues to say that: "stage theories tend to be oversimplified, lead to false expectations and are often misunderstood. We must be careful not to trivialise or minimise the profundity and uniqueness of a personal or communal grief by reducing it to mere explanation or method."*

The most commonly applied theory is that of Kubler-Ross's five stages of grief. Other researchers (Bowlby, Engel, Worden, Parkes, Martocchio) have postulated different "stage" theories. What is helpful about such theories is that they give us a sense of emotional roller coaster experienced by persons who are grieving. In general there appear to be three "phases":

- Denial, shock and protest.
- Disorganisation, despair (hope/despair cycle or emotional suffering).
- Reintegration, repatterning, transformation or adaptation.

"Although it is important to recognise the emotional variability that a dying or bereaved person experiences, it is equally important to realise that interventions may be appropriate and effective at any phase of grieving" (Bertman, 1991, p. 198).

Comparison of grieving theories

| Engel | Kubler-Ross | Weiss | Martocchio |
|--------------------------------|-------------|--|--------------------------------------|
| Shock and disbelief | Denial | Shock | Shock and disbelief |
| Developing awareness | Anger | Working through grief (somatic symptoms, withdrawal, emotional suffering, anger) | Yearning and protest |
| Reorganisation and restitution | Bargaining | | Anguish, disorganisation and despair |
| | Depression | | Identification in bereavement |
| | Acceptance | Re-establishing physical and mental health | Reorganisation and restitution |

Adapted from: Potter and Perry (1993)

Managing the loss: things you can do

Grieve in your own way: Death hurts. It is so difficult to say goodbye. No one can tell you how to grieve. There is no normal time span during which healing takes place. Some may vehemently protest that the death has occurred; others may quietly resign themselves to the reality. Some may cry hysterically; others may remain outwardly impassive and emotionless. Some may even blame themselves for the death; others may project the guilt upon God, the physician, the nurses the clergy, a friend, or even another member of the family. The grief process is never the same for any two people. Don't compare yourself with others in similar situations. Their smiles may not reveal the depth of their sorrow.

Accept your emotions: Allow yourself to feel your feelings, don't bottle them up.

Be your own timekeeper: Heal in your own way and in your own time.

Share your feelings with others: It is not enough to recognise your conflicting emotions, you must deal with them openly. An emotion that is denied expression is not destroyed. You only prolong the agony and delay the grief process. Find a good listener, a friend who will understand that your feelings are normal responses to your bitter grief.

Recall the memories: Sometimes bereaved individuals feel the solution to the grief is to attempt to "forget". However, it is good to recall the life of the person who died. By recognising the past, you can better understand why you are grieving and what your loss is.

Maintain hope: Be patient with yourself. The depth of sorrow diminishes very slowly. You will survive even though there may be times when you won't care if you live or not. Your courage is not the absence of fear and pain, but the affirmation of life despite the fear and pain.

Establish goals for yourself: Concentrating on serving others and developing new interests will relieve your loneliness and give new purpose to your life. You may volunteer to serve in a charitable organisation or help individuals in need. Consider seeking further education, increasing your involvement in work, or joining service or travel clubs as a way of adding new meaning to your life.

Increase your religious affiliation: If you have been active in matters of faith, this is the time to become involved again. The Bible has much to say about sorrow. As time passes, you may find you are not so mad at God after all!

Source: Island Hospice Service, Zimbabwe.

*It is a long way
If you listen to your mind
It is a short way
If you listen to your heart*

Mirko Udzenija

*Keep my eyes from seeing anything in Life as worthless;
Give me Life by means of Your ways.*

Psalm 119:37

Point for discussion:

To what extent do people in Botswana openly talk about experiencing grief and loss?

Four tasks of healing

The Four Tasks of Healing were developed by Harvard Psychologist, Dr. J William Worden and modified by NAB in collaboration with Dr. Bertman. Worden said that for healing to take place, grievors must address and substantially accomplish each of the tasks, although (as noted above) not necessarily in the order presented.

Task I: To accept the reality of the loss.

“It really happened!” – the diagnosis, death, divorce, paralysis etc. You must talk about the loss, and integrate the information both at intellectual and emotional levels.

Task II: To experience the pain of grief.

The “bleeding” stage of grief. Feelings associated with grief reaction are experienced as pain, rage, fear, guilt. There is no right way to grieve and everyone has his or her own grief journey. Absence of grief or interminable grief are considered complications.

Task III: To adjust to life without the person or condition.

Learn who you are without your child, spouse or partner. Learn new skills and perform new tasks now that you are alone or in a new situation. Develop a new identity. Live with the limitations of illness, and accept help from others.

Task IV: To form a new attachment, a spiritual bond.

Modify your energy from the bond you had with the person who died to a new bond of a spiritual nature or a special cause or legacy that comes from that person. In this way, the person who died still lives on in your life, and in the lives of others. But you are not stuck, or bound by that relationship. Life moves on, and so can you.

*Teach me the path of Life, Oh Lord.
In your Presence is an abundance of joy;
Eternal pleasantness is in Your right hand.*

Psalm 16:11

How to help a grieving person



The most important balm, a counsellor can offer is presence and concern. You are facilitating the grieving process by being there: by listening, non-judgementally, and by reassuring bereaved persons that they are not “going crazy”. You can affirm that the acute pain they are experiencing is grief in process, and that the acute, intense pain they are feeling will not last forever. The best time to do bereavement work, if we lucky enough to recognise it at the time, is before the death has occurred (Bertman, 1991).

- Encourage the saying of goodbyes at the bedside, before death, whenever possible.
- Encourage active participation in the care of the person dying, in being present at the moment of death, and even in preparing the body for burial. There is great solace in knowing “I was there and I did all that I could.”
- Encourage involvement with the mourning rituals of funeral, eulogy, celebration, and memorial services. Such rites provide outlets for the expression of sorrow and help delineated the grieving process.

Grief and Loss

- Listen, nonjudgementally, realising, as Samuel Coleridge's *Ancient Mariner* reminds us, that the albatross of grief falls off with retelling the story. Encourage reminiscences, the painful as well as the positive, and expression of the hostile, angry, and negative feelings that seem so incompatible with the genuine love for the dying or dead person. Again, offer reassurance that such ambivalence is normal.
- Monitor your own feelings. You are not immune to sadness, anxiety, or the need to express personal concern. Your reactions are conditioned by your own experiences with earlier losses and by your ability to handle hostile reactions from those you are counselling, be it friend, patient, client, student, or family member.
- Be informed about self-help support groups such as church groups and professional support groups. Such groups may assist in answering practical questions, in understanding feelings, in providing networks and in enabling participants to reach out to others as they gain mastery in their own personal experiences.
- Know when referral is necessary. You are in a good position to detect unresolved and complicated grief and pathological mourning and, when you suspect a severe problem; you should enlist additional psychotherapeutic help.

According to Bertman (1991) grief is not a disease, it is more like love not wanting to let go. It can be compared to a wound that will heal over time. For a while the grieving person is acutely vulnerable, both physically and emotionally. Though grieving can be temporarily disabling, working through it ultimately brings strength.

Accepting grief and loss as part of one's professional life

Due to the impact of HIV / AIDS, caregivers are confronted with death and dying on an almost daily basis. Our initial workshop with Dr. Bertman demonstrated strengthening the inner resources of nurses and other health care providers and maintaining their wholeness (Bertman, 1999) are important aspects of preserving one's own integrity.

Preserving one's own integrity refers to the caregiver's ability to maintain his or her own feeling of self-worth and to maintain an energy level sufficient for effective functioning. By looking inward, valuing personal worth, and acknowledging and questioning behaviours, reactions and needs, the caregiver maintains self-worth and esteem. Energy levels are sustained by various psychological strategies, such as distancing, using humour, hiding personal feelings, learning from mistakes, and sharing frustrations. Self-reflection on the caregiver's part regarding his or her own behaviour and motivations becomes the focal activity of this dimension.

