

# Psychological

## 1. Communication

The concept of exploring end-of-life issues is inherent in palliative care. Communication (and counselling) is the foundation upon which support and care is provided to patients and their families by the healthcare team for the following reasons:

- It provides the opportunity to clarify and work with the client's goals and plans for the future.
- It highlights the difficulties identified by clients, but also their strengths and resources.
- It helps to clarify what is important to them in their lives.
- It's an opportunity to explore feelings, thoughts, expectations and meanings particular to the client and his/her family.
- It offers support at a time of crisis
- It offers support through a relationship which the client experiences as
  - Non-judgmental
  - Respectful
  - Confidential
  - Empathic and compassionate
- It helps the client develop and sustain hope for the future and for quality of life despite the prognosis (Marcus and Norval 2004).

### 1.1 Criteria for ethical communication of Information:

- The communication should be timely and desired by the patient
- The information must be accurate
- The words must be understandable to the patient and the family
- The information must be conveyed in a gentle, respectful, and compassionate manner

### 1.2 Breaking Bad News and Building Hope

Bad news is defined as any news that drastically and negatively alters a client's view of his/her future. Patients and relatives need time to absorb information and to adapt to bad news. Health professionals need good communication skills, including sensitivity and empathic, active listening. Practice and critical self-reflection are also necessary to continue to improve this basic but essential skill.

#### Why is the opportunity presented in breaking bad news so important?

- To maintain trust. The relationship between the doctor, nurse or healthcare worker is based on honesty and trust. Being truthful allows for appropriate discussion in relation to treatment and care.
- To reduce uncertainty in relation to an illness which can be very hard for the client and the family to bear
- To prevent inappropriate hope that can result in unnecessary treatments, expense, pain, guilt and anxiety.
- To allow appropriate adjustment. Adjusting to bad news takes time and is a process. Patients and their families need to know about the situation in order to adjust both emotionally and practically.

- To prevent a conspiracy of silence that can destroy family communication and prevent mutual support.
- It empowers clients to participate in their treatment and care for the future which can include:
  - Identifying goals
  - Developing a care plan

**When breaking bad news is done well:**

- It leaves the client with optimism, realistic hope and trust in the healthcare professional
- It ensures that clients and families are left with the knowledge that no matter how bad the news, there is always something that can be done.
- It helps to prevent situations in which clients and families are left with feelings of anger, fear, resentment and hopelessness which can happen when they are told: 'there is nothing more we can do for you.'

**Difficulties with breaking bad news include:**

- Fear of incompetence with regard to how 'to tell'.
- Fear of blame by client or family for the illness or for upsetting them.
- Fear of unleashing a reaction, and not knowing how to manage an awkward situation.
- Feeling of failure on the part of the medical profession for not meeting the client's expectations of a cure.
- Lack of sufficient time due to heavy work load.
- Feeling awkward and exposed. Breaking bad news reminds us of our human vulnerability, which may get in the way of our ability to support others.

The steps for breaking bad news are based on Robert Buckman's six-step protocol:

**Robert Buckman's Six Step Protocol for Breaking Bad News**

Step 1 Getting started

Step 2 Finding out how much the patient knows

Step 3 Finding out how much the patient wants to know

Step 4 Sharing the information

Step 5 Responding to the patient's feelings

Step 6 Planning and follow through

These six steps should be followed through in sequence from Step 1 through to Step 6.

**Note:** Whenever the word “patient” is used it can also apply to relative/ loved one/ significant other.

### **Step 1 - Getting Started:**

Step 1 is the most crucial step. It should, if at all possible, be carried out in person and not over the telephone.

- It is helpful to take a few seconds to get the physical setting right, to ensure privacy and a safe environment. Be sure to have tissues on hand. Cover the patient if necessary, draw the curtain or close the door. Ensure that you have switched off your cell phone, have your pager on silent and the telephone off the hook. Tell your colleagues that you would not like to be interrupted.
- Set some time aside in your mind so that you know how long you have and you won't feel pressured to hurry through the interview.
- Sit down and place yourself on the same eye level as the patient.
- If you are not known to the patient, introduce yourself.
- Say the person's name – establish with the person how he/she wishes to be addressed (hearing your own name spoken is very grounding, especially when spoken by someone who cares for you).
- Let the patient know that you are unhurried and that this will be uninterrupted time, allowing for discussion.
- Consider who should be there – is there someone else the patient would like to have with them?
- Before breaking bad news to a patient, ensure that you know all the facts, the diagnosis, prognosis and treatment plan.

