

Attitudes of general practitioners towards disclosing a terminal diagnosis

— Illana Perlman



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Curriculum vitae

Illana Perlman studied at the University of the Witwatersrand where she obtained an Honour's degree in Social Work, having specialised in the field of Medical Social Work. She is presently the social worker at the Hospice Association (Witwatersrand). Her practice involves counselling of terminally ill patients and their families, bereavement counselling and the training of lay counsellors.

The primary motivation for undertaking this study was based on an awareness of complexities and serious ramifications involved, both for the general practitioner and the patient or family, with regard to the disclosure of a terminal diagnosis. For the general practitioner, whilst 'truth telling' represents a major ethical principle in medical practice, it is evident that the principle is one that has, from ancient to modern times, been absent from international or local codes of medical ethics¹. As such, the general practitioner's task of disclosure of a terminal illness is neither straight-forward nor easy, involving a myriad of dilemmas associated with whether, who, how and what 'to tell'.

Does the patient have the right to know the truth about himself? Does the doctor have an obligation to tell it?

Clearly, these are the two continually vexing questions at the forefront of this ethical dilemma of disclosure. From the patient perspective, suffice it to say that

Summary

The task of the GP to disclose a terminal diagnosis is discussed, using the findings of a survey which was done to find out what is being practised and what are the attitudes which underlie these approaches. The need for better training in the field of the terminally-ill patient is strongly emphasised.

S Afr Fam Pract 1988; 9: 143-6

KEYWORDS: Diagnosis; Attitude to Death; Terminal Care; Physician-patient relations; Physicians, Family.

studies have clearly shown that in general, patients do want to be informed of a terminal diagnosis².

From the medical practitioner perspective, the debate about whether the patient should be informed of a terminal diagnosis has been protracted and controversial³. In essence, the school opposed to sharing the diagnosis is the more entrenched and long-standing view. However, there appears to have been a shift from the widespread tendency of "not telling" in the 1950s and 1960s, to the tendency of "telling" in the 1970s and 1980s.⁴

Aims of the study

In the light of the above, the study was designed to ascertain the attitudes of general practitioners towards disclosing a terminal diagnosis, an area in which exists a paucity of systematic research in the South Africa context. The central aims were (1) to learn what is practised with respect to disclosure, and (2) to understand the attitudes and bases which may underlie these strategies.

Research methodology

The study sample comprised 100 general practitioners, registered with the South African Academy of Family Practice/Primary Care and residing within the greater Southern Transvaal region.

The research tool utilised was a self-administered questionnaire, comprising both closed and open-ended questions pertaining to the topic under focus. Of the 51% response rate obtained, 60% were randomly selected for analysis.

At this point it is appropriate to refer briefly to the central limitations of the study:

- 1) the scope of the study was severely limited by the time and space constraints of the research. In addition, the small sample used restricts the generalisability of the findings;

Does the patient have a right to know the truth about himself?

- 2) a process of 'self selection' may have occurred since only motivated general practitioners may have responded to the questionnaire, thus introducing an element of response bias into the study. Moreover, responses of general practitioners may not have been reliable in terms of the discrepancy between what practitioners say and what actually occurs in practice.

Main findings of the study

Main findings of the study included:

- 1) Seventy-three percent (22/30) — of general practitioners generally disclosed a terminal diagnosis to a patient. This finding confirmed the trend identified by Klenow and Youngs⁴, that the present tendency among practitioners is "to tell".
- 2) The manner of disclosure to the patient varied from one general practitioner to another, reflecting a certain amount of divergence and inconsistency among the approaches of the practitioners. Most notably, common themes which emerged in this regard, were that practitioners purported to disclose of the diagnosis over a period of time, together with the family, and often first to the family.

The GP's task to tell his patient involves a myriad of dilemmas.

- 3) A variety of factors seemed to influence and underlie the general practitioners' attitudes towards the disclosure. Most significantly, whilst clinical experience appeared to be of considerable importance in developing an individual approach, undergraduate and post-graduate medical training appeared to be given minor credit. Furthermore,

there was a consensus among the practitioners that training in the areas of terminal illness, death and dying is deficient in South African medical education; a finding supported by Levin et al⁵.

