Truth telling in a South African tertiary hospital

M D T H W Vangu, MD, MSc, MMed

Professor and Head of Nuclear Medicine, University of the Witwatersrand, Johannesburg

Introduction. Truth telling forms part of the contemporary debate in clinical bioethics and centres around the right of the patient to receive honest information concerning his or her medical condition/illness and the duty of the doctor to give this information to the patient. Many patients complain that they are not being informed, but on the other hand there may be patients who do not want a truthful answer about their health problems.

Objectives. This study explores the preferences of patients at four Johannesburg General Hospital outpatient clinics regarding the practice of truth telling and their attitudes towards it.

Methods. Four hundred and sixty-five participants voluntarily completed and returned a questionnaire.

Results. The majority of the participants stated that the doctor had disclosed information about their condition (92.9%). Almost all were of the opinion that patients have the right to know about their condition (98.3%) and also that the doctor has the duty to inform them of their condition (98.0%). If they were suffering from a serious condition most participants (86.3%) would prefer to know about it, but a small but significant percentage (13.7%) would prefer not to know. Variables such as gender, age and level of education did not seem to impact significantly on the participants' opinions about the truth telling process, with the exception of gender, as more females than males had knowledge of their condition (p=0.0176), and education, where more participants with higher education supported the right to disclosure (p=0.0430).

Conclusion. The vast majority of participants supported the right of patients to disclosure, but the majority also considered that the level of information given to them was not satisfactory, even when they had asked for more. This implies a need to look at the way we give information to our patients and to seek ways in which this can be improved.

The purpose of truth telling is not only to disclose information necessary for patients to make informed choices concerning their treatment options. It includes providing information concerning their diagnosis.[1] This idea is very different from the paternalistic mode of doctor-patient interactions, such Thomas Percival writing in 1803: 'to a patient, who makes inquiries which, if faithfully answered, might prove fatal to him, it would be a gross and unfeeling wrong to tell the truth'.[2]

The movement from a strongly paternalistic model to one that is (at most) weakly paternalistic has led to better communication between patient and doctor in the Western world. Attitudes of patients towards truth telling generally gained worldwide momentum as a result of open debate in the 1990s.[3] Yet questions remain, and there is variation in the application of truth telling globally, which appears to have a cultural influence.[4,5]

The current Brazilian code of medical ethics, for example, promotes truth telling in that it prohibits physicians from keeping information from the patient. It puts a positive obligation on doctors to provide patients with information about the diagnosis, outcome and risks and aims of treatment, except when direct communication to them may cause harm.[6] This promotion of truth telling is emphasised in the American Medical Association's revised list of medical ethics principles, which unequivocally recommends that relevant information be made available to patients.[7]

Regardless of one's personal belief, it is essential for physicians to understand that they are dealing with autonomous and rational individuals who are capable of deciding on matters concerning their own health. It is therefore an ethical imperative to stress that patients should be the ones to determine what is actually best for them, and this can only be done if they are armed with all the necessary information.

Methods

This was a cross-sectional descriptive method of investigation utilising a self-administered questionnaire. The objectives of the study were to explore the preferences and attitudes of patients attending the outpatient clinics at Johannesburg General Hospital with regard to truth telling, to find out whether they were satisfied with the information actually given to them, and to identify the characteristics of patients who do not want the truth about their condition and/or their treatment plan, as opposed to those who would like to know.

Questionnaires were distributed to patients in the areas of the hospital that host these clinics, namely the oncology, medical, surgical and nuclear medicine units, on a daily basis for about 10 working days.

The questionnaires were in three languages (English, Afrikaans and Zulu) and were given to patients if they were able to read and write, and voluntarily agreed to participate. Patients were requested to return the questionnaires by placing them in a designated box, whether or not they had completed them.

Six hundred questionnaires were distributed (150 per clinic), and 465 responses were received.

The questionnaires were self-administered so there was no need for written informed consent, as completion of the questionnaire implies consent. However, permission was obtained from the Johannesburg General Hospital management to distribute the questionnaires to patients attending the clinics, and the study was submitted to the Human Ethics Committee (Medical) of the University of the Witwatersrand for review and was approved.

To avoid any concerns regarding health care compromise, all patients were requested to return their questionnaires, whether completed or not, by placing them in a box at the clinic. In this way, their identities with regard to non-participation were protected.

All questionnaires were anonymous. Patients were not at risk of being identified during analysis of the returned questionnaires.

Preferences of participants towards disclosure and non-disclosure on their conditions and treatment plans were assessed and expressed as percentages. To establish differences between clinics and to detect associations between variables measured on a categorical scale (gender, age, education and preference), a chi-square test was used with Fisher's exact test when necessary, with the level of significance at 0.05. Data were analysed using SAS software version 9.1 (SAS Institute Inc., Cary, NC).

