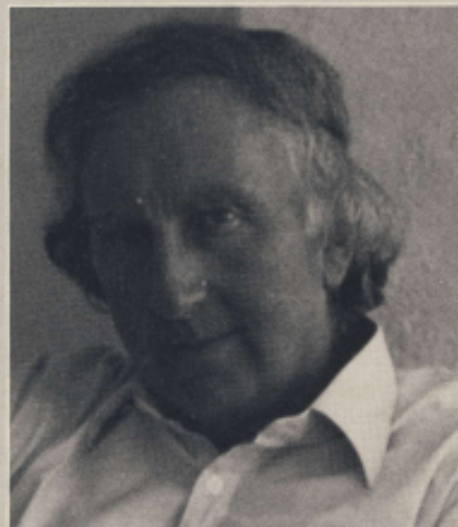


Talking with terminally ill patients and their families — a personal growth experience

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Curriculum Vitae

- MBChB(UCT) 1954
- Internship — Greys Hospital
- General Practice in Sea Point since 1959
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SUMMARY

The author has adapted the traditional model of caring for the terminally ill and dying, to the needs of general practice. The significance of the psychological stages of the dying patient is stressed, and should direct the doctor to respond appropriately, and also help the family to do the same.

Hope should always be given, and genuine support is therapeutic. The role of the family is discussed.

KEYWORDS: Death & Dying;
Doctor — Patient
Relations;
Terminally Ill Patients;
Denial; Anger; Depression;
Acceptance.

Some years ago I appeared on a panel discussion with fourth-year medical students on the topic of death and dying. I questioned the new trend of exposing patients to open communication on terminal disease. As such I reflected an attitude that this new approach was harsh, insensitive and unnecessary. I related two cases which highlighted my dilemma.

Case No. 1. Sam S. aged 72, was told in the presence of his wife that his enlarging abdomen which he had concealed for many months was due to cancer of the liver and that there was no treatment available; and that he should report back in a month's time. Sam's wife, devastated by the news remonstrated later: "Could the doctor not have offered some hope — given some medicine to make my husband feel something was being done?" She felt her husband was being discarded. This was a shattering experience for the patient and his family. The doctor had stuck rigidly to the truth, but in so doing, had alienated the patient and his family. They found it difficult to reconcile themselves with the doctor, and begrudged returning to him.

Case No. 2. Abe P., aged 56, had carcinoma of the prostate. His wife warned me that he would never cope with the knowledge of having cancer, and should he ever become aware of this, he would take his life. She evoked my anxieties, and coerced me into a conspiracy of silence and deception, and I found myself using euphemisms such as 'chronic inflammation', 'congestion' and so forth. At the student seminar I defended this old style of avoidance.

When Abe was ultimately dying a few years later, and he told me "You lied to me", I knew I had erred. It was an equally shattering experience — to see a former trusting and dear patient dying, isolated in his fears, never having been given the opportunity to share with me matters that must have caused him much anguish.

With a troubled mind I set about searching for a new framework in which I could operate in future — in this extremely difficult and sensitive area of communication between patient and doctor.

Each one of us has at some stage or another, experienced difficulties in this regard. Do we or don't we tell? How much do we tell? When do we tell? What effect will it have on the patient or his family? How will they cope? What do we do when relatives insist that we do not tell? How do we tell the patient when the prognosis is fatal? What about our own feelings about death?

My emergence from an 'avoider' to a doctor who can enter into open discussion on the matter of terminal disease and death, has been an enriching period of growth in my life.

There are no easy answers. No one is an expert on the management of the dying, and no one should pretend or claim to be. In the final analysis, each one must experience and learn this for oneself. I do claim, however, to have worked hard and often painfully at this subject, searched through the literature, to have attended intensive workshops and seminars and, by no means least, talked at length and in depth with many patients. My emergence from an 'avoider' to a doctor who can enter into open discussion on the matter of terminal disease and death, has been an enriching period of growth in my life, and something I wish to share with colleagues who may be experiencing similar difficulties.

We have not come to terms with our own death and mortality.