The goal is to prevent the caregiver from experiencing burnout from emotional and physical exhaustion brought on by the demands of caring for dying patients and their families. The dimension of Preserving Own Integrity confirms that the nurse as a professional cannot be separated from the caregiver as a person (Cummings in Bertman, 1999, pp43-50).

Point for discussion:

Is the patient at risk if the nurse/caregiver is not aware of the need to preserve her own integrity as an essential part in providing palliative care?

Grief and Loss

According to Baylor (2001, P. 153) health care workers, like their patients, may display many of the symptoms of the stages of grief, however, as they experience loss after loss, the stages may become jumbled. They cannot work through one loss before another occurs. They may experience frustration, anger, guilt, sadness, helplessness, anxiety, depression and feelings of being overwhelmed. When caregivers experience multiple losses (such as in the HIV/AIDS epidemic) and fail to process them adequately, they can experience bereavement overload. Over time, the unacknowledged sadness, anger and guilt can become compressed and result in cynicism and decreased ability to invest emotionally in patients. It is painful to acknowledge the feelings associated with seeing patients suffer and die, so the professional becomes more callused and expresses less sensitivity and sympathy for the needs of the next patient.

We need to do for ourselves what we do for clients and families. We need to mourn our losses, on individual basis and as part of a larger group (formalized) caring for the **clients**. Caregivers need to develop personal support systems that allow time away from the care giving setting and opportunities to share feelings in non-judgemental relationships, and utilize stress-management techniques that restore energy.

Health providers can help each other by creating a supportive environment in which they feel free to express their feelings. This reduces the isolation and emotional pain that can affect an individual's ability to provide sensitive care. Formal support groups for health care providers will not only reduce the feelings of isolation, but they will also lead to new ways of coping. Unrelieved grief and stress can lead to a diminished sense of well being and inability to care for others.

Point for discussion:

Reactions of nurses/caregivers to the impact of the high number of deaths they see in practice.

Recognising complicated grief

The normal grieving process following a loss can become complicated by a variety of factors. Clinically, it is the degree of symptoms rather than the duration that is most helpful when making this distinction, for example:

- When normal sadness of grieving develops into clinical depression or
- When anxiety over being alone develops into phobic avoidance of the home that was shared with the deceased.

The **delayed grief reaction** is another type of complicated grief in which an individual develops a full grief reaction many years after an earlier loss that was not adequately grieved at the time. This reaction is usually initiated by a new loss or some other triggering event.

When **the loss is sudden** or totally unexpected, grief may be complicated. The survivors may become debilitated by severe symptoms of grief and become unable to function.

How to Recognise Complicated Grief:

- The person may continue to use present tense when talking about the deceased.
- Continually reporting that people seen at a distance or in crowds are commonly mistaken for the deceased.
- Making daily references to death, tombs or graveyard in a (kind of) ritualistic manner.
- Reporting of establishing daily rituals relating to the deceased.
- The continued denial of reality of the death.

While any of these symptoms may transiently occur as a normal part of the grieving process the continued presence of such symptoms may suggest that an episode of normal grief may be developing into a more serious problem.

Multiple loss

Different types of multiple losses exist.

- There are multiple physical, mental, economic and social losses resulting from the different stages of HIV infection and illness. These losses could include poor health, deterioration in the ability to concentrate, memory impairment and loss of mobility, dexterity and in economic terms of employment, finance and housing. There may be diminishing freedom of choice in many aspects of life, such as travel or employment.
- Certain specific deaths also can lead to multiple losses e.g. losing a parent and a bread winner will have more impact on the family than the death of a non employed young mother with school going children.
- Losing more than one person in the family or one's surroundings within a short period of time is also devastating. Caregivers may experience multiple deaths in the line of duty.

Multiple deaths may lead to bereavement overload, especially due to the high incidence of deaths caused by HIV / AIDS.

Reactions to loss may include feelings of grief and sadness expressed by crying, or even a desire to be left alone. These are not the only responses, and while still grieving, some people may experience relief while death finally occurs and ends the patient's suffering. Although death may bring an end to the suffering of patients and their close contacts, it may simultaneously create new problems. The death of a patient with HIV may be the beginning of new problems for close contacts of that person. Sexual partners for example may also be infected and will think about their problems for the first time. In some cases the AIDS diagnosis for the child may be a first indication that there is HIV in the family. The new problem that may arise after the patient dies is that attention shifts to the health or future of the surviving partner or family members. The social stigma or fear of HIV transmission may complicate loss when the cause of the death is revealed.

COPING WITH MULTIPLE LOSSES

- Acknowledge the losses.
- Normalise feelings of "going crazy".
- Engage in physical exercises.
- Get adequate sleep.
- Keep the memory alive.
- Commemorate/perform rituals such as memorial services etc.
- Engage in community services.
- Solicit support (counselling, colleagues, family).
- Seek spiritual comfort.

Conclusion

Bereavement is very complex. Individuals experience grief in many and varied ways. The loss of a loved one is psychologically as traumatic as being physically severely wounded. Grief represents a departure from the state of health and well being. A period of time is needed for the bereaved, to return to a state of equilibrium. The process of mourning is similar to that of healing. Mourning, the adaptation to loss is seen as involving five basic tasks:

- Accept the reality of the loss.
- Experience pain.
- Express feelings in many ways.
- Adjust to the new environment after the loss.
- Rebuild a new life.

It is essential that the bereaved persons receive support and encouragement from friends, family, caregiver and / or a Minister of religion. Above all the services of a professional counsellor may enhance acceptance of the loss, foster growth and development. Counsellors should avail themselves to grieving persons, as the culture in Botswana may not necessarily yet be open for such a service.

Grief and Loss

Pretest key

1. F
2. T
3. T
4. T
5. F
6. T
7. T
8. F
9. F
10. F
11. F

Introduction

*Endurance brings God's approval,
And his approval creates hope.*

Romans, 5: 4



God gave us
two hands,
one to care
for
ourselves,
and one to
care for
others



FREDA BERGER

Stress management is not a luxury it is a necessity. Caregivers continuously providing care to persons and their families, are susceptible to developing compassion fatigue, commonly known as burnout. In our intentions to meet the needs of the clients, we are often overwhelmed by the demanding work involved, and the limitations of the work situation. Professional caregivers are often not able to deal with it, or are not given the opportunity to deal with their stress.

This unit will assist caregivers in acknowledging stressors in their work, recognizing signs and symptoms of stress and burnout, and understanding and developing appropriate strategies for dealing with it.

Stress and Burnout

Purpose

The purpose of this unit is to empower caregivers with knowledge and skills that will enable them to identify and deal with their own stress and that of others.

Objectives

At the end of this unit, the caregiver should be able to:

- Define stress, burnout and related terms.
- Identify situations that lead to stress with particular reference to the workplace.
- Identify signs and symptoms of stress and burnout that affect caregivers and clients.
- Understand and apply relevant coping strategies to manage stress in self and others.
- Acknowledge and contribute to teamwork and the need to care for each other at the workplace.

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Stress and Burnout

Pretest

ARE YOU BURNING OUT?

Instructions: Assign a number from 1 (for no or little change over time) to 5 (for a great deal of change over time).

- Do you tire easily? Feel fatigued rather than energetic?
- Are people annoying you by telling you: "You don't look so good lately?"
- Are you working harder and harder and accomplishing less and less?
- Are you increasingly cynical and disenchanted?
- Are you often feeling sad and you can't explain why?
- Are you "forgetting" lots of things (appointments, deadlines, and personal possessions)?
- Are you increasingly short-tempered? Disappointed in the people around you?
- Are you seeing close friends and family members less frequently?
- Are you busy to do even routine things that you used to do?
- Are you suffering from physical complaints (aches, pains, headaches, a lingering cold)?
- Do you feel disoriented when the activity of the day comes to a halt?
- Do you have difficulty experiencing joy?
- Are you unable to laugh at a joke about yourself?
- Does spending an evening with a friend or loved one feel like it is more trouble than it is worth?
- Do you have very little to say to people?
- TOTAL**

Don't let a high total alarm you, but pay attention to it. Burnout is reversible, no matter how far along it is. The sooner you start being kinder to yourself, the better.

