# Fokus

*Fokus* is ’n rubriek waarin artikels van ’n meer populêr-wetenskaplike aard gepubliseer word. Artikels wat vir hierdie rubriek aan die redaksie voorgelê word, moet voldoen aan dieselfde tegniese vereistes as navorsingsartikels (kyk asseblief die *Voorskrifte vir skrywers*). Bydraes vir *Fokus* word aan ’n interne keuringsproses onderwerp en kwalifiseer nie vir subsidie nie.

## Inhoudsopgawe

# Care for a terminally ill person: A guide for pastors

H. Powell[1]
School of Basic Sciences
Vaal Triangle Campus
North-West University
VANDERBIJLPARK
E-mail: hedriP@oncology-sa.co.za

Abstract:

Care for a terminally ill person: A guide for pastors

*Everybody is faced with unique challenges and experiences during his/her life cycle. Some experiences are sudden and untimely, whereas others are expected. Terminal illness remains an unpleasant experience of an emotional, psychological, social and spiritual nature, whether it was sudden or expected. In order to deal with or care for the terminally ill in an effective way, it is important for professionals such as pastors to understand the terminally ill person's fears, his/her needs and emotional experiences. In this article attention is given to the latter as well as to the specialised skills and techniques that could be implemented to ensure efficient humane and compassionate care for the terminally ill.*

Opsomming:

Sorg aan die terminaal siek persoon: 'n riglyn vir predikante

*In elke mens se lewensiklus word hy gekonfronteer met uitdagings of stresvolle situasies, sommige onverwags en ontydig, terwyl ander meer voorspelbaar is. 'n Terminale siekte is 'n onaangename ervaring wat 'n invloed het op die emosionele, psigologiese, maatskaplike en spirituele dimensies van die betrokke persoon, ongeag of dit verwag is of skielik gebeur het.*

---

[1] Ms. Hedri Powell is a counsellor at the Vaal Triangle Oncology Unit and an *ad hoc*-lecturer at the Vaal Triangle Campus of the North-West University.

*In die Skriflig 38(2) 2004:351-357*

*Om te verseker dat die persoon wat terminaal siek is op 'n effektiewe wyse deur professionele persone soos predikante begelei word, is dit belangrik dat die pasiënt se behoeftes, vrese en emosionele ervarings goed verstaan word. In hierdie artikel word juis aandag gegee aan hierdie aspekte sowel as aan gespesialiseerde vaardighede en tegnieke wat aangewend kan word om professionele en menswaardige hulpverlening vir die terminaal siek persoon te verseker.*

## 1. Introduction

The aim of this article is to make a contribution to the field of pastoral care by reflecting on the findings of recent research regarding terminally ill persons and suggesting how the results of such research can benefit pastors in their care for the terminally ill.

According to Lauria *et al*. (2001:27) distress experienced by a terminally ill person implies

> … an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with the illness. It extends along a continuum, from common normal feelings of vulnerability, sadness, and fear, to problems that are disabling, such as true depression, anxiety, panic and feeling isolated or in a spiritual crisis.

Guidance and support services are of the utmost importance to the terminally ill patient and careful consideration is needed in the management of such a person's care. In this article I shall focus on the following issues in order to arrive at concrete proposals for pastors dealing with terminally ill persons. These issues include the following:

- The factors influencing a person's response to terminal illness;
- the emotional reaction experienced by people suffering from a terminal illness;
- the importance of dealing with the fears such a person might experience;
- an in-depth discussion of the needs and expectations of the terminally ill.

Although this article specifically focuses on persons with cancer, the guidelines listed are applicable to persons affected by any terminal disease.

## 2. Factors that can influence the terminally ill person's psychological response

According to Lauria *et al*. (2001:28) the following are factors that can have an affect on the individual's or the family's psychosocial response and adaptation to terminal illness:

- The type of illness (e.g. stage and prognosis)
- Degree of disability and treatment
- Intensity of treatment
- Person's age and life stage
- Person's past experience
- Current situations
- Each person's unique emotional make up
- Degree of social support and caregiver availability
- Existing coping meganisms or their way of coping with stressful situations

Research findings generally indicate that the period of about a year following upon diagnosis and treatment represents a crisis in patients' lives. It is clear, however, that some people adapt better than others do. Many kinds of differences among people are relevant to adapting successfully to having a terminal illness. Most of us think first of differences originating within the person, but some differences are in fact contextual. Spencer *et al*. (1998:213-215) therefore mentions both social support and personality in this regard.

According to Holland and Gooen-Piels (1998:945) it is important to recognise factors that predict good or poor adjustment, enabling early identification of particularly vulnerable individuals. Factors they consider worth recognising, derive from three areas namely *society-derived* factors which are the social attitudes and beliefs about terminal illness that impact on the patient; *patient-derived* factors; and *illness-derived* factors, which represent the clinical reality of the illness to which the patient must adapt.

## 3. Emotional reaction to terminal illness

Kübler-Ross (1997) delineated the emotional reactions and con-summately, these reactions are typical of a broader coping style, involving particular behavioural strategies.

People usually react to life events from one of two perspectives: the victim – giving rise to passive and/or *reactive coping styles*; or from the point of view that they are responsible for whatever happens in their lives, which is exhibited in *proactive coping styles*.

