The role of the general practitioner in the care of the dying patient and his family..

BY DR STANLEY LEVENSTEIN

ADVANCES IN MEDICINE have resulted not only in people having a longer life-expectancy than was previously the case, but also in patients with chronic, life-threatening, or incurable illness being able to live much longer than would otherwise have been their lot.

In practical terms, this means that terminal care now forms a large part of medical care, and a particularly important part of the general practitioner's work.

However, it must be acknowledged that most doctors, including general practitioners enter their profession inadequately prepared for dealing with this situation, as the medical school training sadly neglects this vitally important area of patient care.

The reason for this neglect may be sought in the nature of the problem itself, i.e. many doctors seem to find death and dying a very threatening subject to think about, and tend to deal with their anxiety by not thinking about it at all.

The result is that they are unable to meet their patients needs at a most critical time in their lives.

This sad state of affairs will only be remedied when death is no longer a taboo subject, and when doctors learn to come to terms with their own anxieties about dying, so that they will be comfortable enough to be able to allow their dying patients to share their feelings with them.

As mentioned earlier the care of the dying is a task which falls squarely within the ambit of the general practitioner's duties.

There are very good reasons why this should be the case.

Firstly, the general practitioner has usually had a relationship with the patient and his family prior to his terminal illness and is therefore particularly well placed to render help.

Secondly, as mentioned earlier, most patients choose to spend the last stages of their life at home (and it has been shown that there are very good psychological reasons why this should be encouraged whenever possible).

Finally, it is the general practitioner who, perhaps more than any other doctor, is imbued with the concept of patient **care** (and not necessarily cure) and he is therefore perhaps best suited by outlook and experience to this area of patient care.

The role of the general practitioner in the care of the dying patient and his family..

Continued

Much has been written in recent years about this important subject. I would like to begin by saying a few words about the physical aspects of terminal care.

As a general rule it may be said that it is the general practitioner's responsibility to alleviate suffering with the minimum of complicated procedures.

The goal is not to prolong life unnecessarily but to enable the patient to die with dignity, and not with a tangle of tubes all around him.

With regard to pain it should be noted that it is only a minority of dying patients, whether they are suffering from malignant disease or not, who actually experience pain.

However, when pain is present it is important to individualise the dosage of opiates needed to keep the patient pain-free without undue sedation to each patient's requirements as there is a wide variation of possible drug dosages needed.

[1]Cicely Saunders points out that judicious use of drugs of the phenothiazine group has a potentiating effect on the opiate analgesics.

It is therefore possible to relieve the patient's pain with lower dose of say morphia than would otherwise be the case, and still enable the patient to remain alert.

With regard to dehydration, Cicely Saunders points out that it is not necessary to set up an I.V. infusion unless the patient complains of thirst.

If the patient does complain of thirst, the general practitioner should re-assess his dosage of opiates, for these drugs do not only relieve the sensation of pain, but that of thirst as well.

It should also be remembered that the sucking of ice cubes can do much to relieve the discomfort of a dry mouth and a concomitant sensation of thirst.

With regard to the psychological management of dying patients, it is this area which seems to present special difficulties to many practitioners.

What do we say to these patients?, they ask, "what do we tell them?" "what do we say when they ask how long they have to live, what do we say when they ask if their disease is incurable, what do we say, what do we say, what do we say?" Perhaps the best answer to these questions is that it is not so important for us to say anything, but far more important for us to listen.

The dying patient has a desperate need to express his feelings, and to communicate them to someone whom he knows will at least try to understand and accept them.

The last thing he needs and wants is for his feelings to be brushed aside with meaningless assurances and such glib remarks as "you'll be allright" or "stop worrying, you'll soon be up and about again".

The general practitioner who has an understanding of the psychological processes which occur in dying patients is at a distinct advantage.

In this regard, [2] Elizabeth Kubler-Ross's book on "Death and Dying" is strongly recommended to all general practitioners.