### **Step 2 - Finding out how much the patient knows:**

This step involves obtaining from the patient an impression of what they already know and understand about their illness.

- It is important to elicit the patient's understanding of the impact of the illness on his/her future.
- It is helpful to ask questions like –
  - *What have the doctors told you?*
  - *It would help me to know what you understand about your illness*
  - *Tell me how it all started*
  - *What happened next?*
- If the patient can tell you his story, a narrative of the events leading up to the present, it helps you to know at which level to pitch your communication of the bad news to him. While the patient is telling you his story, listen to the words he uses. What vocabulary is he using? What is his education level? What words is he avoiding? For example, “cancer”, “AIDS”, “dying”. The reason one does this is that when you break bad news to a patient you need to start off at his/her level using words familiar to him/her.
- Observe the patient's body language.
- Be on the lookout for signs of denial.

### Step 3 - Finding out how much the patient wants to know:

This is a vitally important step. If this step is left out it leaves subsequent parts of the interview on very delicate and insecure ground.

- The real issue is not '*do you want to know?*' but '*at what level do you want to know what is going on?*' This step helps you judge how much a patient is able to absorb.
- Some patients may not be ready or able to hear more news about their situation.
- Some might be in denial. Denial is a way of coping with fear and should be respected as a coping strategy. It would be harmful for you to break bad news to them at this stage.
- Few patients adopt a stance of denial permanently. If it is clear that the patient is in denial, then do not give unwanted information. If a patient does not want to know, leave them with the knowledge that you are available anytime for questions if they change their mind.
- Fortunately most patients wish to know exactly what is happening.
- Some questions that could be asked in Step 3:
  - *Are you feeling ready to hear the results?*
  - *Would you like me to tell you anything else about your illness?*
  - *Are you the kind of person who likes to know exactly what is going on?*
  - *Would you prefer me to give an outline only?*
  - *Is there anything that is worrying you right now?*
  - *Would you like me to explain ...?*

**Note:** If you already know the patient well and are fully aware of what he/she understands about the illness, this step is not necessary.

### Step 4 - Sharing the information:

Before telling a patient bad news, you should have a clear idea of the details of the diagnosis, prognosis and treatment plan.

- When sharing the information start from the patient's point of view. Reinforce those parts that the patient has said which are correct. Use his words, start on the baseline of his knowledge and build from there. You need to gently bring the patient's perception of the situation closer to the medical facts.
- Start by giving a warning shot, e.g.
  - *You were right when you said it might be more serious than we first thought...*
  - *I am sorry but your results are not as good as we had hoped...*
  - *I'm afraid I have some bad news to tell you ...*
- Use kind words; avoid "med speak" and jargon. Speak clearly and simply. Give the information in small chunks. Most patients are unable to take in more than two to three new ideas at a time.
- Clarify frequently –
  - *Am I making sense?*
  - *This is a lot to take in ...*
  - *Are you following me?*

- Repeat yourself to reinforce the information.
- Use diagrams and written messages to help reinforce and clarify the information.
- Most patients fail to retain up to 50% of information given. When the diagnosis is serious, the information retention is even less.
- Know when to stop!
- It is not necessary to tell the patient absolutely everything all at once. You could always go back later or the next day to discuss it further.
- You have completed Step 4 once you have covered the patient's agenda – his/her concerns, worries, anxieties and expectations.

*Have we covered all that you want to talk about?*

Remember, it is not about your agenda, but the patient's.

### **Step 5 - Responding to the patient's feelings:**

This step is the therapeutic part of breaking bad news. Allowing a patient time to express, give meaning to, and identify their feelings, is therapy in its own right.