People with either a passive or reactive coping style, usually look towards others in planning behavioural strategies. Typically, the passive person exhibits denial, isolation, depression and a passive acceptance or surrender. Reactive people are more emotionally exhibiting and intense. They may hold on to denial for longer, as a reaction rather than a natural initial response to the diagnosis. They may isolate themselves, but more often they seek out others, second opinions, fears and foes, and drag them into the crisis as rescuers. Their anger is usually fiercer, as it is their way of bargaining. These people put up a brave face and label depression as "negative thinking" and will avoid it at all costs. Acceptance is very difficult for them to attain, as they will not resign as the passive person will do, but they may not come to acceptance unless they are cured. They often need time and assistance in working towards emotional well-being.

A person with a proactive coping style will experience the initial avoidance, but usually for a short period of time. This kind of person tackles the crisis, will actively seek fresh ideas and deploy new coping skills. Hence a proactive person usually is open for alternative and complementary intervention, including psychotherapy and counselling, changing his/her life styles and proactively seeking a sense of control and meaning. Once a proactive person attain acceptance, it is usually more authentic and realistic.

## 4. Specific feelings associated with cancer

In this section the five stages Kübler-Ross (1997) identified in coping with terminal illness are discussed:

### 4.1 Denial and isolation

This stage is associated with a numb feeling of shock and an inability to discuss the diagnosis or problem e.g. in the response: "No – it can't be true". The phase of denial allows people time to compose themselves and to activate their defence meganisms. It therefore functions as a buffer.

Patterson as quoted in Rosser (1994:13) identifies different levels of denial. Existential denial is a healthy disregard of our own mortality that allows us to get on with life; psychological denial is the unconscious repression of information, while non-attention denial occurs when we direct our attentions elsewhere, rendering us momentarily unaware of the stressful issue.

Denial can be seen as a way of anaesthetising the pain until the patient or family is ready to deal with it. Prolonged denial can become counterproductive for some patients, blocking communication, eventually increasing stress and impeding other defence mechanisms. The resultant breakdown in defence mechanisms is likely to manifest itself through signs of severe anxiety, sleep disturbance and altered appearance and personality.

### 4.2 Anger

Rage, anger and resentment may replace denial. A typical response may be: “Why me?” This is a stage that is difficult to deal with because anger is usually displaced in all directions and projected onto the environment. The family may react by feeling very guilty. Furthermore, it is characterised by feelings of frustration, anxiety, fear, helplessness, hopelessness, loss of confidence and a decrease in resistance to external stimuli such as noise, change, procedures, etc.

### 4.3 Bargaining

This stage is associated with a child-like reaction – the possibility is entertained of reward for good behaviour. An agreement is entered into with God to postpone the inevitable. It also includes an implicit promise of no further requests if this one is granted. It is therefore often a process of negotiation between the dying person and his or her spiritual beliefs, and is not actually put into words. Psychologically speaking, promises may be associated with quiet guilt, which could be explored and alleviated. It is unfortunately often detrimental to the quality of the person’s remaining part of life.

### 4.4 Depression

When there can no longer be denial and bargaining seems to be of no avail, depression may occur. It is a natural reaction to a sense of loss. The first kind of depression is reactive, the second preparatory. They are different in nature and must be dealt with differently. Reactive depression is characterised by the assessment of past losses and their meaning, verbal and physical “viewing” of loss, active verbalisation of loss, the seeking of interventive assistance, and a preoccupation with loss. Preparatory depression is a quiet, non-verbal sadness where the person seemingly is not aware of others and an expression of sorrow in attitude is noticeable.

### 4.5 Acceptance

Given enough time, a person, with help, will work through the previous stages, and having mourned his/her loss, can reach quiet expectation. He/She will be tired and probably weak. The person who has reached acceptance is not resigned or hopeless nor is he/she happy. The person is able to focus upon future life goals and realistic progress and plans.

### 4.6 Summary

Kübler-Ross's conceptual framework for understanding the process of dying and our established ways of dealing with death is not intended to be taken rigidly. The stages give us a useful guideline for identifying problems and improving communications between dying people, their families and professional caregivers. It cannot be assumed that everyone needs to negotiate these stages in order to cope effectively with impending death.

## 5. Fears associated with terminal illness

In this section a number of fears related to terminal illness are discussed. Although these fears may differ according to the specific focus of the article, a definable pattern does emerge.

### 5.1 General fears related to hospitalisation

Strain and Grossman as quoted in Muskin (1998:621-622) outline seven broad categories of psychological stress, which affect the patient who is hospitalised due to illness. These categories are:

- The basic threat to narcissistic integrity
- Fear of strangers
- Separation anxiety
- Fear of loss of love and approval
- Fear of loss of control of developmentally achieved functions
- Fear of loss of or injury to body parts
- Reactivation of feelings of guilt and shame with accompanying fears of retaliation for previous transgressions

## 5.2 Fears related to death and dying

According to The National Cancer Association of South Africa (s.a.:50-52) the fears of death and dying includes fears related to the following:

- Process of dying
- The effect on the body
- Family and survivors
- Loss of this life and this future
- Unfinished business
- Feelings of guilt
- Afterlife
- General fears related to previous experiences

Kirkpatrick (1990) associates the following fears specifically with patients dying of Aids (cf. also Pervan *et al*. [1995:705] and Lauria *et al*. [2001:40-41]):

- Fear of physical pain
- Fear of rejection by partner, family, friends, society and God
- Fear of being disabled, disfigured
- Fear of losing control of mind, emotions and life
- Pain of being part of a minority viewed with suspicion
- Fear of exposure

## 5.3 The impact of fear on a person's physical well-being

A sufficient amount of social support available to the dying person alleviates many of the fears of the terminally ill patient. Reliance upon spiritual beliefs and rituals can provide great comfort and peace. Opportunities for life review with loved ones and staff brings closure and satisfaction for many.