She describes five psychological stages which occur in dying patients, namely: 1st stage: Denial and Isolation — 2nd stage: Anger — 3rd stage: Bargaining — 4th stage: Depression — and 5th stage: Acceptance.

There is one element common to all these stages and that is **hope,** and it should be borne in mind that while the general practitioner should attempt never to be dishonest with his dying patients he should never deprive them of hope.

I will deal briefly with each of these stages, but before doing so, I would like to point out that not all dying patients go through all these stages, and if they do not necessarily go through them in that order, they may in fact go through more than one stage at a time.

It is the general practitioner's task to try and get in touch with what stage or coping mechanism his patient is at, as each stage is necessary for the patient to work through in order to try and reach the final stage, namely the stage of acceptance.

Having identified the stage the general practitioner should support the patient in the employment of that particular coping mechanism, but not reinforce it too strongly as this may make it more difficult for the patient to move on to the next stage.

1st stage: Denial and Isolation

The patient says "no, not me, it cannot be true". Practically all dying patients manifest denial as an initial response to the awareness of a terminal illness, and some patients never pass beyond this stage.

As mentioned before, the general practitioner should not challenge this reaction by the patient as it is a necessary adaptive response to a highly traumatic stimulus, but at the same time he should not be responsible for entrenching it so strongly, so that it is difficult for the patient to move beyond his denial processes when he would otherwise be ready to do so. This is perhaps the biggest pitfall facing the general practitioner.

When the patient says "its nothing serious, is it?" the general practitioner is best advised to say "what do you feel about it?", or "it sounds as though you're quite worried about it" rather than something like "no, of course its not serious" which effectively silences his patient, and increases his patient's anxiety even if it reduces his own.

2nd stage: Anger

"Why did it have to happen to me?" In contrast to the stage of denial, this stage of anger is very difficult to cope with from the point of view of the family and the general practitioner.

The reason for this is the fact that this anger is displaced in all directions, and projected onto the environment at times almost at random.

The doctors are just no good, they don't know what diet to advise or what treatment to prescribe.

The patient may have an ourburst of anger over an apparently trivial cause, such as the bed not having been made to his satisfaction, or the general practitioner arriving to see him a few minutes later than he intended.

It is most important for the general practitioner to identify this anger, and to recognise that his patient has a need to express his anger and to know that it is being accepted.

When the patient castigates the general practitioner for example for not doing more about his illness, he (the general practitioner) should avoid rushing to his own defence and justifying his treatment, but should say

The role of the general practitioner in the care of the dying patient and his family..

Continued

something like "it seems as though you're very angry — would you like to talk about it?"

It should be remembered that it is actually a frightening experience for a patient to have to express anger towards a person like the general practitioner on whom he is so dependent for support. He needs to know that he can express his anger, including anger at the general practitioner, without fear of rejection or any decrease in the quality of his care.

3rd stage: Bargaining

This often takes the form of imagined bargaining with God "If I promise to be a better person will you give me a little more time?"

4th stage: Depression

The patient develops a sense of great loss. To some extent this may be due to the reality of such problems as loss of job, possibly loss of home (if the expenses of treatment have been great or the patient cannot be treated at home) etc.

However, as Kubler-Ross puts it, we often tend to forget the preparatory grief that the terminally ill patient has to undergo in order to prepare himself for his final separation from this world.

With regard to this latter type of depression, there is little or no need for words. It is much more of a feeling that can be mutually expressed and is often better done with a touch of a hand, a stroking of the hair or just a silent sitting together.

It is a time when too much interference from visitors who try to cheer him up hinders his emotional preparation rather than enhances it.

From what has been said here, it will be apparent that the patient's depression and withdrawal is an adaptive response to his situation, and as such anti-depressant medication is usually inappropriate.

5th stage: Acceptance

This is the stage which may be regarded as the goal for dying patients to achieve.