- Acknowledging the patient's feelings without judgment is the first step to healing.
- At this stage the patient might be showing signs of denial, shock, tearfulness, withdrawal or anger. It is helpful to just sit with the patient (just to be there for him/her). There is no need to talk! Silence is uncomfortable, but at this stage it is often necessary to give a patient the opportunity to react.
- It might help to gently and softly touch the patient on the arm, shoulder or back, to hold a hand, or to offer a tissue. Be guided by the patient as to how much contact is comfortable – some people want eye contact or physical contact – others feel it is an intrusion.
- Try not to fall into the temptation of filling the silence with excessive explanation or premature reassurance –

*- It's going to be OK ...*

*- You will be fine ...*

*- Don't worry ...*

*- Don't cry...*

- Use empathy. Identify and acknowledge the patient's feelings. Help the patient to name his/her feelings. Naming a feeling brings a sense of control and powerful feelings may subside once acknowledged.

*- You must be feeling overwhelmed ...*

*- This is so hard to take in ...*

*- How does this leave you feeling at the moment?*

### **Common mistakes when breaking 'bad news':**

- Use of jargon
- Either being too direct or too vague
- Talking continuously
- Giving false reassurances

### **Never say:**

- 'I know how you feel.'
- 'There are many other clients with your problems.'
- 'All of us have to die some day.'
- 'It could happen to anybody.'

### **Step 6 - Planning and follow through (Building hope):**

The patient may at this stage be feeling overwhelmed, bewildered, disorganised and without hope.

- Enumerate problems in a list – remember that the patient's problems may be different from those on your agenda.
- Encourage the patient to prioritise problems. Together with the patient make a plan and explain it (give the patient choices).
- There is always something that can be done – even if it is just to offer a glass of water or a cup of tea! For example –  
*Mrs. White, the next thing we are going to do is make sure that your nausea is controlled. Then you will feel more able to spend some time with your pastor which I know is so important to you.* Be specific about how you can help and what is going to happen.
  - ◆ Distinguish the fixable from the unfixable
  - ◆ Identify coping strategies and reinforce them
  - ◆ Identify other sources of support
  - ◆ Summarise the main points
  - ◆ Allow questions
  - ◆ Make a contract for the future – never leave the patient without a follow up appointment, a promise of a telephone call or visit or referral to another member of the interdisciplinary team, e.g. *We will try this for 3 days, I will see you in a week.*
  - ◆ Be available –
    - For further explanation
    - To meet relatives
    - For support

## 2. Psychosocial Care

### 2.1 Psychosocial Assessments:

A psychosocial assessment is an integral part of the holistic assessment of patients and families and will include the following considerations for care and support:

- Family composition and genogram
- Housing
- Transport
- Income and grant applications
- Will
- Funeral policy status
- Cultural considerations
- Gender in relation to roles and responsibilities
- Role of religion/spirituality; religious and spiritual support
- Spiritual or existential distress (loss of hope, alienation from God)
- Insight into illness
- Relationships (partners, children, parents, extended family)
- Child care
- Emotional distress (worry, sadness, despair, depression, anxiety)
- Emotional resourcefulness (such as hopefulness, acceptance)
- Social stigma
- Social support structures which include family, church community, friends and neighbours
- Presenting problems
- Plans for care

### 2.2 Psychosocial Interventions

It is usually the task of the social worker to explore the feelings and the understanding the client and family may have regarding the illness and to highlight resources that will sustain them through the process. Unfortunately, due to late referrals, the psychosocial professional may have to provide support to those clients whose death is imminent; however, even at a late stage of referral, end-of-life conversations can be truly helpful to clients and supportive of families. It is important to pay attention to those issues that have been highlighted by the client as being important to address. Some of these issues may include:

- **Material and practical assistance.** Poverty is a huge factor in many of our communities; facilitating and providing material relief is integral to the care of patients and families. Grants may not come through before the death of a client and the psychosocial professional will have to facilitate material support from other sources within a community to ensure that clients and families have some basic comfort in this regard. Practical assistance may include planning for the future care of children; future care for the patient; arranging transportation to hospitals and institutions, facilitating the funeral policy and assisting with unemployment benefits.
- **Becoming familiar with the client's medical situation;** to be able to assess the client's physical condition which will guide the psychosocial professional in structuring

the counselling session/s. For example, in the case of a very ill person, having shorter sessions or limiting the number of questions, so as not to exhaust the client. The psychosocial professional should familiarise her/himself with the medical situation of the client and work in conjunction with the interdisciplinary team to ensure that s/he is fully informed about the symptoms that the patient is suffering from (Nieuwmeyer 2006). The psychosocial professional is also responsible for informing the supervising professional nurse of any symptoms that may have been reported by the client during the counselling session.