As described by Evans and Hucklebridge (2000), the thoughts and feelings associated with the emotion of fear have powerful effects on immune system functioning. Fear – particularly chronic fear – results in dramatic immune suppression. Sieber *et al.* (1992:141-156) states that the impact of fear on the immune system should not be under-estimated, neither for its direct effects (i.e. cortisol or adrenaline effects), nor for its indirect effects (i.e. helplessness, giving up, hopelessness, apathy, depression, and many other consequences).

When a person is afraid, he/she can either "flee", try to ignore the fear, or face the fear head on. Depending on a person's general coping style, fear either reinforces his/her feelings of helplessness, or it drives him/her further to control or to reach the goal of "must succeed". A great deal of distress experienced in general can be explained in terms of fear.

Weidenfeld *et al*. (1990:1082-1094) conducted a study on the effects of confronting fears on the immune system. The results were astounding and important: there was an increase in the immunity / biological resistance after the intervention, and an average decrease of 30% in cortisol levels. Cortisol is a substance secreted in the human body that can be associated with increased feelings of helplessness and depression. The results were maintained for months after the intervention.

Some people think facing fear is diametrically opposed to "being positive". Nothing could be further from the truth. If one holds the belief that thinking can influence physical reality, then one cannot merely focus on the positive effects of positive thoughts. Fears are highly energised negative mental images, which are generated 24 hours a day, unlike the occasional "positive affirmations", which is often a very poorly energised thought.

The possibility of death is the one thing therapists, friends and family avoid discussing, and insist that "this will upset them" (which it will), and that this would constitute "negative thinking". Yet it may be the very effects of this chronic fear, which destroys the remainder of the immune system. Therefore, when faced with a life-threatening illness, the first fear to confront should be death.

Fear can be seen as an unanswered question which pervades thinking processes, with images, sounds and feelings produced as a result. The obvious solution in dealing with the fear would therefore be to answer the question. If a person can deal with the worst that can happen, then they are not only prepared for it, but they may be able to avoid it turning out as badly as they imagined.

# 6. The needs and expectations of the terminally ill person

## 6.1 Dimensions of needs and expectations

Young (1999) distinguishes between four dimensions of the patient's needs:

- Physical needs e.g. symptom control
- Psychological needs such as safety, understanding and self-esteem.
- Social needs. These include acceptance, a feeling of belonging, and the opportunity for disengagement.
- Spiritual needs e.g. love, reconciliation, self-worth and a sense of purpose.

## 6.2 Maslow's needs hierarchy

In view of the above-mentioned dimensions, it is obvious how they fit into the needs hierarchy of Abraham Maslow, whose classification of basic human needs has been the most familiar description since 1957. In Jordaan and Jordaan (1998:607-608) these needs are classified according to priority, as the following:

- Physiological needs (hunger, thirst and reproduction)
- Security needs (safety and stability)
- Need for love (acceptance and affiliation)
- Belonging and self-worth (acknowledgement)
- Cognitive needs (knowledge and understanding)
- Esthetic needs (beauty and order)
- Self-actualisation (developing and fulfilling of potential)

In the case of a terminally ill person, it is important not to only focus on their primary needs of care, which is more visible and obvious. It is also important to focus on the higher levels of needs, as they can in the terminal stage of life, be seen as just as important as the needs on lower levels and sometimes for some people even more important. Care should be taken as to what the person view as important at a specific time.

### 6.3 The dying person's rights

According to McKenna (1991:546) individualisation cannot be overemphasised. Some concepts that should be stressed are that individuals should be treated individually, with the right to accept or refuse offered treatment; they may choose to discuss their cancer with others, or may refuse to do so if they prefer; they should remain free of the stigma of cancer and its implications and they should be accepted for what they are and what they were before the diagnosis.

### 6.4 Power and control

In a study done on 119 cancer patients, it was reported that 60% claimed that it was important to have a strong sense of power and control as they battled their disease. The attempt to gain power and control often involved looking for meaning in the experience of illness, learning to communicate effectively with health care professionals, participating in informed decision-making, exploring alternative approaches to dealing with illness, dealing with unresolved personal and family issues and planning for death when that becomes a reality (cf. Vachon, 1985:33-40).

The struggle of patients to gain some type of control may lead them into conflict with health care providers and others assisting them who may have their own need to maintain power and control in the clinical situation. Those who come into a potentially stressful situation with a need for power and control have increased motivation to deal with the problem and experience and express more anger and assertiveness when their efforts are thwarted. If such people are unable to have power when they expect it, then they may develop a decreased motivation to fight the disease or to comply with treatments. The person may then become more passive and depressed.

A significant issue in power and control is that of decision-making. Writing on the issue of informed decision-making, Coulton (1990) found that the individual needs to know that a decision must be made. He or she should be actively involved in looking at and considering the consequences of the alternatives and must weigh and make the decision based on the alternatives and consequences. Participation in decision-making can be impeded by a sense of hopelessness, a lack of available information, the feeling that one does not have the ability to choose, the lack of problem-solving skills and family- and inter-personal conflict. Signs of avoiding decision-making include denial, procrastination, rushing to the most obvious alternative and letting others make the decision.