It should not be mistaken for a happy stage. It is almost void of feelings.

It is as if the pain had gone, the struggle is over, and there comes a time for "the final rest before the long journey" as Kubler-Ross quotes one patient as putting it.

This is also the time during which the family usually needs more help, understanding and support than the patient himself.

While the dying patient has found some peace and acceptance, his circle of interest diminishes. He wishes to be left alone or at least not stirred up by news and problems of the outside world.

Visitors are often not desired, and if they come, the patient is no longer in a talkative mood.

He often requests limitations on the number of people and prefers short visits.

The general practitioner's role is to sit quietly with the patient and hold his hand. As Kubler-Ross puts it "we may just let him know that it is all right to say nothing.

It may reassure him that he is not left alone when he is no longer talking and a pressure of the hand, a look, a leaning back in the pillows, may say more than many "noisy words".

A few words about the family of the dying patient. As Cecily Saunders put it recently, for the family of the dying patient they are losing what she called "part of their assumptive world", and it may be said that as a patient dies part of his family dies as well.

It is important for the general practitioner to remember that not only does the dying patient pass through the stages of denial, anger and bargaining, depression and acceptance but the members of the family do as well, and it is just as important for the general practitioner to help them through these stages as it is for him to help the patient.

His task may be complicated by the fact that different family members may not be experiencing the same stages as the dying patient or the same stages as other family members.

For example, one family member may be angry while another family member may still be denying the magnitude of the dying patient's illness — the patient himself may be going through the stage of depression.

The general practitioner's role is to help **all** family members through these stages.

He can achieve this best by encouraging open discussion of feelings with them whenever possible, then helping to prepare them to grieve the impending loss of their loved one.

It may be said, that part of the general practitioner's task in caring for the family of the dying patient is to try to prepare them for bereavement.

He (the GP) should look out for the family-member "at risk" for eg. the family-member with "a stiff upper lip" is the one most likely to cope badly with the bereavement situation.

At the time of bereavement the general practitioner should try to present the family with the opportunity to mourn their loss and to speak about their feelings of loss.

In an excellent book entitled[3] "Bereavement", Colin Murray Parkes gives a most valuable analysis of the grief reaction.

Time does not permit a discussion of its contents, but he gives a most informative description of such reactions as "alarm", "searching and pining", "anger and guilt", and finally "gaining a new identity". I recommend the book strongly to all general practitioners.

In conclusion, I hope it will be clear that general practitioners have a vitally important role to play in the care of dying patients and their families.

I have no doubt that if the necessary attention is given to this area of patient care, general pactitioners can make an ever increasing contribution towards making this period of his patient's life a highly meaningful and worthwhile experience.

Speaking for myself, I freely acknowledge that the care of dying patients and their families has been one of the most emotionally stressful experiences of my career as a general practitioner.

At the same time, I have no hesitation in adding that it has also been one of the most rewarding and personally growth enhancing experiences I have had the privilege to have.

References

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ABOUT THE AUTHOR

Dr Stanley Levenstein qualified at Pretoria in 1970 and has been in active general practice since 1972, acquiring the MFGP (SA) in 1974. He is secretary of the Cape Region of the Faculty of General Practice and Chairman of the Human Behaviour Sub-committee.

He has been actively involved in under- and post-graduate education for several years, and has taken special interest in the psychological aspects of general practice.

He was one of the founders of the original Balint Group in Cape Town and was elected founder President of the South African Balint Society in July 1979.

He has authored numerous publications, one of which, entitled "Anxiety and the General Practitioner — a Psychotherapeutic approach" was awarded the Louis Leipoldt Memorial Medal in 1977 for the best article by a general practitioner in the South African Medical Journal.

He has presented numerous papers at national and international congresses, the accompanying one (The Role of the GP in the Care of the Dying Patient and the Family) having been presented at the South African Medical Association Congress in Durban in July 1979.