A large proportion of the general practitioners — 83% (25/30) — recognised the influence of personal factors on their approach to disclosure, with half of this group specifying the role of religion in this regard.

"As a Christian who believes in eternal life, it is of paramount importance to disclose to the patient."

"My religious views as a Protestant help me to look at death as a stepping stone to a life hereafter..."

Clearly, personal and emotional factors of the general practitioners appeared to be a central and frequently underlying theme in the research, shaping their attitudes towards disclosure. Specifically in this regard it has been posited that the doctor's personal relationship to the concept of death has implications for the manner in which he approaches the terminally ill patient, and hence the issue of disclosure⁶.

- 4) In debating whether or not to disclose a terminal diagnosis, numerous characteristics of the patient appeared to be considered by each general practitioner within his approach to disclosure. The

Yes, patients do want to be informed of a terminal diagnosis.

three most commonly identified characteristics were: emotional stability of the patient, specific family requests about disclosure or non-disclosure, and the extent of enquiry from the patient about the illness.

- 5) The majority of the general practitioners — 87% (26/30) — indicated that research with respect to the issue of disclosure should be conducted, and furthermore, 80% (24/30) stated that they would like to attend lectures/seminars/courses focusing on such areas as death, dying, bereavement, and the care of the terminally ill patient and his family. These aspects, together with the high response rate attained in the study, point to the interest of doctors in and concern with the topic of disclosure.
- 6) Interestingly, 90% (27/30) of the general practitioners stated that if they were the terminally ill patient, they would wish to be informed of the terminal diagnosis. In elaborating on their responses, frequent mention was made to the effect of *"I am strong at heart"* *"As a medical man I can accept it better than a lay person"*. Moreover 68% (13/19) of the general practitioners stressed that they would want to be informed of the diagnosis so that they could plan and prepare for the future. Significantly, it appeared that the practitioners did

not seem to recognise the relevance and similar importance of this aspect for the patient: at no one point in any of the responses in the questionnaire was it noted that the patient may have equally strong needs to plan and prepare for the future.

Recommendations

Recommendations of the study included:

- 1) The central recommendation was made that general practitioners attain an awareness of their attitudes towards the issue of disclosure of a terminal diagnosis — as asserted by Oken⁶, such an

The religious sympathies of the GP shape his attitude towards disclosure.

awareness is the first step toward developing enhanced knowledge of more sensitive and skilled approaches to the issue.

It was recommended that general practitioners make active use of the substantial body of literature that has emerged to guide them in dealing with

the issue of disclosure — for example, Weisman⁷, Parkes⁸ and Silbert⁹.

- 2) It was suggested that medical trainers and curriculum planners need to pay serious attention to the deficits in medical training that appear to be prevalent, by providing more extensive training in the field of death, dying and the care of the terminally ill patient. Moreover, it was tentatively recommended that an increased number of courses/lectures/workshops be offered to address the needs of the general practitioner caring for a terminally ill patient.
- 3) In focusing on the present need for a multidisciplinary approach to health care, it was advocated that the social worker be valued and used in such a health care team, particularly in terms of the social worker's skills and training in the psychosocial aspects of human behaviour.

In this context, the social worker has an important role to play as mediator between the general practitioner and the patient — to assess the functioning of the patient/family, to offer them support, and to feedback the assessment to the general practitioner, to aid him in his task of disclosure.

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Conclusion

Numerous factors may influence and determine the general practitioner's approach with respect to the disclosure of a terminal diagnosis. Perhaps the primary variable in this regard is the factor that death has been referred to as the "great taboo of the 20th Century", resulting in a conscious and unconscious conspiracy

Death should no longer be that great taboo of the 20th Century.

of silence and denial toward it in society, such that the general practitioner's reluctance to disclose a terminal diagnosis to a patient may be, in part, a reflection of this perspective in society.

In this context, the challenge for the general practitioner, and indeed for all health care workers, is to untie the shackles of this taboo, to make death a more open and acceptable issue. In this process the gains for the patient can only be considerable.

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