The exploring of alternatives, sufficient information, stress management, problem solving, dealing with unfinished business, symptom control, discussing the manner of death and planning for the future of those who will survive, can help the terminally ill person to maintain some sense of power and control even until the time of death (cf. Vachon, 1985:33-40).

### 6.5 Support

It is not uncommon for patients with serious illness and their families to feel isolated even from close friends and family members. Emotional bonds and a sense of support and being cared for and loved by a community of family, friends and professionals are of the utmost importance. This might be the most powerful psychosocial factor in health and illness. It is one's support network that has the greatest influence on health risk behaviour and this upholds the idea of and lends importance to the professional caregiver's partnership with patients and family members.

### 6.6 Hope

In health care, hope as a concept has almost always been seen as hope for a good recovery. This is what health professionals are taught in their training, and certainly it is the usual hope of many patients prior to understanding their disease and its prognosis. This rather narrow view overlooks the concept of hope in the short term. If a patient is ready to understand that his/her life expectancy is much shorter than he/she thought, then he/she can be encouraged to look and plan ahead to the time that he/she have. This will mean looking at achievable goals. Many patients who set short-term goals often reach them with a little bit of time to spare, sometimes in spite of a more pessimistic medical opinion. It is very important to understand that a patient is not neutral over his/her disease but has ideas and feelings that are often reasonably accurate (Faulkner & Regnard, 1994:246).

Beliefs have a significant influence on the way in which people can maintain hope during an illness experience. Hope is not the same as desires and expectations and is not exclusive to the wish for a cure; thus, patients and their families can explore the possibility of maintaining hope for a broad range of physical, emotional and relational outcomes. The dominant medical system may not address the idea of hope and optimism in the illness experience; yet caregivers can gain some understanding of the existence of hope by asking family members their beliefs about a future coping with the illness. Patients and their families generally feel discouraged during the early phases of an illness and find it difficult to maintain hope. Yet, they also look eagerly for positive stories from those who experienced a similar condition. After the illness has stabilised to a greater extent, patients and families are often reassured and become more hopeful (Shell & Kirsch, 2001:952).

In view of the above it seems as if hope is a goal-directed vision that enables one to live effectively in the present and more confidently towards the future. Hope affirms a worthwhile future in spite of present circumstances.

## 6.7 Need to preserving self-esteem

A person has many fears but in particular he fears a loss of self-esteem – that his integrity as a human being and his sense of personal dignity will be violated, and that his independence and control will be lost.

Many people cling to a desire to do things in the way they choose and to maintain their life-style unchanged for as long as possible. They experience an increased sense of control when they are still able to prioritise their lives and activities (Shell & Kirsch, 2001:952). It is therefore important to ascertain why a person behaves as he/she does, rather than take offence and condemn him/her as difficult. According to Hepworth and Larsen (1986:17) people in every phase of the situation, require attention, listening and respect. Dying with dignity may also imply that patients are not ignored, not excluded from conversations and while they are able to express it, their wishes will always be taken into account.

## 6.8 Spirituality

Of specific importance to pastoral counsellors is the issue of spirituality. Since spirituality and religion can be reflected on in a range of ways, it is important to distinguish between religion and spirituality. Religion, as the term typically used, refer to beliefs and practices associated with organised groups such as churches. Spirituality, on the other hand, is a broader term that includes religion, but goes far beyond that. Spirituality is defined in terms of personal views and behavioural patterns that express a sense of relatedness to a transcendent dimension or to something greater than the self. Spirituality refers to a more personal search for meaning and purpose in life (Fitchett & Handzo, 1998:790).

In an influential study of religion and health among the elderly, Idler as quoted by Musick *et al*. (1998:781) proposes four ways in which religion might influence health in general:

- Religious groups may encourage their members to refrain from certain activities that might adversely affect health.
- Active participation in a religious group could provide certain types of instrumental and cognitive support that are beneficial to the individual.
- A religious belief system may provide the individual with meaning in life and better enable him/her to cope with painful circumstances.
- Certain religious worldviews may actually influence the ways in which individuals perceive and handle problems.

Studies concerned with spiritual well-being, spiritual coping strategies, and the relationship of spiritual well-being and hope, indicate that an awareness of spirituality should be fundamental to the study of psychosocial distress related to any life-threatening or terminal illness. An essential principle for meaningful intervention is the fundamental perspective that as human beings we are far more than either the sum of our biologic parts or the influence of our environment. Acknowledgment of the spiritual aspect of a person, propel us towards greater wholeness and integration. Terminally ill patients often approach illness, dying, and death from a fearful and reactive stance. People can be helped to accept their own mortality within a framework that normalises death and explore what life and death mean to them. As they begin this exploration, traditional values and spiritual belief systems are questioned and challenged. A redefinition of one’s attitude towards death may be necessary to formulate a personal death perspective that serves as a comfort, rather than as a threat. If a patient is unable to find a comforting death perspective, or if the level of spiritual orientation is inadequate, the patient may experience significant psychosocial distress (Zabora *et al*., 2000:2263).

Zabora *et al*. (2000:2263-2264) also found higher levels of spirituality to be associated with an increase in the patient’s ability to normalise death. As a result, patients experienced lower levels of psychosocial distress. In this study of 116 adult medical oncology outpatients, a significant negative relationship was found between the interaction of spiritual well-being and spiritual distress. Patients accrue spiritual perspectives over their life span and as a result, they can maintain a sense of well-being in the face of perceptual losses associated with a life-threatening illness and death. They also propose a model of intervention in the transpersonal realm to facilitate and normalise death, and to heighten spiritual awareness.