The tendency which exists among many doctors to avoid the topic with their terminally ill patients has evoked a comment from social workers that "whereas 80% of patients want to talk, 80% of doctors will not allow them to do so." Psychologists and sociologists interpret this as avoidance of a topic which causes discomfort because we have not come to terms with our own death and mortality. Fear of death makes us distance ourselves from people threatened by death. This avoidance is a way of pretending that we are immortal, although we all know that we will die. Stewart Trillin¹ says, "we need this deception, it is one of the ways we stay sane, but we also need to be prepared for the time when it doesn't work". For doctors who confront death when they go to work in the mornings as routinely as other people

deal with balance sheets, it is particularly important to face death squarely and to talk about it to one another.

No framework has been evolved for the GP working within the family setting in the community.

Much has been written about this subject relevant to the disciplines of psychiatry, social work, the hospital setting, the hospice, but as yet no framework has been evolved for the GP working within the family setting in the community.

It is now universally recognised, and substantiated by workers such as John Hinton, that the majority of terminally ill patients are aware of their illness, no matter how much secrecy prevails, and that they need to talk about it.

Our attitudes and policies towards discussing terminal disease with our patients often reflect little more than an inconsistent *ad hoc* practice evolved from the early examples of our tutors. As recently however as 1980, Charles Fletcher in a publication *Listening and talking to patients*, states:² "A few doctors advocate a frank and firm statement of the truth, but many prefer a policy of concealment. Both of these actions can cause distress. Our difficulty in telling the whole truth is that prognosis is seldom accurately known at the time of diagnosis". John Hinton warns:³ "no dogma is universally acceptable, and the protagonists for open communication may look askance at those using evasion and lies, while those who adhere rigidly to the whole truth may be criticised for unkindly destroying hope". The two case illustrations highlight this dilemma.

Another reason for our difficulty in communicating with the terminally-ill is that doctors lack the necessary communication skills because of inadequate training in the basic principles of counselling and communication techniques. Medical educators and curriculum planners need to take a hard look at this serious defect in undergraduate training.

How then can the family doctor, beset by the aforementioned dilemmas and possessing limited counselling skills, effectively communicate with his terminally ill patients and their families?

An appropriate framework has been evolved by contemporary thinkers, notably Elizabeth Kubler-Ross,⁴ based on two important factors:

- (a) The doctor's own feelings, philosophy and attitude towards acceptance of death or mortality.
- (b) The patient's coping or defense mechanisms, and the doctor's awareness and skill to tune into these.

The doctor should provide a safe, comfortable, sensitive and unhurried atmosphere for his patient, so that he can talk, if and when he is ready.

Using the above framework, the doctor's task is to facilitate acceptance by providing a safe, comfortable, sensitive and unhurried atmosphere for his patient, so that he may feel, *if and when he is ready*, to talk of growing awareness of the seriousness of his illness, his feelings of anxiety, fear, depression, anger and even impending death.

Kubler-Ross' classical model⁴ of the *psychological stages* which the terminally ill experience, and which reflect the patient's coping or defence mechanisms, will be used to demonstrate how this framework may be implemented in practice. Four of the stages will be discussed; denial, anger, depression and acceptance. (Although these stages are presented in sequence, they do not necessarily follow one another, and patients may slip in and out of these stages as the illness progresses).

Denial

The characteristic response experienced would be 'it can't be true' often preceded by a sense of shock and numbness at being told the news. Research workers have found that patients often block out at this stage and will later ask the doctor details he may have repeatedly tried to get across at the initial interview. It would therefore be inappropriate to communicate details in any depth at this stage.

During this initial denial stage, patients may wish to block out words like 'cancer', but could accept 'tumour' or 'growth'. "We have found a tumour", would be an appropriate introduction to breaking the news. Should the patient's coping mechanism be such that he would want to know whether the tumour is malignant, he should be told the truth. Experience shows that patients whose defences are such that they block out this type of news at this stage, invariably come to accept it in the course of time.

Kubler-Ross⁴ sees denial as healthy — allowing time for the patient to collect himself, and with time, as the reality of the illness becomes more manifest, to mobilise other less radical defences. Some patients use denial until the end however, and the doctor may well have to go along with this and allow them this defence.

We dare not assault the patient with a grave prognosis until he is ready to handle it.

There is universal acceptance that we dare not assault the patient with what we think is a grave prognosis until he is ready to handle it. It is usually possible to temporise, allowing the patient to set the pace, become adjusted, and mobilise other coping mechanisms as the prognosis becomes clearer.