Source: H.F. Freudenberger and G. Richelson, Search and Rescue Society of British Columbia.

Psychosocial impact of HIV/AIDS on health care workers

The best way to handle burnout is not to cure it but to prevent it.



Health care workers who have lost many patients to HIV/AIDS eventually may begin to suffer because they have inadequate time to deal with stress or work through one loss before being confronted with others. Loss of multiple patients can lead to complicated and ongoing grief that prevents the health care worker from processing the thoughts, feelings, and responses to patients in healthy and helpful ways. Over time, the unacknowledged sadness, anger and guilt can become compressed and result in cynicism, withdrawal, numbness and decreased ability to invest emotionally in patient care. It is painful to acknowledge the feelings associated with seeing patients suffer and die. The danger is that the professional becomes more callused and expresses less sensitivity and sympathy for the needs of the patient.

Environmental factors contribute to the stress of health workers who care for people with HIV/AIDS. Caregivers suffer stigma similar to that of their patients and are often unable to talk with family and friends about their work with patients suffering from an often-unmentionable disease. In addition, HIV counselors and caregivers must face their own fears about being HIV-infected as they encounter patients who may have risk behaviors similar to their own. In a study of HIV counselors in Zambia, 72 percent worried about their HIV status, but less than one fourth had been tested for HIV. Half of the counselors said that they did not want to be tested because they did not want to deal with the hopelessness of a positive result or they thought it pointless because there is no cure and only limited treatment. This would seem to have a detrimental effect on the ability to counsel effectively or encourage others to seek testing (Baylor, 2001).

Stress and Burnout

Health care providers working with people who have tested positive for HIV see many patients with complicated family situations and seemingly unlimited needs. Frequently, there are insufficient resources such as medication and supplies to meet the needs of patients. A high caseload combined with inadequate staffing make it difficult to provide sufficient counseling to the patient. Caregivers are acutely aware of personal limitations and powerlessness to fix the patient's situation. The provider should remember the power he or she has to provide the medical treatments which are necessary and available, to be with the patients when they are suffering, to provide hope and humor in a potentially devastating situation, and to be a positive factor in the midst of so many negative ones.

Health care providers can help each other by creating a supportive environment in which they feel free to express their feelings. This reduces the isolation and emotional pain that can affect an individual's ability to provide sensitive care. Formal support groups for health care providers can not only reduce the feeling of isolation, but they can also lead to new ways to cope with the stress of work.

Research issue:

The prospects of caregivers utilizing counseling services within and outside health care settings.

Causes of stress and burnout

Stress refers to a psychological reaction within the person to events that generate strong emotions that cannot be easily regulated. When caring too much for others and not for one's self stress will result in burnout and compassion fatigue.

Research issue:

The perception of stress and burnout by caregivers themselves and by clients/patients and their families.

CAUSES

Below follow some of the causes of stress that caregivers may experience:

Social stressors

- Stigma associated with HIV and AIDS.
- Secrecy and fear of disclosure among people with AIDS.
- Inability to meet needs of individuals, children and/or families.
- Becoming over involved with patients/clients.
- Expected to be a professional even when dealing with own family and personal issues.
- Financial burdens.

Environmental stressors

- Shortage of professional staff.
- Improper use of referral mechanisms.
- Lack of support and supervision.
- Fear of being infected.
- Lack of care and support for caregivers.
- High demand on supervisors, not in control of the situation.
- Lack of privacy and space in work environment.
- Shortage of equipment and supplies.
- High number of deaths.

Stress and Burnout

Perception stressors (thoughts)

- How to provide care so that caregivers are loyal to all clients.
- Lack of specific skills for supervision.
- Lack of respect and recognition.
- Lack of appreciation (no positive feedback).
- Lack of understanding (appreciation) from the recipients of care.
- Lack of recognition for their work.
- Lack of mutual respect or liking between caregiver and client.
- Difficulty of putting ethical considerations into practice.
- Loneliness / isolation.

Professional stressors

- Working with an over stressed supervisor.
- Oppressive workloads (work overload).
- Multiple roles in care giving.
- Lack of bill of rights for caregiver.
- Lack of transparency at the workplace.
- Lack of involvement in policy-making decisions (lack of an effective voice in decisions that affect them and their work).
- Too little autonomy or responsibility.
- Inadequate support and supervision.
- Inadequate training, skills and preparation for the work.
- Lack of clarity about what the caregiver is expected to do.
- Unrealistic demands from supervisors.

Nurses' rights:

The right to find dignity in self-expression and self-enhancement through the use of our special abilities and educational background.
The right to recognition for our contribution through the provision of an environment for its practice, and proper, professional economic rewards.

The right to a work environment, which will minimize physical and emotional stress and health risks.

The right to control what is professional practice within the limits of the law.

The rights to set standards for excellence in nursing.

The right to participate in policy making affecting nursing.

The right to social and political action on behalf of nursing and health care.

The right to participate in professional decision making.

Source: Kelly, 1985

Policy implication:

Create a caregivers bill of rights for Botswana

Signs and symptoms of stress

Many of the signs and symptoms below are not of themselves unhealthy, but they become so if they are neglected, suppressed and/or are allowed to accumulate.

Continued exposure to stress and the underestimation of it may result in burnout. Burnout happens to people who remain in "crisis mode" too long. Health care providers who serve HIV affected and infected persons are at high risk for AIDS related burnout. The continuing AIDS epidemic and the exposure of care givers to rapidly increasing numbers of terminally ill and dying patients of all ages increase their chances of burnout dramatically. Signs of burnout vary from person to person, however the following symptoms seem to be the most common:

Physical symptoms:

- Continual exhaustion, inability to get sufficient rest.
- Susceptibility to illnesses and illnesses lasting longer.
- Frequent accidents.
- Sleeplessness.
- Bowel disturbance.
- Headache.
- Sweaty palms.
- Increased muscle tension in neck, shoulders, back.
- Elevated pulse.
- Increased respiration.

Emotional symptoms:

- Impatience or irritability with other people.
- Increasing desire to be alone, away from people.
- Forgetfulness.
- Emotional numbness or flatness - inability to enjoy.
- Feelings of panic.
- Feelings of inadequacy, helplessness and guilt.
- A tendency to withdraw.
- Loss of sensitivity in dealing with clients.
- Difficulty getting on with people.
- Tearfulness.
- Depression.

Coping symptoms:

- Denial of burnout symptoms.
- Increase in compulsive, addictive behaviours.
- Withdrawal, fewer social contacts.
- Discontinued hobbies, recreational activities.
- Few activities outside of care giving responsibilities.
- Loss of confidence and self-esteem.
- Irritability and impatience.
- Loss of concentration.
- Dreams and nightmares.

Spiritual symptoms:

- Questioning the purpose of living.
- Loss of meaning.
- Feelings of emptiness.

Work related symptoms:

- Loss of interest and commitment to work.
- Loss of punctuality and neglect of duties.
- Withdrawal from clients and colleagues.
- Loss of quality in performance of work.

Adapted from: Bertman, 2001

Dealing with loss.

One of the consistent factors in Home Based Care that we cannot control is the fact that there is an element of constant loss - the loss of a parent, child, health, income, the ability to work, etc. As care givers, we are in the presence of grief and grieving people daily. It is not something we can ignore because it affects us personally as well. Caregivers who want to avoid burnout must therefore address life and death issues in their own lives in order to be able to deal with their client's grief. If we deny our own emotional needs, we will go into burnout. Dealing with issues around life and death is an integral part of taking care of yourself.

Tony Jungo, Catholic AIDS Action

Strategies for prevention and reduction of stress and burnout

Stress is often a response to life changes, which one needs to adjust to. Many strategies exist to prevent or reduce stress, in order to avoid its accumulation and burn out.