Speck (1998:803-816) strongly states that competent practice of terminal care includes exploration of the patient's spiritual concerns and Hay (1989:25-31) developed a systematic approach by suggesting that caregivers explore

- spiritual suffering (interpersonal and/or intra-psychic anguish of unspecified origin);
- inner-resource deficiency (diminished spiritual capacity); belief-system problems (lack of conscious awareness of a personal meaning system), and
- religious requests specifically expressed by dying patients.

In view of the above it is clear that spiritual assessment and intervention are important elements in the complete care of any dying person. All caregivers and healthcare professionals must be prepared to get involved in helping the person meet his/her spiritual needs to ensure a holistic treatment plan.

## 6.9 Quality of life for the terminally ill person

The Constitution of World Health Organisation (1997:4) uses six broad domains to measure a person's quality of life. These domains are the physical aspects, psychological aspects, the person's level of independence, social relationships, the environment and spirituality/religion/personal beliefs.

According to Mitchell (2001:247) quality of life is an abstract idea, not bound by time or place; it is situational and encompasses many overlapping concepts. Mitchell also classifies quality of life in four domains, namely functional well-being, physical well-being, emotional well-being and social well-being.

Calman (1984) as quoted in Mitchell (2001:247) suggests that "quality of life" measures the difference, at a particular moment in time, between the hopes and expectations of an individual and that individual's present experiences. Therefore expectations regarding quality of life will differ according to their position in life in the context of their culture and value systems and in relation to their goals, expectations, standards and concerns.

Researchers at the University of Texas MD Anderson Cancer Centre and the University of Texas School of Public Health devised a questionnaire for patients with less than six months to live. They began by asking 74 patients to identify their main concerns. These issues were then ranked according to importance by a second group of 120 patients. In view of the findings of this particular study, Greisinger *et al*. (1997:3) reported that patients’ spiritual, existential, familial and emotional needs should be considered along with their physical needs.

McMillan (1996) assessed various instruments for the measuring of quality of life and all included physical, functional and symptom control as well as psychological and social aspects. According to her findings financial and spiritual aspects were, included less often and she suggested further development and refinement of instruments specifically for the terminally ill.

## 7. Considerations when dealing with the terminally ill person

The aim of respecting the values of a person, ensuring better communication, educating and guiding the terminally ill person towards regaining control and the inclusion of the family and significant others in the process, will ensure that problems experienced during the helping process can be limited or even eliminated. Discussion of these aspects are therefore of importance.

### 7.1 Values

When dealing with people it is important to remember the basic values in professional service rendering. Hepworth and Larsen (1986:17) highlight the following:

- To acknowledge every person’s uniqueness;
- to maintain a professional relationship with the person at all times;
- to acknowledge their right to self-determination;
- to take in consideration the person’s rights, preferences and goals when structuring services, even in their absence;
- helping the person to strive towards his/her maximum potential;
- to maintain confidentiality at all times.

## 7.2 Communication and communication skills

“Social interaction is a term for the dynamic interplay of forces in which contact between persons results in a modification of the behaviour and attitudes of the participants” (Toseland & Rivaz, 1984:57). Verbal and nonverbal communications are the components of social interaction. Communication is the process by which people use symbols to convey meanings to one another. Communication entails the encoding of a person’s perceptions, thoughts, and feelings into language and other symbols, the transmission of these symbols or language, and the decoding of the transmission by another person.

### 7.2.1 Nonverbal communication

According to Hepworth and Larsen (1986:83) nonverbal behavioural patterns strongly influence interaction among people. Examples of nonverbal actions are facial expressions, posture, voice and physical proximity.

It is also important to be aware that different cultural groups ascribe varied meanings to certain forms of nonverbal behaviour. Failures to understand the differences can result in misinterpretations of nonverbal cues.

### 7.2.2 Verbal communication

According to Hepworth and Larsen (1986:86-95) the following skills are deemed effective in communication:

- Respecting the values of a person
- Attentive/Active listening (verbal and nonverbal)
- Expressing empathy
- Acknowledgment of needs, feelings and expectations
- Reassurance
- Rephrasing to clarify, with the purpose of communicating understanding and prevent incorrect assumptions
- Focusing on aspects with specific importance to the person’s situation
- Exploring all areas of functioning
- Open-ended questions

### 7.2.3 Communication in advanced illness / terminal stage

Kinghorn (2001:167-180) pays special attention to communication in advanced illness and states that inadequate communication may be the source of much distress for patients and their families and mitigate against the adjustment to life-threatening illnesses. Effective and sensitive communication is the heart of comforting, assessment of need, expression of psychological/social spiritual distress, as well as of planning for what may be perceived to be an undesirable and premature end of life.

Enhancing our capacity to support patients with advanced illnesses is dependent on the development of appropriate skills and the possession of a specific attitude in order to help patients make sense of the past and come to terms with the present and future. Some of the challenges in communicating with the terminally ill are discussed below.

#### 7.2.3.1 Breaking bad news

The sharing of bad news cannot be dependent on intuition, but requires careful assessment, interpersonal competence, sensitivity and a capacity for handling a wide range of distressing emotions. Buckman (1992) as quoted by Kinghorn (2001:169) suggests the following steps: getting started, finding out how much the patient knows, sharing the information, responding to the patient’s feelings, answering questions and planning and follow through.