The GP, because of his continuing care and trusting relationship with the patient and his family, and because of his knowledge of his patient's coping mechanisms and needs, is uniquely and ideally placed to be the one to break the news. Thus he may feel it appropriate to confront the patient at a

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talking with terminally ill patients

very early stage of the illness. In fact frequently the patient is told the news immediately the diagnosis is confirmed with no significant detrimental effect on his psyche. Difficulties, psychological and interpersonal, can however ensue when the patient and his family are relatively unknown to the doctor, as for instance in the hospital setting, and neither of them ready to handle a bad prognosis. The case history of Sam S. illustrates this point.

Patients who are initially told of a serious diagnosis without a sense of hope never quite reconcile themselves with the doctor who presented the news in such a callous manner. All authorities agree that hope must not be extinguished, and support must be ever present. Patients may enquire as to their prognosis. Responses such as "We will need to observe you closely for the next year, and thereafter only 3 or 4 times a year", or "We require to see how you respond to treatment over the next 12 months" imply to the patient that his outlook appears reasonable. The doctor is in fact not withholding the truth within the framework of his knowledge as to prognosis at that moment in time, and moreover⁴ credibility and trust are maintained.

The patient should never be left without hope, hope provides the situation with some meaning from which the patient may gain strength to persevere in the face of fear.

The patient should never be left without hope. Does this not however appear contradictory? If one of the goals of open communication is to create awareness of a fatal illness, how can we reconcile this with hope? The answer is that hope needs to be seen not only in the context of survival. As the reality of the illness becomes more apparent, the patient may *hope* that he will be spared suffering, that he will not have pain, that he will not be isolated and left alone, that his family will manage. As Sylvia Ross in her book *Towards death with dignity* states, "hope provides the situation with some meaning from which the patient may gain strength to persevere in the face of fear".

The GP should always be aware of the different stages so that he can respond appropriately.

The doctor can reinforce his support at all times during the illness by visiting and phone calls, rather than by avoiding his patient. Unfortunately there is a tendency for the doctor to limit his visits because of a sense of his own discomfort. Those doctors who can freely talk to their patients about their illness will find the visits not so onerous or anxiety-provoking, and indeed frequently experience personal enrichment and growth in their day-to-day communication with their terminally ill patient. Attending to seemingly trivial problems, e.g. constipation, nausea, urinary symp-

toms, bed sores, is not only important but often helps both doctor and patient to digress for a while from the more tormenting issues.

Who to tell first, the patient or the family? It is apparent that the confidentiality which operates in the privacy of the consulting room, may break down for instance when family members are anxiously awaiting the doctor to emerge from the operating theatre with the news of the diagnosis.

Families as well as patients set their own pace towards acceptance as the illness progresses.

Family members may also experience their own denial and, in their attempt to shelter the patient, coerce the doctor into secrecy. Experience has shown that such families also require counselling, and that families, as well as the patient, set their own pace towards acceptance as the illness progresses and there is growing awareness of the seriousness of the condition. Ideally, counselling the patient together with his family effectively avoids misinterpretations and confusion, and *promotes an atmosphere of sharing.*

Anger

Anger is the next stage when denial cannot be maintained any longer and the patient becomes gradually more aware of the seriousness of his illness. (These stages, as previously stated, are not clearly delineated, and patients may slip in and out of them as the illness progresses. What must continually be borne in mind is that we must be aware of these stages so that we can respond appropriately and also use them as a catalyst for further discussion.) Anger is often accompanied by envy or resentment. "Why me?", "Why my best friend?" Anger is difficult to cope with because, although vented against God or fate, it is displaced onto seemingly innocent people — members of the family, nurses, doctors. The doctor, nurse, or members of the family must, however, not interpret the anger as directed at them, and retaliate with anger. I alert family members to this dynamic.

It would be opportune to digress, and reflect on an aspect of doctors' anger toward their patients. Doctors may become irritated or annoyed when confronted repeatedly by patients who present symptoms which *defy cure*. Situations which immediately come to mind are those associated with geriatric problems, hypochondriacs, neuroses. Doctors may rationalise by calling these patients 'difficult'. The patient senses that the doctor appears irritated and feels he is rejecting him. This rejection is interpreted by psychologists as defensive behaviour by doctors who have a need to see their patients get better. Curing, healing, restoring to health is seen as our defined role inculcated in our medical training. Patients who do not get better are a threat to this defined role, and unconsciously make us anxious and doubt our ability or competence. We react defensively by rejecting the object of our failure — the patient. Terminal patients may also at times constitute a threat to this defined role. When, in addition the patient is experiencing his own anger towards his illness and displacing it to the doctor, the relationship between doctor and patient becomes threatened.