- Rely on your religious faith e.g. pray; meditate if you are religious.
- Redirect your energy - have quality time with your family after work.
- Anticipate stressful events and plan ahead.
- "Shelf" the memory - do not talk about the subject that brings stress when you are out of that environment.
- Acknowledge your limitations - inform clients on what you are able and not able to do. Be able to refer.
- Accept that you are not perfect and that you cannot reach all clients at the same time. Make appropriate priorities.
- If possible, reschedule appointments if you cannot go another mile.
- Take responsibility for yourself. If stress is too much, stop and take a break. Explain your situation to those expecting you to continue.
- Take a "worry break" - allow yourself ten minutes at a set time each day to sit down and worry about everything that is bothering you.
- Diet
 - establish good eating habits
 - do not miss your meals
 - take regular nutritious meals
 - do not over eat as a way of reducing stress.
- Rest
 - get enough rest and sleep.
- Exercise
 - this can include walking, gardening, playing some sport.
 - develop an exercise routine.
- Muscle relaxation - relieves muscle tension (tense different muscles then relax them).
- Breathing and Relaxation
 - engage in good breathing habits.
 - take deep, slow breaths.
- Nurture yourself
 - take time out (take a break).
- Meditation / Yoga.
- Visualization (guided imaginary) - close eyes and imagine a scene of beauty and tranquility and project yourself into it.
- Get organized - organize activities and manage time effectively.
- Set priorities
 - instead of trying to do all activities in too little time, pace yourself and do one task at a time.
 - list your activities in order of importance, and do the most important ones first.

- Develop close relationship with family, and other people in the community (develop possible support systems - spouse/ partner).
- Stay in control of yourself and your life as much as possible. Avoid stressors that can be avoided. Develop a positive attitude for stressors that cannot be avoided.

Serenity Prayer:

God grant me the serenity to accept the things I cannot change;
Courage to change the things I can; and wisdom to know the difference.

- Get involved in other work e.g. volunteer work, church, community-work group.
- Have variety -do not do the same thing everyday (if possible).
- Address grievances immediately (within the care unit).
- Talk to and listen to each other. Just talking things out, even if they are not resolved, can be healing.
- Develop a culture of talking and sharing problems, in regular and frequent meetings between caregivers and their supervisors.
- A good relationship with the supervisor is of critical importance in maintaining health and morale.
- Look after yourselves and each other as caregivers before you look after others.
- Hold regular retreats for caregivers (where possible) to get away completely from their normal work environment and spend time in structured bible study and prayer, or simply relaxing and having fun.
- Create a broadly supportive environment - the supervisor and the manager should know what problems and difficulties are experienced by the caregiver.
- Credit or acknowledgement should be given to the caregivers.
- Appoint a counselor for caregivers.
- Involve caregivers in decision-making.

Managing stress

IDENTIFY THE PROBLEM

- Find out what is causing the stress.
- Become aware of your stress and your emotional and physical reaction.
- Notice your distress, do not ignore it but acknowledge its occurrence. Determine what events distress you.
- It is necessary for every one working in the health care setting (especially dealing with HIV/AIDS) to acknowledge the fact that the feelings of distress are legitimate and not signs of personal weakness or lack of professionalism.
- Determine personal levels of stress.

EXPLORE SOLUTIONS TO THE PROBLEM

- Empower yourself. Knowledge gives people confidence, control and choices in life, and it has everlasting value. Through reading and using opportunities such as stress seminars, you can learn how to build the necessary skills to understand and manage stress. Knowing your work well also reduces errors that cause stress.
- Ask yourself if you can change your stress by avoiding it, eliminating it or shortening periods of exposure to it (e.g. taking a break).
- Recognize your limitations. Caregivers need to be relieved of the burden of responsibility for things they cannot help. Learn to say no or no more on what you cannot or can no longer handle. Learn to refer and use your corporate environment to the maximum to reduce your workload.
- Try one of the options that you think is more helpful and see if it works. Pick the best solutions.

Research issue:

Caregivers use of communication to prevent, reduce and / or manage stress.

REDUCE THE INTENSITY OF YOUR EMOTIONAL REACTIONS TO STRESS

- The stress reaction is triggered by your perception of danger, i.e. physical, social and/or emotional danger. Are you viewing your stressors in exaggerated form and/or taking a difficult situation and making it a disaster?
- Are you expecting to please everyone?
- Are you overreacting and viewing things as absolutely critical and urgent and feel you must always prevail in every situation?
- Work at adopting more moderate views; try to see the stress as something you can cope with rather than something that overpowers you.
- Try to temper your excess emotions. Put the situation in perspective. Do not focus on negative aspects and the "what ifs."

LEARN TO MODERATE YOUR PHYSICAL REACTIONS TO STRESS

- Slow, deep breathing will bring your heart rate and respiration back to normal. Relaxation techniques can reduce muscle tension.
- Medications, when prescribed by a physician, can help in the short term by moderating your physical reactions. However, they alone are not the answer.
- Learning to moderate these reactions on your own is a preferable long-term solution.
- Taking long hot baths, have some time on your own or take a periodic nap.

BUILD YOUR PHYSICAL RESERVES

- Exercise for cardiovascular fitness three to four times a week (moderate rhythmic exercise is best, such as walking, swimming, cycling, or jogging).
- Eat well-balanced, nutritious meals.
- Maintain your ideal weight.
- Avoid nicotine, excessive caffeine, and other stimulants.
- Mix leisure with work. Take breaks and get away when you can.
- Get enough sleep. Be as consistent with your sleep schedule as possible.

MAINTAIN YOUR EMOTIONAL RESERVES

- Develop some mutually supportive friendships/relationships.
- Pursue realistic goals, which are meaningful to you, rather than goals set for you that do not share.
- Set your own boundaries.
- Expect some frustrations, failures, and sorrows.
- Always be kind and gentle with yourself - be a friend to yourself.
- Reward yourself, give yourself a treat, you deserve it.



Let go of your guilt, forgive yourself as life is a learning experience.

IDENTIFY AND UTILIZE YOUR RESOURCES ADEQUATELY AND APPROPRIATELY TO DEAL WITH THE STRESS

- Time management: Plan your work and use your time effectively to manage it.
- Financial management: Budget properly within the limits of your financial resources.
- Human resources: Tap support from family / friends and existing social systems e.g. church, clubs and societies.
- Determine what you can do and cannot do and search for assistance, collaboration or referral.
- Self-empowerment: Learn more about stress taking control and building self-confidence.
- Recognizing personal strengths and use them to eliminate, avoid, reduce and manage stress.
- Set realistic work targets; understand your job description and referral mechanisms.
- Initiate, identify or join existing meetings where health workers discuss issues and share problems, to dispense emotional burdens.
- Seek opportunities where you can voice out your feelings and be involved in decisions.
- If all else, seek health care when not well. Recognize symptoms of stress and the need to seek appropriate medical attention. Seek counseling as necessary.

Family and caregiving support

Family members, loved ones, caregivers and health care workers all need to be supported and cared for as they provide terminal care to the PLWHA. Support groups, counseling (both individual and group), and instrumental care, are all helpful strategies to support the caregivers. Instrumental support includes the provision of adequate resources (medical supplies, medicines, and personnel) to make effective terminal care possible. Emotional and spiritual support should also be available. The kind of support that caregivers need will vary. Acknowledging the need for such support and providing ways to access such support are essential. If such support is not available, the burden of care can become too great and caregiver exhaustion may follow.

Research issue:

The psychological impact of HIV/AIDS on caregivers.

Support groups provide a forum in which the individual is understood and accepted; members of this group are individuals who are undergoing a similar experience or have successfully dealt with their experience. These groups are a wonderful source of comfort and validation for caregivers and other health care workers dealing with daily experience of losing patients and close relatives.