- **Facilitating the participation in end-of-life rituals that provide meaning to the client and family.** The psychosocial professional will explore the end-of-life customs or rituals that may hold meaning for the client and family. In our diverse cultures however, it is important that the psychosocial professional does not assume that specific rituals will be significant to a client and family, simply because they are members of a particular ethnic or religious group, but to facilitate those rituals that the patient requests.
  
- **Assisting with the resolution of relationship issues and concerns with family and/ or significant others.** Patients may experience a variety of unresolved issues in their relationships with family and friends; some of these relationships may have a long and complicated history, and a resolution or reconciliation of these relationships may be unrealistic in terms of the length of time that is available. Depending on the meaning of, and importance attached to the relationship, people may be encouraged to express love, gratitude and forgiveness, which can transform the relationship and their lives; 'whether it lasts for decades or just a few days' (Bycock (2004) in Matzo and Witt Sherman 2006:230).
  
- **Facilitating the opportunity for clients to review their life stories.** When clients are encouraged to tell their life stories, they are often able to see the purpose and meaning in their lives. Being present while a client does a life review may not require much more than a commitment to time by the psychosocial professional and an active listening ear. A life review can give the client an opportunity to reflect on the meaning and importance of relationships, for instance, which may help to bring a sense of inner peace.
  
- **Providing support in the loss of unfulfilled dreams, desires and wishes.** Bereavement begins at diagnosis; patients diagnosed with a life-threatening illness may carry a range of unfinished dreams, desires and wishes. These dreams are shaped by age and developmental level. For example, a young adult may have wanted to complete a degree at university; a young mother may have hoped to see her children become independent; an older person may have wanted to witness the arrival of the first grandchild. To be able to identify some of these hopes and dreams, the psychosocial professional may ask:
  - *Is there something that you need to do that would still add a great deal of meaning in your life?*
  - *What would need to be done for this to happen?*

It may require the bending of 'rules' to accommodate these wishes; for example, grandchildren being allowed to visit a grandparent in an intensive care unit; pets being allowed in a care facility. Generally it requires that resources be expended so that the event can take place. A young parent who is dying and leaving young children behind may need assistance from the social worker to find ways of leaving lasting words of comfort and reassurance for the children. Younger adults may need to be supported through having to die and having to leave with so much of their lives still 'undone and incomplete'.

Some clients seem to be able to 'postpone' dying until after an encounter with a significant other or loved one. Death may often only occur after an important event such as a birthday or holiday.

**- Support to Older Persons.** Healthcare providers can make the assumption that older adults, having lived a full life, are more prepared for death. Yet these adults, who have enjoyed a good quality of life may still believe that they have the potential for many healthy, happy years. The psychosocial professional should not underestimate the effects of illness on this group and their loss, and their need for support through the illness process. People in this age group may also believe that they have no choice when it comes to their treatment options and care. The psychosocial professional can assist older clients with participating in decisions regarding their treatment and care.

### 3. Loss, Grief and Bereavement

Grief is a normal reaction to bereavement or other major loss. Loss and grief are present from the moment of diagnosis of a life-threatening illness. Price (1997:51) notes that in the course of an illness the patient and family members will be expected to make a number of decisions about treatments and possible alternatives. These decisions, he says, are made in the “context of grief”, at a time when well-being, energy, status, dignity and independence are slipping away. In addition to these considerable losses, the person’s self-image undergoes changes and adjustments along the way. We are therefore looking at a continuum of change, loss and grief along the road from diagnosis to death - and beyond into bereavement. Its manifestations will vary from person to person but will often include physical, cognitive, behavioural and emotional elements (see below). In close personal relationships, grief is likely to continue for a long time and may recur in a modified form, stimulated by anniversaries, future losses or other reminders. People are likely to be changed by the experience of grieving but most, in time, find that they are able to function well and enjoy life again.

#### Models of Grief

Grief and bereavement have been analysed over the years using different models. Older ‘traditional’ psychological models emphasised changing emotions and thoughts.

Understanding bereavement has been developed through models which see it in terms of coping with a profound stress. More recently bereavement models have focused on social and relationship frameworks. Some writers have described psychological stages or phases of grief through which bereaved people pass, but these models have been seriously criticised.