Awareness of these dynamics may help us to allow patients to express anger without engaging in counter arguments. Anger can, in fact, be used constructively as a tool for further discussion. "You seem upset today", may open up a flood of feelings about his illness which the patient has hitherto suppressed.

Anger can often bring to the surface latent or suppressed family stresses and problems. In such situations we may have to intervene as family counsellors, or call in a professional counsellor. This is a significant aspect of our commitment to total care of the terminally ill patient and his family. Mrs B, semi-paralysed from an arterio-cytoma, was finding fault with one and all. She suddenly exploded into anger one day when her daughter, without prior discussion with her, brought a wheel-chair home for her use. The husband had previously confided in me that he was finding it difficult to cope with his wife: she had been bitterly resentful of him, demanding to know why he was avoiding sexual contact with her.

They must be allowed to feel they're involved — even during the earlier part of the illness.

I used the opportunity for family counselling. Everyone was encouraged to express their feelings freely. The husband also communicated his love and concern for his wife in our presence. The family were alerted to the patient's need to participate in decision-making. (The wheel-chair had been acquired without consulting the patient and reinforced her anger about her crippling and demeaning illness). This case therefore also illustrates the anger patients feel because they are no longer in control of their lives. Terminally ill patients must be allowed to make decisions or share in decision-making. They must be allowed to feel they are involved even during the earlier part of the illness. This positive regard is helpful in maintaining self-esteem, and is one of the cornerstones of Rogerian type of communication,⁵ and is extremely appropriate to promoting good doctor-patient relationship. Other appropriate Rogerian principles are *empathy*, the ability to put yourself in the patient's position or frame of reference, and see things from his point of view; and *congruence* or genuineness of feeling. The Rogerian style also embraces *non-directive communication* which is particularly appropriate when talking with the terminally ill. "Doctor, is it serious?" "Well, how do *you* feel about it; how does it seem to *you*?" is a non-directive or reflective style of communication which provides opportunity for the patient to explore and expose his own feelings about his illness while at the same time providing clues to the doctor as to his patient's level of awareness. It may be difficult to implement this technique universally because of trans-cultural and ethnic differences. At a workshop on this topic, a black doctor felt that this approach was inappropriate because black patients expected their doctors to talk to them in a more directive way; the doctor was the authority and had to tell.

The direct opposite to reflective style of communication when the doctor levels out with his patient is the authoritarian style when the doctor talks down to his patient. A survey

done by four medical students at Wits⁶ reveals that many terminally-ill patients feel they are treated like children. They resent this. This reinforces the previously stated contention that such patients feel they are not in control of their lives, and are left out of any decision-making. Levelling out with the patients along the lines of the Rogerian approach avoids all these demeaning assaults on their self-esteem.

Depression

Depression is the next important stage that follows denial and anger. The GP will often pick up depression in family members too, often accompanied by guilt: "I shouldn't have left him alone". Audrey Gordon in a book edited by Rabbi Riemer entitled *Jewish reflections on death*, states that this may portray unconscious anxieties about our own death: "Will I be left alone to suffer?": "Will anyone care for me?"

There is a tendency to want to cheer up terminally ill people who are depressed. Seemingly innocent remarks and platitudes dispensed by well-meaning friends, nurses and doctors are often unhelpful. A patient of mine when told "I know how you feel" replied angrily "You don't know how I feel: you couldn't possibly know: you haven't got cancer".

A comment such as "You'll be better tomorrow" is incongruous and lacks credibility for the patient. These statements are often expressions of our inability to cope with the depressed person and our own unrealistic expectations.

I make a point of introducing students attending my practice to Fanny L. and exposing them to her feelings of her motor neurone disease. I ask her to recount her dismay she felt when, breaking the news of her disease to her, I said; "I am sorry". To her it was a close-off comment and made her feel that nothing further could be offered to help her. It worsened her depression.

Silence can become a comforting form of communication.

A friend and colleague suffering from carcinoma of the colon resented the doctor visiting him in hospital when he was pre-terminal, and making reassuring noises eg. "You're looking better today". At that stage of his illness he just wanted someone to sit and be there. If one is at a loss for words, particularly when the illness has progressed to a pre-terminal stage and the patient is depressed and withdrawn, silence becomes comforting communication.

My own sadness at seeing a patient dying did not reinforce the patient's depression, but provided support.