Following are some of the benefits that can be endorsed by members in a group process:

- Instillation of hope, that is, assurance that treatment will work.
- Universality, that is, what seems unique is often a similar or identical experience of another group member.
- Imparting of information, that is, instruction about mental health, mental illness, and how to deal with life problems usually through group discussion.
- Altruism, which is sharing experiences and thoughts with others, helping them by giving of one's self.
- Corrective recapitulation of the primary family group, that is, reliving early familial conflicts correctly and resolving them.
- Development of socializing techniques, that is, learning basic social skill.

For further reading

Bertman, S.L. (1999). **Grief and the Healing Arts, Creativity as Therapy.** New York, Baywood publishing Company, Inc.

Dow, U. (2000). **Far and Beyond**. Gaborone, Longman.

Potter, P.A. and Perry, A.G. (1993). **Fundamentals of Nursing: Concepts, Process and Practice, 3rd Ed.** St. Louis, Mosby (Chapter 28).

Black, J.M. and Matassarini-Jacobs, E. (1987). **Luckman and Sorensen's Medical-Surgical Nursing, a Psychophysiological Approach, 4th Ed.** W.B. Saunders.

Zakes, M. (1995). **Ways of Dying.** London: Oxford Press.

Learning activities

ACTIVITY 1

Share individual experiences of grief and loss following death by answering the following questions:

What was the most significant or first loss in your life?

What hurt you most about this?

Describe your experiences.

How did you cope with the loss (What helped you to cope)?

Purpose:

The purpose of this activity is to recognise common experiences, grieving stages and coping mechanisms.

Instructions:

Each participant writes down short answers to the above questions, after which each participant will be invited to present her/his story to the group. After group discussion, the facilitator summarises, points out commonalities, etc. on experiences, stages and coping mechanisms.

ACTIVITY 2

Illustration of grief and loss through art and popular culture.

Purpose:

To release and reveal feelings of grief and loss through visual art.

Instructions:

Choose any of the images in this manual that depict grief (or bring some of your own) and discuss what it depicts. As with the previous activity, we can identify a future and healing possibilities in the present.

Stress and Burnout

- Imitative behaviour, that is, modeling positive actions of other group members.
- Interpersonal learning, that is gaining insight and correctively working through past experiences.
- Group cohesiveness, that is, the proper therapeutic relationship between group members and the group leader, and the group as a whole.
- Catharsis, that is, experiencing and expressing feelings.
- Existential factors, that is, accepting responsibility for one's life in basic isolation from others, recognition of one's own mortality, and the capriciousness of existence.

Research issue:

Exploring support systems and stress management strategies for caregivers in health care settings.

Conclusion

Caregivers often develop stress and burnout because of the service they provide and the conditions surrounding that service. Due to the HIV/AIDS scourge caregivers are exposed to frequent loss of those for whom they care. They may grieve for and with their clients. Cumulative loss and unaddressed grief is a breeding ground for the development of stress. Caregivers should be able to identify and manage their own stress. Dealing with their own stress enables them to be far more effective with their client's strains and tensions.

For further reading

Potter, P.A. and Perry, A.G. (1993). **Fundamentals of Nursing, Concepts, Process and Practice**. Mosby Yearbook, Chapter 30.

Learning activities

ACTIVITY 1:

EXPLORING THE SOURCES OF STRESS

Purpose:

To assist caregivers to recognize the origins of stress.

Source: AIDS/STD Unit 2001

Instructions:

Divide participants into small groups and get them to identify where stress emanates from. Participants are encouraged to brainstorm and write down all possible sources according to three categories:

- From self
- From environment
- From others.

Place categories side by side on the wall and discuss findings.

- Identify common causes of stress.
- Highlight / emphasize the following causes of stress:
 - work
 - relationships
 - illness and death
- Explain that caring for PLWHA's is a stressful experience.
- Summarize the activity by stating that as caregivers to help ourselves and our clients, understanding the causes of stress is a prerequisite.

Learning activities

ACTIVITY 2:

EXPLORING THE SIGNS AND SYMPTOMS OF STRESS

Purpose:

To recognize and understand a person's reaction to stress.

Instructions:

Ask participants to think of a stressful period or experience in their life. Briefly answer the following questions:

- What was the stressful experience?
- What physical symptoms did you experience?
- What were your emotional responses?

In a plenary setting, write down all the signs and symptoms on a board or flip chart.

Follow up with a plenary discussion.

ACTIVITY 3:

COPING STRATEGIES

Purpose:

To understand coping mechanisms when experiencing stress.

Instructions:

In a plenary session, ask participants to identify coping strategies for stress.

The following categories can provide guidance:

- strategies that involve self and others
- strategies that involve physical exercise
- strategies which involve withdrawal
- strategies which involve confrontation
- strategies targeted at mood change
- strategies involving emotional reactions

Explain the importance of coping mechanisms, and focus on the impact of HIV/AIDS.

Introduction

Children are a gift from the LORD; they are a real blessing.

Psalms, 127:3



Expressions of grief assist in the healing process, but the forms that expression takes varies greatly. What matters most is feeling understood.



JOSHUA MILLER

If few of us know how to honor grief with a grieving adult, or how to handle our own losses, how much harder it is to imagine helping a child through the process. Children do grieve deeply and over time. Their experience and expression of grief may be different from an adult's, but it will be no less painful or severe. Like adults, these smaller people benefit from attention and love. They may need solitude and companionship, someone to talk to and someone to cry with. Sharing the reality of what is happening allows children to begin to understand, to cope with and integrate the experience of loss into their lives.

The question is not whether children grieve; rather, it is how they grieve, what questions might they ask, and how best can we respond, not just to a particular incident, but to influence positively a child's ability to cope with illness, change and loss.

Children and Grief

Many children in Botswana have experienced a major loss by the age of 18, such as the death of one or both parents, siblings or close relatives. Children of all ages are affected (even infants), however considering emotional stress, children of ages 5 – 7 appear to be especially vulnerable i.e. they are old enough to understand permanent loss, but lack the social skills to deal with it. Following death of a parent, girls appear to be more vulnerable to social risks given their social status and economic dependency i.e. they are at greater risk of sexual exploitation and abuse.

Children may also experience a series of losses overtime. Each loss brings up the other losses and must be dealt with anew. Children may experience feelings of guilt, fear and anxiety related to the cause of death and they can start asking questions. They need answers to their questions, opportunities to express their concerns and extra hands to regain their balance in life. If they are not helped, our society may end up with many unproductive and antisocial adults in the long run. It is an area that we must approach with great care but that needs our undivided attention.

Helping in anyway with the bereaved is emotionally painful and the behaviors of the caregivers, no matter what their intentions are subject to the same defenses against that pain as those they are trying to help. The grieving child presents a challenge to the caregiver that confronts him/her as an individual person and parent, beyond their profession practice.

The caregiver constantly should encourage children to reveal and express their grief feelings and painful feelings. The intensity of communication, emotional outpouring and sadness can feel overwhelming to the caregiver. It is impossible to help the bereaved child successfully by remaining professionally detached and aloof, the helper (must) share(s) in the pain.

Purpose

The aim of this unit is to explore how children grieve, the emotional pain of caring for grieving children and coping strategies.

Objectives

At the end of this unit the caregiver should be able to:

- Explore concepts of death and grief in children.
- Demonstrate skills in communicating with grieving children.
- Assist children in dealing with grief.
- Identify ways caregivers can meet their own needs regarding dealing with grief in children.

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Pretest

Instructions: Tick whether an item is True or False
(Answers can be found at the end of this unit).

- When somebody has a life threatening illness, the family should be the unit of care.
- Family members often attempt to protect each other by denying their own needs.
- The care (or lack of care) we received when we grew up as children affects the way we cope with illness, trauma and bereavement.
- Even the achievement of secure attachments later in life cannot undo some of the damage done by earlier insecurity.
- Children need to be included in the family's preparation for the death of a parent, sibling or close relative.
- As of three years old, a child develops an understanding about death.
- All children experience grief in the same way.
- Children often think that they may have caused the death.
- Communication is the least important requirement in the grieving process of the child.
- Children's way of grieving is the same as that of adults.