#### 7.2.3.2 The truth/collusion

Collusions are defined as protecting another from bad news. Kinghorn (2001:172) indicates that most patients would like to know the truth about their condition and there is little evidence to suggest that sharing a diagnosis will be psychologically damaging to a patient. Anxiety is a common emotion following the sharing of bad news, but can be successfully managed.

#### 7.2.3.3 Handling awkward questions

In this scenario it is important to acknowledge that the question is important, thus to use open questions to help facilitate the ventilation of feelings, to listen intently throughout, to summarise what has been said, to clarify the nature of the problem and to decide on the appropriate response.

#### 7.2.3.4 Maintaining communication

Families generally do not talk with one another about their illness concerns, yet when family members are able to discuss their needs and desires they generally do better in managing the illness experience. The fear of the unknown can render patient and family unsure of how to speak about what they are feeling. Open-ended questions should enhance open communication, and have the potential to invite an honest sharing of feelings, to strengthen a family's sense of connectedness, and provide emotional support.

## 7.3 Taking back control

Victor Frankl (1969) was an inmate in a concentration camp during the second World War, living with daily deprivation, suffering and death. He argued that everything could be taken from a man but one thing – to choose his own way of dealing with the problem. He used imagery and emphasised the importance of finding meaning in the suffering. He therefore concluded that a person's strength might raise him/her above his/her outward fate.

These assumptions lead to the development of Logo therapy. When using this approach the person's determining and conforming attitudes are investigated until they reach a sense of spiritual freedom. They are also motivated to take on the risks in life and to seek until they find meaning in all situations. They are made aware of something meaningful in their world their transcending abilities and to accept responsibility. Techniques used in Logo therapy are the following:

- Paradoxal intention, where the therapist encourages the patient to intend or wish for precisely what they fear.
- Dereflection where the therapist diverts the patients away from their problems towards something meaningful in their world.
- Orientation towards meaning. Meaning is developed in the past, present and future, and creatively, experientially and attitudinally.

Applied to the circumstances of the terminally ill patient this entails the following:

- He/she has choices in attitude toward cancer and treatment and can choose to be a survivor and not a victim.
- To fight against learned helplessness. Learned helplessness is a theory developed by Martin Seligman which had a major influence on psychological research into depression in the

1970's. Seligman discovered the phenomenon of helplessness by accident whilst studying the effects of inescapable shock on active avoidance learning in dogs. The theory of learned helplessness was then extended to human behaviour, providing a model for explaining depression, a state characterised by a lack of affect and feeling. People suffering from depression apparently have learned that they have no control. This theory emphasises the importance of gaining control after being diagnosed with a life-threatening disease. Seligman (1990:319) suggests that one can overcome depression by learning new explanatory styles.

- During the terminal stage of the disease the therapist can therefore activate a patient in a realistic, goal-directed way to move toward adaptive coping and assign therapeutic tasks mutually determined by the therapist and the patient.

Van Zyl (2002) suggests the use of the "Self-care" model where optimism and recognition of emotions are the two central issues. According to this model, a person has in all difficult or negative situations a choice of how to deal with the situation. He quotes various studies that have proved that a positive attitude without denying feelings, promotes emotional well-being. This statement is also strongly supported by the science of Psycho-Neuro-Immunology (cf. Evans & Hucklebridge, 2000).

### 7.3.1 Skills and techniques used to assist persons in gaining control/coping with terminal illness

#### 7.3.1.1 Positive thinking

Positive thinking or cognitive restructuring involves the changing of a negative thought pattern into a constructive and positive one. In doing so negative thoughts are challenged and the person is motivated to focus on the advantages of e.g. the treatment, rather than the negative effects thereof (Hepworth & Larsen, 1986).

#### 7.3.1.2 Stress management

Terminally ill patients and their families or caretakers must cope with both physical and emotional stresses. These may result in anxiety, anger, depression, insomnia, fear and a sense of helplessness as mentioned above. Relaxation exercises and imagery offer patients and their families a new way of coping. Communicating fear, relaxation and imagery provide a useful vehicle to become comforted, to get in touch with the inner life, specifically the inner strength and inner wisdom that every living human being possesses

(Billings, 1985:208). For Christian believers this will include prayer and meditation on the Bible.

#### 7.3.1.3 Acknowledge and develop insight in the process of grief and loss

The knowledge and understanding of the process of loss are important matters when dealing with the terminally ill person and his/her family. This process and the implications thereof have been thoroughly investigated by Kübler Ross (1997). This process has already been discussed under the specific feelings associated with a terminal disease.

#### 7.3.1.4 Gathering sufficient information about the illness and treatment

According to Shell and Kirsch (2001:962) knowledge is power, and for the patient and family this knowledge can promote the feeling of increased control and independence, especially for the patient. It is the responsibility of the professional to clarify patients' concerns and articulate their fears and needs.

#### 7.3.1.5 Goal setting

In order still to find meaning in their lives and in suffering, it is important to assist terminally ill persons to continue to set goals. These goals should be specific, measurable, attainable, realistic and time-set. Attainable goals relieve stress, create hope and give meaning to their daily lives (Hepworth & Larsen, 1986).

### 7.3.2 Dealing with anxiety and depression

#### 7.3.2.1 Anxiety

For most patients a terminal illness is an emotionally stressful, even traumatic event. Anxiety is a normal reaction when experiencing physical and emotional discomfort. Some patients show an exaggerated response with symptoms that overwhelm them and impair their functioning. Treatment of anxiety includes pharmacological and psychological intervention. The latter include behavioural training, educational interventions and group interventions (Noyes *et al*., 1998:557-558).