<b>Kubler- Ross</b>	<b>Parkes</b>	<b>Worden</b>	<b>Rando</b>
<b>Phases of Grief</b>	<b>Phases of Grief</b>	<b>Tasks of Mourning</b>	<b>Grief Processes</b>
Shock/denial	Disbelief	Accept the reality of the loss	Recognise the loss
anger	Searching/yearning	Experience the pain of grief	React to the separation
Bargaining	Isolation/loneliness	Adjust to life without the deceased	Recollect/re-experience the deceased
Depression	Mitigation		Relinquish old attachments
Acceptance	Reinvestment/new identity	Emotionally relocate the deceased and move on with life	Readjustment

The above table is taken from one compiled by Elizabeth A Keene Reder (2003). It should be noted that the models are biased towards Western cultures.

#### Stress and coping model:

Stroebe and Schut (1999) in their dual process model of coping with grief suggested that bereaved people tend to oscillate between loss-oriented experiences and restoration-oriented activity and that both are necessary to successfully negotiate the bereavement journey.

#### Social and relationship-focused models:

White (1996), Walters (1996) and Silverman et al (1996) have explored continuing bonds, emphasising the importance for the living of interpreting the memory of the dead into their ongoing lives, recognising the enduring influence of the deceased.

## Symptoms of grief

Physical	Emotional	Behavioural	Cognitive	Spiritual
dry mouth	numbness	passive or very active	denial/disbelief shock	loss of faith
tightness in throat/chest	yearning	searching	confusion	
dizziness	sadness	crying	self doubt	comfort from faith
breathlessness		sighing		
<i>butterflies or a huge 'hole' in tummy</i>	anger	indecisiveness	sense of the presence of the person	search for meaning
	guilt	sleep disturbance.		
	anxiety	changes in appetite		
loss of energy	loneliness	forgetfulness	preoccupation with the deceased	changes in relationship with Divine
		social withdrawal		
loss of sexual desire	relief	mood swings. substance abuse		alienation

It should be noted that not everyone will experience all of these symptoms since individuals react differently to loss and grief.

### Assessment:

When doing an assessment within limited resources it is important to know which bereaved individuals/families are likely to be at risk. The following clients should be prioritised for an assessment and support:

- young single parents with children
- the parents after the death of a child, or a young adult
- people with very little, if any, support systems
- an elderly person who has been very dependent on his/her deceased spouse
- if the death was perceived to be traumatic, sudden or unexpected
- where there was an ambivalent or conflicting relationship with the deceased
- if the death was AIDS related and the spouse and children are infected
- there is a psychiatric history
- orphaned children

At first contact, the bereavement supporter/health professional will use an assessment tool to evaluate the following:

- Is this normal grieving?
- Are there children left on their own? Who will care for them?
- How are school-going children coping at school? Does the class teacher know of the child's loss?
- Are there any gender considerations with regard to role adaptations?
- Is the evident depression within normal limits or is medical assistance required? Is there any previous psychiatric history?
- Is spiritual help required?
- Is there a physical handicap or are there other family members who are ill?
- Is there financial/material need?
- Is assistance needed to apply for any unemployment benefit/grant/pension for which the family may be eligible?
- What are the support networks for this family?
- How is the family functioning as a system?
- Are there other resources in the community available to this family?

### **Factors which may influence the grief process**

- Culture and belief systems within the community and how the bereaved person interprets these
- The type of relationship/closeness/alienation experienced with the deceased person
- Age of the bereaved, personality and his/her past experiences of handling crises
- Habitual use of alcohol or drugs in order to cope in times of personal difficulty
- The bereaved is physically or mentally challenged or suffering from dementia
- Previous psychiatric illness
- The cause of death and possible stigma attached to that (see below)
- Whether those closest to the dying person could communicate freely with him/her and with each other (see below)
- The length of the illness
- Support systems (family, friends, church)
- Financial problems
- Concurrent stresses, including multiple losses
- Hidden losses that cannot be openly mourned