How children understand death

As with other aspects of normal growth and development, when children become older they change in their understanding of themselves and of the world in which they live. In like manner they change their concepts of life, death and grief. At first we may think that all children grieve in the same way. But because children develop overtime, there are large differences (Marlow and Redding, 1988).

Birth (0-3):

Children under three have little understanding about death. Young children believe that the dead person they see still lives, although that person is no more. To a small child the deceased still eats and breathes. Death doesn't usually frighten very young children. What threatens them when someone they love dies, is the fact that they have been left alone, that they have been separated from the sources of security and love. Much grief can come from "missing mommy". Concrete explanations are of little help. But telling them that mommy cannot come back but that she loves the child can help a great deal.

Preschool years (3-6):

Children 3-6 years old have somewhat concrete thought. They probably have heard the word death but do not understand the finality or how it will affect their life. They may worry a great deal about missing the parent, as their life without a caretaker is inconceivable. They believe death is gradual. After they have begun school, children imagine death as personified in some form. Some children begin to conceptualize death as a person who carries living people off, especially after dark if they are bad. Some children believe that death is the same as a dead person who lies in a coffin.

Early school years (6-9):

Children 6-9 years believe that death is invisible that no one can really see it until they are carried away themselves. To them death has become final, but they believe it can be avoided if one can outsmart the "death man" or ran fast to beat him.

School years (9-12):

At about 9-10 years of age, children begin to understand that death is the end point of the life of the body that it is inevitable and eventually every living thing must die. They are beginning to have more insight into death. They might have known some one who died. The thinking is still very concrete, "he is sleeping in the ground" and they don't understand finality, although

they have some sense of longer time. They may get glimpses into the extent of the devastation and the death cause and they are very reliant on a caregiver for everyday needs.

Adolescents (13 - 18):

Children 13-18 are in full adolescence. Their thoughts concerning death depend on past memories, the degree of belief in a religion, cultural differences and thoughts of the future. They understand the finality of death and grasp the emotional implications. Children of this age are also likely to exhibit high-risk behaviors.

Once children realize that a parent or a loved one may die, the future becomes a major concern. "Where will I go?" and "Who will pay my school fees" are common questions. When children are not given the opportunity to express their emotions about the situation, those feelings are left to fester and could have long-term effects such as depression or nightmares.

"I dream a lot about my deceased father. He comes to me, this is the third time. Sometimes I see him as if he is walking in his sleep. It frightens me"

(Daliusi at a Humuliza counseling session for orphans in Itongo, United Republic of Tanzania).

The way children grieve

The way children grieve is different in some ways from adults. In addition, adult's perceptions of grieving children may not always reflect reality, such as 'Children don't understand'; 'he is young, he will get over it'; 'she is playing with her friends'; 'children soon forget'. How children grieve may also differ from one to another, however they usually have the same intense feelings but those do not necessarily form a progression.

Grief often begins when the first signs of loss occur. It increases during the person's illness and becomes cemented at the time of death. Many times children have to become caregivers to their sick relatives. This is also a source of loss- of childhood, of school and of friendships with their peers. If children have to move because of their parents' death, or if they are split up from their siblings, their loss is compounded. But in many situations, there is little choice. The second caregiver may also become ill and die (the grandparents or aunt, for example). Each loss brings up the other losses, and must be dealt with anew.

John Bowlby, of the Tavistock Institute of Human Relations in London, studied the reactions of very young children to separation from their mothers and developed this outline of what happens as a result:

Phase 1: Feeling numb. This may last days, weeks or longer (where the child is silent, or seems not to show any feelings at all), although it can also be interrupted by periods of intense distress and anger.

Phase 11: Searching. The child may try to recover with searching, yearning, lost and anxious behaviors.

Phase 111: Bereavement. Despair sets in as hope of recovery fades; muted longing, apathy, generalized hostility, and withdrawal – mourning (grief) behaviors.

Phase IV: Adjustment: The child gradually detracts from what was lost and accepts his or her new situation. He or she is willing to engage in new relationships, your love and support as a caregiver becomes all-important.

It is important to understand that feelings of loss and grief may surface again periodically. Sometimes there is a delayed reaction because a child may not understand what death means; that it is final and that the parent or loved one will not return to this earth.

A child may not be able to express his or her feelings in words, but the feelings are still present (sometimes they come out indirectly during play, drawing pictures, bullying behaviours, etc.). The caregiver must be patient and listen carefully. Do not deny or minimize the child's past. Tell stories about the parent or loved one, so that the child can still feel the connection.

Children often ask one or more of the following questions:

- Did I cause it?
- Will I catch it or will it happen to me?
- Who will take care of me now?
- Could I have prevented it?

Allowing children to ask and receive answers to these questions is necessary and important. It is recommended to show objects or tell stories which help them to remember the loved one. It is important that they define their own grief. This process is not linear and they may need to go back and forth as they process the loss. Loss is not a single event but a series of events over time. There is no real stopping or starting but instead a lot of overlapping. Children who lose a parent, sibling or close relative, actually lose twice (if not more) as they lose the person and the way that person would have served them over time.

Support for grieving children

The process of grief for children is one of negotiation and re-negotiation over time, to adjust to the loss. It is necessary for children to reconstruct their relationship with the one who died, as they move through their life stages. They must be allowed to experience the one who died in whatever way it might occur for them via sight, hearing, or a sense of the deceased in their lives. Even when a caregiver is thoroughly exhausted, there are still things that can be done. Children can get great benefit from small interactions. A simple "I love you" or "You are doing so well" can make a huge difference. A smile from a sickbed can encourage a child.

Grief and Children's Rights

Organizations, parents, caregivers, teachers and other people working with children, should give priority to children's rights and make decisions based on the "best interests of the child". In order to seriously respect, protect and fulfil children's rights, it is vital that their psychosocial needs are met. Therefore, caregivers need to be aware of the convention on the rights of the child, which includes:

- Affection, love and understanding.
- Adequate nutrition and medical care.
- Free primary education and the opportunity for secondary, general and vocational education.
- Full opportunity for play and recreation
- A name and a nationality.
- Special care if handicapped.
- Be first to receive relief in times of disaster.

Source: Convention the Rights of the Child.



Psycho-emotional support for orphans and vulnerable children:

In Botswana, the number of orphans and vulnerable children is increasing rapidly. If children are not helped, our society may, in the long run, end up with many unproductive and antisocial adults. Children respond to loss with different levels of vulnerability. One big risk factor is their past experience; whether they have experienced repeated loss and whether a strong and nurturing support system exists for them.

It is important to find out from the child what s/he understands before starting any kind of support or counseling. The helper should not make incorrect assumptions. Children who have a terminally ill parent and are experiencing anticipatory grief are often helped by being told there is a possibility of death, and then can start anticipatory mourning, which helps them to prepare for the event in their own way. This, which is only possible if the adults also have reached the point of acceptance, enables mutual comforting to start before the actual event.

Children and Grief

After the death it is most important for the children that adults are honest and open. A tragedy has happened and the children will be grieving as much as the adults although in different ways; both the depths and the manifestations should be acknowledged. They need to know that it is acceptable to be sad at times and to be encouraged not to forget. This can be done with great sensitivity. Looking at photographs, remembering special meals or treats are all means of keeping memories alive and are especially important in the early days of grieving. Relatives and friends, or a well-liked teacher may help.

After trust has been established, children will be helped by therapeutic play where they can express guilt for what they might have done to hurt their parents and what they failed to do to please them. The counselor can also help children revive positive memories of the deceased with drawing and stories, but at the same time they may need to be given straightforward explanations to questions that are asked.

Family counselling can also be beneficial to children especially by providing an opportunity for all to share their feelings of sadness and fears for the future. Sharing such pain, whether with families or with children alone, is difficult heart-breaking work for everyone.