### 7.3.2.2 Depression

Billings (1985:208-210) outlines the differences among the types of depression. The kind of depression experienced by the majority of terminally ill patients is reactive depression. Usually this kind of depression lasts up to several weeks and remits spontaneously, although patients are often helped by the opportunity to talk about their distress with a professional or non-professional caretaker.

A major depression is characterised by dysphoria, poor functioning, feelings of worthlessness, hopelessness, helplessness, a pre-occupation with guilt, poor concentration, attention deficit, sleep disturbance, agitation, weight loss and recurrent wishes to be dead. Without treatment such depression may last for months and is associated with an increased risk of suicide. The presence of major depression demands active therapeutic intervention with psycho-therapy and/or medication.

When a patient has a depressive personality or experiences dysthymic disorder, he/she generally has a history of recurrent prolonged depressive episodes or a sustained depressive style throughout life. These patients tend to be pessimistic, negativistic, critical, and unsatisfied. This type does not respond satisfactorily to short-term psychotherapeutic or pharmacological treatment.

The assessment of depression is difficult in terminally ill patients because of the presence of chronic pain, organic brain syndromes, anger, social withdrawal, weight loss, fatigue and normal feelings of sadness.

## 7.4 End-of-life decisions

Ideally, end-of-life decisions are made early in the process. Although these issues are not pleasant or easy to think about, they are often part of an individual’s philosophical, moral, religious, and spiritual make-up. Because of the sensitive nature of these decisions, patients do not want to worry their families; families are afraid that should they initiate discussion about the topic, they will upset the patient. Often though, when the time for end-of-life decisions has come, patients are not able to make decisions, the issues remain unresolved, and these decisions are made by people who may not know the patient’s wishes (Glaser & Strauss, 1968).

### 7.5 The family of the terminally ill person

According to Billings (1985:211) the family's response to terminal illness is important in itself as an indicator of personal distress and as a predictor of the response to bereavement, and is also a mediator to the patient's adaptation. Billings identifies renegotiation of roles, maintaining stability, restitution and mending, anticipatory grieving and approaching the moment of death as tasks confronting the family of a terminally ill person.

Lederberg (1998:981-990) describes the family as a provider of complete patient care. These roles include the provision of emotional support and containment, informational needs and shared responsibility for decision-making, concrete care-giving, the meeting of financial and social costs, the maintaining of stability and adapting to change. He further states that the spouse, the parents, children and siblings should all be included when planning family interventions. Education, improving family communication, the provision of services and the mobilising of social support systems will enable the family to provide the necessary patient care for their loved one.

Attention should also be given to anticipatory grieving sparked by the approaching moment of death. The long process of letting go while also incorporating and retaining parts of the relationship begins when a potentially terminal illness is first diagnosed. Early grief tends to be conditional and is held in abeyance while the patient is doing well. It intrudes itself as a palpable and unavoidable issue when the patient becomes terminally ill. As the terminal illness progresses, family members may more fully acknowledge or experience the feelings associated with loss. A sense of sadness and heaviness develops. As the end approaches, the family members may immerse themselves in clinical tasks as a means of reducing the unimaginable. No matter how much the family has prepared themselves, the moment of death comes as a shock. There is also often a sense of relief that the patient is no longer suffering, that the uncertainty has ended, and that it is finally possible to move on to the next phase which is grief (Billings, 1985:212-214).

## 8. In conclusion

Everybody is faced with unique experiences and challenges during his/her life cycle. Some experiences are sudden and untimely, whereas others are expected. Terminal illness will alter the physical and emotional balance, influence finances and the division of responsibility, social activities, as well as the rest of the functioning of a family. The support network of health-care providers, the extended family, friends, neighbours, spiritual counsellors, employers, and available community resources will contribute to efficient and complete humane and compassionate care for the terminally ill person.

## List of references

BILLINGS, J.A. 1985. Outpatient management of advanced cancer. Philadelphia: Lippincott.

COULTON, C.J. 1990. Research in patient and family decision making regarding life-sustaining and long-term care. *Social Work Health Care,* 15:63-78.

EVANS, P. & HUCKLEBRIDGE, F. 2000. Mind, immunity and health. The science of Psychoneuroimmunology. London: Free Association.

FAULKNER, A. & REGNARD, C. 1994. Handling difficult questions in palliative care – a flow diagram. *Palliative Medicine,* 8:245-250.

FITCHETT, G. & HANDZO, G. 1998. Spiritual assessment, screening, and intervention. (*In* Holland, J.C. Psycho-Oncology. New York: Oxford University Press. p. 790-808.)

FRANKL, V.E. 1969. Man’s search for meaning: an introduction to Logotherapy. New York: Square.

GLASER, B.G. & STRAUSS, A.L. 1968. Time for dying. Chicago: Aldine.

GREISINGER, A.J., LORIMOR, R.J. & ADAY, L.A. 1997. Terminally ill cancer patients: Their most important concerns. *Cancer Practice*, 5:3.

HAY, M.W. 1989. Principles in building spiritual assessment tools. *American Journal of Hospice and Palliative Care*, 6:25-31.

HEPWORTH, D.H. & LARSEN, J.A. 1986. Direct social work practice – Theory and skills. Chicago, Illinois: Dorsey.