### **Factors which may pre-dispose families to complicated grief**

- a minor event triggers intense grief; or the person experiences intense or overwhelming sadness at particular times of the year, for example an anniversary
- the person experiences chronic depression, guilt and has low self-esteem
- the person indulges in self-destructive behaviours
- deep attachment to all the deceased's possessions
- the person develops a phobia about death or illness
- the person experiences intense or overwhelming grief when talking about the deceased
- radical life style changes
- the death of a child
- avoidance of death related rituals and activities

- multiple losses or deaths

**Support to bereaved families includes:**

**Practical issues:**

Assist the family to find practical solutions for specific problems once identified. These problems may include:

- No provision for funeral arrangements or funeral policy
- No income if deceased was the breadwinner
- Claiming death benefits from department of labour
- Making application for child support or care dependency grants if the deceased was collecting this money, or there is no income for the children
- If the deceased had life insurance; helping the survivors with the necessary steps for this to be paid out
- Liaising with the child and family organisations in the community as appropriate

**Social and Emotional support includes:**

- Non-judgmental and compassionate listening
- Encouraging conversations about the deceased
- Allowing the opportunity for the expression of feelings, thoughts and experiences
- Offering reassurance about the 'normality' of feelings, thoughts and experiences
- Providing information, when requested, about the illness and death of the loved ones - and about the range of grief responses if requested
- Educating, and information sharing with others (family members and other support networks) about how to support the bereaved person/s
- Counsel or refer appropriately on issues such as depression, anxiety, fear, stigma, superstitions, isolation, loneliness and rejection

## 4. Culture and Spirituality

When caring for people with a life-threatening illness, it is important to obtain a general outline and understanding of their philosophy of life, religious beliefs and expectations of the continuity of life after death. Such knowledge is valuable if a dying patient is to be sensitively and efficiently cared for. The best way of obtaining this information is through gentle, tentative enquiry to the patient and family.

### **Culture:**

*'Culture refers to learned patterns of behaviours, beliefs and values shared by individuals in a particular social group. It provides human beings with their identity and a framework for understanding experience. When culture is referred to in its broadest sense, it is about a group of people with a similar ethnic background, language, religion, family values and life views.'* (HPCA 2005)

In culturally diverse societies like South Africa, people of very different ethnic, racial, religious or social groups live side-by-side maintaining their own values and traditions. As culture provides people with a framework to understand experience, it will inform and shape their concept of illness, death and bereavement and how they respond.

**Cultures are constantly evolving and changing.** There are many cross-cultural effects and a diversity of sub-cultures in African societies (HPCA 2005). It is therefore important that we constantly *challenge our assumptions* when supporting people living with a life-threatening illness in our diverse communities. We also need to pay attention to the following:

- **Language difference** which precludes direct communication (interpreter is necessary), which can create barriers
- **Funeral and death practices, rites and rituals**, for example, who is included or excluded; what happens if they are excluded from these through distance; timing of funeral service and social issues such as the different roles and responsibilities of family members at the funeral
- **The inclusion and exclusion of children** in death and dying and funerals, for example, viewing the body, being allowed to participate in the ceremony or being excluded from it.
- **Dress and behavioural expectations** after death
- **Expressions of feelings** in relation to grief, 'extreme' reactions versus 'containment'
- Expectations with respect to the **'time allowed'** for the outward expression of grief
- Expectations of **future roles in the family**, in terms of taking on responsibilities, loss of status
- **Belief systems**, for example, life after death and how this influences the living, ghosts, spirits
- **Inter-generational issues** and differing expectations of these within families

**Gender:** 'All aspects of patient care should take into account the differing physical, social, emotional, and spiritual needs and interests of women and men, girls and boys, and are addressed in a gender sensitive and gender appropriate manner' (HPCA Gender Guidelines 2008).

**Spiritual beliefs:** Even without a particular religious discipline, these vary enormously and a religious label noted down on a hospital form may have little to do with the patient's past or current ways of thinking. Moreover, the behaviour and beliefs of an individual enjoying full health may change dramatically when they become terminally ill and reach the threshold of a period of life which had not been previously contemplated.

Most religions provide both ritual procedures and pastoral (or existential) care. Although a Christian cleric will administer both, this may not be the case in other religions. Existential care and comfort may well be provided by lay groups. Brief guidelines are put forward regarding the care of dying patients of the most commonly encountered faiths.