Children find different means of comforting themselves, often through things associated with the deceased, such as carrying a token of the loved person with them, e.g. daddy's handkerchief or mummy's bracelet, or it might be a toy that seems to hold special memories.

What should be done?

- Help the child recover from the shock of loss.
- Make him/her aware of own resources/strengths.
- Help the child overcome feelings of helplessness and that there is no future.
- Help the child maintain (or develop) self-esteem and self-confidence.
- Make the child aware that society or community hasn't abandoned her/him.

Role of the family:

- Prepare the dying parent to learn to cope, and emotionally prepare the child. Give clear and understandable information. Lack of information creates greater anxiety, and the child feels less important or even responsible for the death. Ensure the child's inclusion in both the preparation and in the death rituals.
- Tell them the truth! Trust is the key in healthy grieving. Many children lament: "If I had only been told the truth. If only I had gotten more information". This brings up issues of anger for children who wanted to be "invited in" to the situation happening around them that so deeply affected them. Hiding the truth and not including children in the death and dying process actually hurts their ability to grieve in a healthy manner.
- Many children will not appear sad or depressed, but rather anxious and worried. Their clarity of thinking is lost and they need to experience their grief not in phases but as an ongoing process. Grieving relatives and others can also help by asking the child what he/she thinks when a child poses a question, rather than providing them with their adult answer.
- Many times people are afraid to mention the deceased for fear of making children sad. This in fact teaches the children that it is not okay to talk about their loved one and bottles up any expression they may naturally feel and want to share. It is important for adults to share memories of their loved one.

Role of the community:

Teachers, church leaders and community members need to be informed when there is a crisis at home, although the diagnosis of the illness need not be shared. Perhaps, many children in the school have experienced losses, but unless they are communicated, children often believe they are the only ones. Support groups for children and regular visits by caring volunteers can help to lessen the isolation and normalize their journey of grief. Whether it is the actual death or the funeral, making sure that there is someone to care for the child can help facilitate the grieving.

Group therapy:

Generally when children are in difficult circumstances, they feel worse about it when they feel alone in their experience. Another way to assist children's psychosocial needs is to establish a peer group where they can share similar experiences and support each other. Often a major concern expressed by vulnerable children or orphans is isolation from other children and the community. The aim of sessions is to help the children in the group to identify their feelings and to enhance their capacity to cope with their new and difficult situation.

Each counseling session should follow a routine and provide a stable environment to comfort children whose lives are in chaos after losing a parent. The group atmosphere encourages the children to lose their sense of isolation by working and sharing experiences with other children in similar situations. The children have the opportunity to vent their feelings to the group.

Communicating with children

In communicating with children, you are trying to understand the thoughts and feelings of the child and trying to understand the child in a way that is helpful. You need to understand the cultural environment in which the child lives and is brought up. In every culture, there are distinctive ways of communicating, expressing feelings, and dealing with difficult circumstances. Children learn those ways as they grow up, as part of their social knowledge. Styles of communication vary according to social class, urban and rural residence, and the age of the child.

In order to communicate well with children you need skills in listening, observing and understanding their messages. You need skills in getting your ideas and feelings across so that they can be helpful. The presence of at least one familiar person who normally cares for the child is essential for communication. This is true for all children, but especially for young children who find it difficult to trust and communicate with someone unfamiliar.

Why we sometimes find it difficult to communicate with children:

In our country, we have not been encouraging children to talk about themselves. In health care settings and even at home, information about children is often obtained through third parties – parents or carers even when the children can ably provide the same. Other reasons why it may be difficult to communicate with children include:

- **Difficulty in talking to strangers.**
A child who does not know you well may find it difficult to talk to you about his/her feelings.
- **Cultural and traditional factors.**
Traditionally children are not encouraged to ask questions (children are not heard).
- **Putting emotions into words.**
Children who have had a particularly bad experience find it hard to talk. Some children may not speak for months, or even years after suffering the experience.
- **Lack of trust and suspicion.**
Do not be surprised if you find some children who are suspicious or difficult to talk to. They may have good reason not to trust adults. Children living on their own in perhaps child headed households or in other difficult circumstances are the worst affected. They may be afraid that adults will take advantage of their age, and grab their property and force them to move elsewhere.
- **Anger and hostility.**
Some children are angry with adults because they have been treated badly and not cared for properly.

Helpers should avoid the following when communicating with children:

- Talking too much.
- Being critical or judgmental.
- Laughing at or humiliating a child.
- Being aggressive or bullying a child.
- Getting upset.
- Arguing.
- Being uncomfortable or embarrassed when a child is upset.
- Not responding to the child's beliefs.
- Not creating a situation of trust.

Children have many ways of communicating. They express themselves through play, drawing (sometimes on the ground), making toys, and acting out situations through music, singing, dancing and sometimes writing. While allowing children to talk freely can help build up confidence, activity based strategies like play can sometimes work better with those children that have particular difficulties in revealing their feelings.

Activity Based Strategies:

● **Make Believe Play**

Either on his own or with others a child may play out distressing experiences. You should encourage this spontaneous play as it helps the child deal with his emotions and memories.

Using puppets and masks, children can pretend to be someone else. This allows them to communicate ideas or feelings that otherwise would be too difficult to say. They can hide behind a mask or a puppet and talk to a puppet or mask of the helper, without feeling as exposed as if they were talking directly.

- **Using Stories**

Stories about characters who overcome difficulties in their lives help children to imagine themselves overcoming their own difficulties. For example stories about people who do magical deeds, communicate that even the apparently weak can succeed and sorrow never lasts forever. This encourages children's confidence in themselves.

Through drawings, children communicate experiences and feelings that are hard for them to talk about. Make sure that you do not influence what the children draw. Children who are new to this activity may lack confidence and ask what to draw, or copy what someone else has done or what they see in a book. It is a good idea to suggest first that children draw whatever they want to. Later you could suggest a topic like "my future", "a dream", "my brothers and sisters" that stimulates their imagination without influencing how they deal with the idea.

When the child has finished the picture, you can ask him to tell you about it, but do not pressurize him or her to do so. Drawing may be a relief in itself or may open the way for communication in words. If you can, put the picture on the wall or keep it safely, to show that you value what she/he has done.

- **Music and Dance**

Music and dance and singing are very powerful means of helping those who are emotionally distressed, especially if the songs and tunes are familiar and linked with happy memories. The movements and rhythm help to release tension, and produce a feeling of well being. The group activity makes the child feel safe and able to express himself without having to use words or feeling self-conscious.

- **Drama**

Taking part in drama can be equally helpful as the children can create their own story, or make up a story that expresses something important to them. They can use a mask as a way of distancing themselves from the emotions of the characters.

They may for example make a play about their own experiences and experiment with different kind of endings for their stories, both happy and sad. At the end you can discuss with them how they feel about the play and about how it ends.

- **Writing about experiences**

For those children who can write, producing stories, poems, or accounts of their experiences, are a useful means of expression.

In all those activities, leave the children free to express themselves as they wish. Do not get caught up in criticizing the techniques and standards of the productions, as this will inhibit free expression.

How to help caregivers of grieving children

The answer lies within the carers rather than those they are trying to help. The carer should not get upset especially when the child's situation is frustrating such as when the support does not seem to provide immediate healing of the pain. Grieving is to be expected. It is the human response of loss.

It should be noted that it is not the words of the caregiver that help most, but the outlet they offer for their clients grief and it should be similar for the carers themselves. Services need to recognize that the plight of the caregiver is as valid as the distress that they are trying to resolve.

Only by expressing and facing up to their feelings as caregivers can they encourage those they are trying to help to do likewise. The availability of counseling services and prayer opportunities for staff will help alleviate the build up of stress (see also unit 3).