HOLLAND, J.C. & GOOEN-PIELS, J. 1998. Principles of Psycho-Oncology. (*In* Holland, J.C. & Frei, E., *eds*. Cancer medicine. Ontario: Decker. p. 943-958.)

JORDAAN, W. & JORDAAN, J. 1998. Mense in konteks. Johannesburg: Heineman.

KINGHORN, S. 2001. Communication in advanced illness: Challenges and opportunities. (*In* Kinghorn, S. & Gamlin, R. Palliative Nursing: Bringing comfort and hope. Toronto: Tindall. p. 167-181.)

KIRKPATRICK, B. 1990. AIDS – Sharing the pain. Cleveland: Pilgrim Press.

KÜBLER-ROSS, E. 1997. On death and dying. New York: Touchstone.

LAURIA, M.M., CLARK, E.J., HERMANN, J.F. & STEARNS, N.M. 2001. Social work in oncology – supporting survivors, families and caregivers. Atlanta: American Cancer Society.

LEDERBERG, M.S. 1998. The family of the cancer patient. (*In* Holland, J.C. Psycho-Oncology. New York: Oxford University Press. p. 981-993.)

McKENNA, R.J. 1991. Supportive care and rehabilitation of the cancer patient. (*In* Holleb, A.L., Fink, D.J. & Murphy, G.P. Clinical Oncology. Atlanta: American Cancer Society. p. 544-554.)

McMILLAN S.C. 1996. Quality of life assessment in palliative care. http://www.moffitt.usf.edu/pubs/ccj/v3n3/article4.html [2003-06-19].

MITCHELL, A. 2001. Quality of life in palliative care: Patient as expert. (*In* Kinghorn, S. & Gamlin, R. Palliative nursing: Bringing comfort and hope. Toronto: Tindall. p. 245-248.)

MUSICK, M.A., KOENIG, D.B., LARSON, D.B. & MATTHEWS, D. 1998. Religion and spiritual beliefs. (*In* Holland, J.C. Psycho-Oncology. New York: Oxford University Press. p. 780-789.)

MUSKIN, P.R. 1998. Personality disorders. (*In* Holland, J.C. Psycho-Oncology. New York: Oxford University Press. p. 619-629.)

NATIONAL CANCER ASSOCIATION OF SOUTH AFRICA. s.a. Volunteer training manual Southern Transvaal Region. p. 50-52.

NOYES, J.R., HOLT, C.S. & MASSIE, M.J. 1998. Anxiety disorders. (*In* Holland, J.C. Psycho-Oncology. New York: Oxford University Press. p. 548-563.)

PERVAN, V., COHEN, L.H. & JAFTHA, T. 1995. Oncology for health care professionals. Kenwyn: Juta.

ROSSER, M.C. 1994. The problem of denial. *Journal of Cancer Care*, 3:2-17.

SELIGMAN, M.E.P. 1990. Learned optimism. New York : Pocket Books.

SHELL, J.A. & KIRSCH, S. 2001. Psychosocial issues, outcomes and quality of life. (*In* Otto, S.E. Oncology nursing. London: Mosby. p. 948-968.)

SIEBER, W.J., RODIN, J., LARSEN,L., ORTEGA,S. & CUMMINGS, N. 1992. Modulation of human natural killer cell activity by exposure to uncontrollable stress. *Brain Behaviour Immunity,* 61:141-156.

SPECK, P. 1998. Spiritual issues in palliative care. (*In* Doyle, D., Hanks, G.W.C. & McDonald, N., *eds*. Oxford textbook of palliative medicine. New York: Oxford University Press. p. 803-816.)

SPENCER, M.S., CARVER, C.S. & PRICE, A.A. 1998. Psychological and social factors in adaptation. (*In* Holland, J.C. Psycho-Oncology. New York: Oxford University Press. p. 211-222.)

TOSELAND, R.W. & RIVAZ, R.F. 1984. An introduction to group work practice. New York: MacMillan.

VACHON, M.L.S. 1985. Power and control and the person with cancer. (Unpublished paper. Delivered at the meeting of the Clinical Oncological Society of Australia. Sydney.)

VAN ZYL, D. 2002. Self care – Have a heart for you and for others. (Unpublished paper. Delivered at the First South African Oncology Social Work model conference. October, Pretoria.)

WEIDENFELD, S.A., O'LEARY, A., BANDURA, A., BROWN, S., LEVINE, S. & RASKA, K. 1990. Impact of perceived self-efficacy in coping with stressors on components of the immune system. *Journal of Personality and Social Psychology,* 59(5):1082-1094.

WORLD HEALTH ORGANISATION. 1997. WHOQOL – Measuring Quality of live. p. 1-15. web: http://www.who.int/mental_health/media/en/68.pdf [2003-06-19].

YOUNG, C. 1999. Pastoral care of the dying and the bereaved. (Unpublished paper. Delivered at the Hoping is Coping seminar. GVI Oncology, Vereeniging.)

ZABORA, J.R., SMITH, E.D. & LOSCALZO, M.J. 2000. Psychosocial rehabilitation. (*In* Abeloff, M.D., Armitage, J.O., Lichter, A.S., Niederhuber, J.E., *eds*. Clinical oncology. New York: Churchhill-Livingstone. p. 2255-2269.)

**Key concepts:**

pastoral care: guidelines for
pastoral support
terminal illness

**Kernbegrippe:**

pastorale bystand
pastorale sorg: riglyne vir
terminale siekte