One of the lessons I have learned is that as a doctor, my own sadness at seeing a patient dying did not reinforce the pa-

patient's depression, but rather provided support. After a long illness, Jennifer had asked me about the swelling in her abdomen. I told her, and I admit I found it difficult, that the cancer of her ovary had involved the liver. She responded by saying that she now knew where she stood: "Why did the consultant always evade the issue when she asked him?"

Genuine expression of feeling is therapeutic in the doctor-patient relationship.

I was moved by her courage, and it was then that I asked her, knowing my eyes were moist, whether my apparent distress upset her. She responded by saying that she knew how I must feel about her, and it gave her a sense of immeasurable support and comfort. This also illustrates how congruence, or genuine expression of feeling, the other Rogerian principle, is therapeutic in the doctor-patient relationship.

Acceptance

Acceptance is the final stage, and does not necessarily come to everyone. As previously stated, there are some patients who will use denial to the very end, and most authorities agree that they must be allowed to do so. Patients, however, who can successfully, with support along the lines previously discussed, work through their feelings, are able to achieve this more readily. Religious resources in strongly-believing people do help, as do other resources; these include ethnicity, family and social supports, the resolution of unresolved family and personal conflicts and the availability of health care supports — significantly the hospice.

Doctors appear divided on the 'hospice philosophy' of open discussion, preparation for, and acceptance of impending death. Ultimately, however, cues from the patients and the family may very well be the factor which influences the direction which the doctor takes. Carole was dying of acute lymphoblastic leukaemia. I had accompanied her husband to the consultant's office where we were told that a final programme of chemotherapy would be tried, but that the outlook was extremely poor. I told Carole of the planned treatment. "And if this one doesn't work ... does it mean it's the end ...?" she asked. We remained silent. The husband cradled her head in his arms, and they both wept. Soon after, she was discharged from hospital, and assistance was sought from St. Luke's Hospice. The family derived invaluable comfort from their support and counselling. Time was spent in engaging Carole in recounting and sharing pleasurable past family experiences. Psychiatrists claim that this sharing is supportive to the patient and family. However, soon Carole became *detached* and the family would merely sit, taking turns to hold her hands. Morphine had soon to be introduced because of intractable bone pain. She died peacefully while under sedation.

Detachment may be difficult for the family to cope with: they don't understand this withdrawal.

Acceptance is not a happy state of resignation, and very often patients manifest this detachment from their environment: they appear devoid of feeling — what Sylvia Poss⁷ refers to as "one of the final tasks of the patient when he or she reverses physical survival processes, relinquishing responsibility and independence, and separates self from former experience, as a preparation for death". Detachment may be difficult for the family to cope with: they don't understand this withdrawal. Providing the family with insight into this pattern of behaviour and its dynamics, may be one of the final tasks we have to perform in talking to the terminally ill patient and his family.

Conclusion

I have attempted to adapt the traditional model of caring for the terminally ill and dying, to our needs in general practice. The significance of the psychological stages of the dying patient, have been highlighted: this provides us with a framework for opening up discussion in response to the patient's coping and defence mechanisms and his setting the pace. We also need to sensitise family members to these psychological stages, and, by so doing, facilitate *their* acceptance. The importance of maintaining appropriate support and hope has been stressed. The significance of a non-directive style of communication, and the importance of maintaining the self-esteem and dignity of our patients, and allowing them to participate in decision-making have been highlighted. Latent or suppressed family and interpersonal problems may emerge, and our role in managing these has been stressed.

There are, however, aspects which call for further debate. Do the logistics of general practice allow for us as GPs to get involved in protracted programmes of intensive psychological care and preparation for death, or is this the province of social workers, psychologists, pastor, or even lay self-help groups? What about the important role of the hospice movement and how does the GP integrate this effectively into his personal care of the terminally ill?

A framework has nevertheless been evolved in which the GP can operate and try to find some of the answers to a most difficult and sensitive problem. There are of course no universal answers. There are no dogmas. No one is an expert on the management of the dying, and no one should pretend to be. This is something which, in the final analysis, each one must experience and learn for oneself, so that we can hopefully change for our patients what is too often a miserable stretch of suffering and anxiety, into a period of comforting and sharing, of peaceful acceptance, and meaningful reconciliation.

Abe, with his carcinoma of the prostate, did not die or suffer in vain. He led me to personal growth and enrichment.

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