Conclusion

Children understand the concept of death at the early stages of life. Like adults, children grieve and mourn the dead, though in a different way. They need an extra helping hand to regain their balance in life, when one or both of their nurturing / support systems disappears / dies (Marlow and Redding, 1988). Even though they respond to loss with different levels of vulnerability, one big risk factor is their past experience, whether they have experienced repeated loss, and whether a strong nurturing family environment existed by then. It is therefore very important for the parents and caregivers to help the children understand and accept the reality of death / loss as this may avoid complications later in life. If children are not helped to go through the grieving process, our communities may end up with more, less well-adjusted adults in the long run.

For further reading

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Learning activities

ACTIVITY 1: ROLE PLAY

Purpose:

To understand the impact of grief on children and how to deal with it.

Scenario:

Sudden death has occurred of a father of 3 children who lost their mother last year. Unable to accept being progressively crippled by AIDS, he took an overdose of painkillers and sleeping tablets. Upon arrival at the hospital he was declared dead. The children have been told by family members that their father's death was accidental and they are devastated. The eldest son carries the guilt of his father's death based on a standoff he had with him recently regarding his mother's death due to HIV/AIDS and had secretly wished him dead. The elder daughter is busy denying her father's death means anything to her. The younger son who was very close to the father is on his way home from school and will be calling on him at his office as usual. You as the caregiver will meet everybody at their home.

Instructions:

- Divide the participants into groups according to numbers. The groups are then led to separate rooms if available. Each group should have a facilitator.
- Participants are randomly given a script containing their roles and describing their attitudes and feelings, the general situation facing all players and a start off point for the role-play. The role-play scenario should be the same for all groups.
- This should not be followed to the letter but should act as a guide and framework from which the role-player will fill in from the fabric of personal experience with grief and grieving children he has tried to help.
- Please note that men may play female roles or vice versa and adults play children.
- After five minutes the facilitators collect the scripts and the role-play is initiated. The role-play should run for 20-30 minutes. The time may seem not long enough, but the role-play doesn't have to come to any particular conclusions or resolutions or any resolution at all.
- After the role-play, engage participants in the sharing of feelings and experiences of the role-play. Members should discuss how the characters they played relate to own personal experiences. The facilitator should highlight issues regarding support for grieving children emanating from the sharing of experiences.
- Conduct a de-roling activity. For example each member restating their real name and occupation in order to distance themselves from the characters they played in the role-plays.

Children and Grief

Pretest key

1. T
2. T
3. T
4. T
5. T
6. T
7. F
8. T
9. F
10. F

Glossary

ACCEPTANCE

Acceptance is a type of coping with the specific characteristics: Disposition to manage and handle stress over time, eliminate or reduce feelings of apprehension and tensions, restraint of destructive behaviours (ICNP, 2001).

BEHAVIOR

An environmental condition that causes physiological, emotional, behavioral, or cognitive changes in an individual. The changes or effects resulting from such environmental demands.

BEREAVEMENT

Is the state of thought, feeling, and activity that follows loss, it includes grief and mourning. Deprived of a relationship especially after death.

A response to loss through death, it is a subjective experience after losing somebody with whom one had a significant relationship.

BURNOUT

A process which negatively affects one's productivity and feelings of well-being. When caregivers' resources are so overburdened that their mental and/or physical health are undermined. Loss of feeling (callousness), pleasure in work and life may lead to depression and job dissatisfaction. It is a process in which everyday stresses and anxieties that are not addressed gradually undermine the carers' mental and physical health, so that eventually care giving and personal relationships suffer (Bertman 2001).

BURNOUT SYNDROME

A type of endurance with the specific characteristics: Energy depletion due to a longer period of chronic, unrelieved stress, lack of support, lack of respectful relationship, external pressure, conflicts between realities and expectations accompanied by physical illness. (ICNP, 2001).

CAREGIVER

A professional (e.g. nurse, counselor) or a family member, who takes care of the physical and / or emotional needs of the patient or client.

CAREGIVER STRESS

A type of coping with the specific characteristics: Disposition taken to manage physiological and psychological pressure on a care provider caring for a family member or significant other over an extended period of time, diminished problem solving capacity in response to the demands of care giving. (ICNP, 2001).

Caring for the Caregivers

CAREGIVER ROLE

It is a type of role interaction with the specific characteristics: Interacting according to responsibilities of caring for somebody, internalizing expectations held by the health care institutions and health professionals, family members and society regarding appropriate or inappropriate role behaviours of a caregiver, expressing these expectations as behaviours and values; primarily in relation to caring for dependent family member (ICNP, 2001).

CASE STUDY

A practical situation that can be used to derive meaning to apply to a particular situation.

It is an attempt at understanding a person, institution, etc. from collected information, the use of a particular instance as exemplar of general principles (Swannell, 1995).

CHILD

According to the International Convention on the Rights of the Child (ICRC) a child means every human being below the age of 18 years unless, under the law applicable to the child, majority is attained earlier.

COPING

Problem-solving. Dealing effectively with a crisis or situation that permits new information to be used and behavior modified in light of new insights, such as bringing about relief, resolving anger and / or mastering other uncomfortable feelings.

DEATH

Final, natural cessation of vital functions in an organism. It is the ending of life. It is considered either as the end of existence or as a transition to another state of being.

DENIAL

A type of Coping with the specific characteristics: Disposition taken to reduce, avoid or, disavow knowledge or meaning of an event in order to minimize anxiety or conflict by unconscious refusal to accept thoughts, feelings, desires, impulses or external facts that are consciously intolerable (ICNP, 2001).

DIGNITY

It is a state of being worthy of honour or respect.

DYING

At the time of death, connected with death.

GRIEF

Deep or intense sorrow or mourning.

HELPLESSNESS

Is a type of emotion with the specific characteristics: Feelings of inability to take control and to act independent without help, defencelessness, accompanied by disabling coping abilities or learned helplessness, submission to authorities, such as caregivers, associated with development of sick-role behaviour (ICNP, 2001).

HOLISM

The philosophy that nature entities such as individuals and other units cannot be reduced to the sum of their parts. In health care, holism refers to meeting the entire client's needs, including physiological needs, psychological development, socio-cultural relationships and fulfillment of spiritual needs. Holistic care is best provided by a team of health care professionals, such as doctor, nurse, and social worker, in conjunction with family members.

HOPE

Expectation and desire combined, e.g. for a certain thing to occur (Swannell, 1995).

PALLIATIVE CARE

Providing care to relieve or alleviate without curing. Serving to relieve or alleviate without curing. The World Health Organization (WHO 2000, pp 8-2) defines palliative care as: "The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families".

POWERLESSNESS

A type of emotion with the specific characteristics: Feeling of lack of control of a current situation or immediate happening, reduced capacity to choose, inability to act due to the understanding that one's own actions will not significantly affect an outcome (ICNP, 2001).

RECOVERY

A type of coping with the specific characteristics: Disposition taken to regain strength, return to health, normal position or livelihood (ICNP, 2001).

SPIRITUAL

The application of spiritual knowledge concerned with soul or spirit in the holistic care of the patient, based on the assumption that man is a spiritual being. Refers to a system of beliefs, a Supreme Being, including the relationship with humanity and nature present within each person. A spiritually healthy person finds a balance in relationships between self, others and a Supreme Being.

SPIRITUALITY

Looking for answers from a greater being. A human need to search for the meaning and purpose of life. Something greater than ourselves.

STRESS

A pressure or tension exerted on a material object, a demand on physical or mental energy (Swannell, 1995). It is an event that disturbs the well-being of a person. Stress responses may be biological, psychological or socially adaptive or maladaptive. Stress is commonly viewed as a frustrated 'fight and flight' response, a basic human survival mechanism; it is a powerful internal communication to raise awareness, and a source of energy.

SUFFERING

Undergoing or being subjected to pain, loss and grief.

VISUAL ART

A technique of using art to facilitate people to reveal and release feelings of grief and loss. It is a form of expressive therapy where art is used to facilitate an individual to reveal and express feelings of loss and grief.

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