### **Spiritual Assessment**

When assessing the spiritual care of patients, it might be useful to consider the following principles, which will assist psychosocial professionals broadly in their approach to the assessment, as well as to pay attention to the individual needs of clients and families.

- Each person has a spiritual dimension that should be considered along with intellectual, social, emotional, and physical dimensions
- A spiritual orientation will influence the other dimensions of our being in relation to illness and death
- Dying and bereavement may be an opportunity for spiritual growth
- No single approach to spirituality can be helpful to all individuals
- Spirituality is expressed and enhanced in formal and informal, religious and secular ways, including symbols, rituals, practices, patterns, art forms, prayer and meditation which should be accessible and available
- Care should be taken to offer settings which will accommodate individual preferences as well as communal experiences
- Healthcare systems should support spiritual care in their written statements of philosophy, and in terms of resources of time, money and staff
- Patients should feel free to express humour and to laugh as this does provide medicine for the soul
- A caring environment should be in place to promote spiritual work at any time

Having looked at the impact of illness and principles of spirituality in palliative care, we will now look at an assessment tool devised by Puchalski (1998).

The tool is called the **FICA** spiritual assessment which is an acronym for:

F: Faith or beliefs

I: Importance or influence

C: Community

A: Address

Possible questions that may be asked in each of the areas of FICA in relation to a patient's spirituality are as follows:

**Faith:** *What is your faith or belief?*

*Do you consider yourself spiritual or religious?*

*Does your religion or spirituality play an important role in your life?*

*What are the things that you believe in that give you meaning in life?*

**Influence:** *How does your religion/spirituality influence your health?  
The way you take care of yourself?*

**Community:** *Are you part of a spiritual or religious community; are there people from your church who support you?  
How do they support you?  
Are there any other people who are important to you and supporting you at this time?*

**Address:** *Would you like any to assistance in addressing these issues?  
How could I be helpful?*

When assessing patients' spiritual needs, it must be remembered that the above assessment 'tool' should serve as a guide. In all instances, we must be guided by what the patient is prepared to offer and talk about in relation to religious and spiritual beliefs and practices.

**Patients from different religions have different needs:**

Buddhism, Christianity, Islam, Judaism and Hinduism all have a wide range of denominations or variations. They all contain more conservative groups for whom the correct procedures are most important and more liberal groups who are unlikely to take offence, provided sensitivity and openness are displayed. Religious demands and taboos are frequently found in relation to the following subjects:

- 1) Food
- 2) Alcohol
- 3) Privacy
- 4) Washing
- 5) Cross-gender care
- 6) Touching/preparing the body after death
- 7) Religious objects.

**There are two important considerations:**

- 1) ALWAYS CHECK with the patient (and/or family) as to their beliefs and affiliations even if these are not current.
- 2) WHEN IN DOUBT, follow the more orthodox procedures.

**Faiths, preferences, and special considerations:**

BUDDHISM

**Preferences:** Buddhists may want a Buddhist (or even a Christian!) priest to help with prayer and meditation. With regard to food, Buddhists are commonly vegetarian. It is also usual for Buddhists to prefer cremation to burial. Buddhists may wish to avoid palliative treatments that lessen either the experience of pain or mental control.

**Special considerations:** None, except to inform a Buddhist priest of his/her persuasion after death.

CHRISTIANITY

**Preferences:** Christians may want a priest/minister of their persuasion for confession (formal or informal), prayers, communion or anointing.

**Important considerations:** None, unless communicated indirectly.

## ISLAM

**Preferences:** Muslims may have special dietary requests and strict Muslims may even reject medicines if they contain alcohol. There are special fasting times, but an ill patient is allowed to eat when necessary. During festivals, routine medical examinations and tests should be avoided. Women may want to be seen by a female doctor.

**Important considerations:** Muslims require adequate facilities for washing which is an essential part of worship. The family should be consulted to ensure that the body is specially prepared for burial. Disposable gloves must be used if a body is to be touched. The eyes should be closed and the limbs straightened; the head should be turned towards the right shoulder and the body wrapped in a plain sheet. The family may wish to wash the body themselves. Muslims are always buried and this should/must be arranged as soon as possible. Post mortem examinations or any operation on the body is forbidden unless ordered by the coroner, in which case it must be carried out as soon as possible. Traditional demands for burial within 24 hours of death and in the deceased's native country need sensitive handling.

## JUDAISM

**Preferences:** Jewish people may want 'Kosher' meals or vegetarian food. They will probably want a Rabbi and women may want to remain fully clothed and have their hair covered. The religious emphasis on life may mean that the family or patient will question any treatment that could be seen to weaken the fight for life.

**Important considerations:** Orthodox Jews have strict dietary laws and the family or Rabbi should be consulted for advice. At death the body must be handled as little as possible, and even then only by his/her children and then covered. The family, or in their absence, a Jewish undertaker should be informed immediately and a funeral held within 24 hours. The exception is during the Sabbath (Friday dusk to Saturday dusk) during which time the body should not be touched. If there is to be an inquest or post mortem, it should be carried out as soon as possible.

## HINDUISM

**Preferences:** Hindus are often vegetarian. The dying are treated with great reverence and many relatives may want to come and sit with the patient. The family may want a dying patient to be nursed on the floor. Hindus do not object to a non-Hindu handling the body, but relatives may want to wash the body.

**Important considerations:** The cow is sacred and beef must not be eaten. The eldest son, however young, must be present when the patient dies. Hindus are cremated, never buried, and the eldest son takes the leading role in making arrangements.

## AFRICAN SPIRITUALITY AND PRACTICES

**Preferences:** As with all cultures, African spirituality is intimately interwoven with cultural and religious beliefs, practices and values. Spiritual support to the dying is drawn from the community and 'all types of relatives, both living and living-dead (ancestors)' (2006:14). The traditional belief is that the dead continue to live but remain unseen by the living. The general use of the word 'death' does not apply to people but to other forms of life.

**Important considerations:** It is customary for the deceased to be buried in the place of their birth. The obligations of the chief mourner include:

- Informing all the family and community members , and those living far away, of the death
- Assigning people to do the eulogies and declarations about the deceased
- Arranging for an animal to be sacrificed
- Medicinal herbs need to be collected for mourning, cleansing and re-integration
- Vessels are collected for ritual washing

People are usually buried with some of their personal possessions, and facing 'home' so that they can continue to watch over their families. Female mourners are expected to sit on the ground to settle the spirits of the deceased. The family of the deceased determine the terms and conditions of the mourning period.

## 5. Psychosocial Emergencies:

### 5.1 Suicide Ideation: Patients at risk include:

- older age
- poor performance
- advance stage disease
- severe depression
- physical distress other than pain
- past history of suicide ideation
- history of depression
- anxiety
- feelings of loss of control
- social support
- patient-doctor relationship
- economic status
- individual coping styles

### Management:

- Assess potential risk and need for a psychiatric assessment
- Counselling and support for factors linked to suicidal ideation
- Counselling and support to the family

### 5.2 Social Emergencies:

- **No funeral cover**

### Management:

- Explore possibility of financial support/assistance from extended family or relatives
- If this is not an option the family can approach their local authority and arrange burial, but will need a signed affidavit declaring their financial status.

- **Orphaned children**

### Management:

- Ideally orphaned children are placed with a responsible family member or relative with the view to a permanent placement.
- If this cannot be arranged, a form 4 has to be completed by a professional at a police station to place children at a place of safety for 48 hours. Immediate arrangements need to be made for an alternative placement, either with a responsible family member, at a place of safety or with a foster care family.

### 5.3 Existential crisis

Spiritual and existential problems encountered by the terminally ill can be broadly grouped:

#### ● relating to the past

- value and meaning of a person's life
- worth of relationships
- value of previous achievements
- painful memories or shame
- guilt about failures, unfulfilled aspirations

- **relating to the present**

- disruption of personal integrity
- physical, psychological and social changes
- increased dependency
- meaning of a person's life
- meaning of suffering

- **relating to the future**

- impending separation
- hopelessness
- meaninglessness
- concerns about death

- **relating to religion**

- strength of their faith
- whether they have lived according to, and not disgraced, their faith
- existence of after-life

## **Management**

- Patients will vary in their desire to pursue issues relating to existential or spiritual distress
- Existential or spiritual support is person-centered and needs to begin with the patient's insight
- Existential support may just need the supportive presence of another; however refer patient to minister of religion or pastoral counsellor as appropriate.

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