Results

Four hundred and sixty-five participants completed and returned the questionnaires. Not all patients answered all the questions, which accounts for the variance in numbers in the results presented. There were 298 females (64.5%) and 164 males (35.5%). Of the patients 51 (11.0%) were aged 18 - 30 years, 73 (15.7%) 31 - 40 years, 96 (20.6%) 41 - 60 years, 97 (20.9%) 51 - 60 years, and 148 (31.8%) over 60 years. About three-quarters (73.3%) of participants were aged 41 or older (Table I).

The majority of the participants (92.9%) stated that a doctor had told them about what was wrong with them. Almost all (98.3%) thought that patients have the right to know about their condition, that the doctor has the duty to inform patients about their condition (98.0%), and that the information about the condition should be detailed (98.2%).

Most of the participants (86.3%) said that if they were suffering from a serious but not life-threatening condition they would want to know about their condition and would therefore be in favour of disclosure, while a small but significant proportion (13.7%) would not want to know. Of the group who did not want to know, half indicated that they would change their position if their condition was life-threatening.

The majority of the participants (96.6%) said that they would like to receive detailed information relating to their treatment, and a high proportion (87.8%) said that they would want their family members to be informed of their condition. The majority of the latter group said that they would want the information to be given to their family members in detail (96.4%).

About a fifth of the participants (19.6%) were not satisfied with the information given to them by their doctors, and 70.9% of them had requested doctors to provide more information. However, only few of them (40.0%) were satisfied with the additional information they had received from their doctors.

More than half of the participants who were not satisfied with the information given to them also felt that doctors do not provide patients with all necessary information concerning their condition (57.1%) or related to their treatment (58.8%).

Table I. Demographic characteristics of the participants

Participants	*N*	%
Gender*		
Female	298	64.5
Male	164	35.5
Age (yrs)		
18 - 30	51	11.0
31 - 40	73	15.7
41 - 50	96	20.6
51 - 60	97	20.9
> 60	148	31.8
Education[†]		
Primary school	58	12.6
High school		
Without matric	202	44.0
With matric	125	27.2
Graduate		
From college	51	11.1
From university	17	3.7
Postgraduate	6	1.3
Clinic		
Oncology	137	29.5
Surgical	123	26.5
Medical	106	22.8
Mixed	99	21.3

* 3 participants did not indicate their gender.

[†] 6 participants did not indicate their level of education.

A considerable proportion of participants (23.7%) felt that in general doctors do not disclose all the necessary information regarding the condition and treatment of their patients.

Characteristics of participants

Table II sets out the characteristics of participants according to knowledge they would want to have about their condition (what was wrong with them). Only gender was a significant factor (p=0.0176), while age (p=0.2672) and education (p=0.4509) did not appear to influence the opinions of participants on knowledge of their condition.

Table III sets out the characteristics of participants according to preference regarding disclosure and non-disclosure of a less serious condition, and Table IV their characteristics according to preference regarding disclosure and non-disclosure of treatment details.

Tables V and VI set out the characteristics of participants according to their opinions on the right of patients to disclosure and the duty of doctors to disclose all the necessary information concerning a patient's condition and treatment.

Table II. Characteristics of the participants according to knowledge or ignorance of their condition

	Knowledge *N* (%)	Ignorance *N* (%)	*p*-value
Age (yrs)			
18 - 30	46 (9.8)	5 (1.1)	
31 - 40	64 (13.8)	9 (1.9)	
41 - 50	92 (19.8)	4 (0.9)	0.2672
51 - 60	91 (19.6)	6 (1.2)	
> 60	139 (29.9)	9 (1.9)	
Gender			
Female	283 (61.3)	15 (3.2)	0.0176
Male	146 (31.6)	18 (3.9)	
Education			
Primary school	54 (11.8)	4 (0.9)	
High school			
Without matric	187 (40.7)	15 (3.1)	
With matric	119 (25.9)	6 (1.2)	0.4509
Graduate			
College	47 (10.2)	4 (0.9)	
University	14 (3.1)	3 (0.6)	
Postgraduate	5 (1.1)	1 (0.2)	

Table III. Characteristics of the participants according to preference for disclosure or non-disclosure of a less serious condition

	Disclosure *N* (%)	Non-disclosure *N* (%)	*p*-value
Age (yrs)			
18 - 30	46 (10.2)	5 (1.1)	
31 - 40	65 (14.4)	6 (1.3)	
41 - 50	80 (17.7)	14 (3.0)	0.1615
51 - 60	84 (18.6)	10 (2.2)	
> 60	115 (25.4)	27 (6.0)	
Gender			
Female	248 (55.2)	40 (8.9)	0.9473
Male	139 (30.9)	22 (4.9)	
Education			
Primary school	48 (10.8)	7 (1.6)	
High school			
Without matric	165 (36.9)	29 (6.5)	
With matric	106 (23.8)	17 (3.8)	0.9007
Graduate			
College	45 (10.0)	6 (1.3)	
University	14 (3.1)	3 (0.7)	
Postgraduate	6 (1.3)	0 (0)	

Age, gender and education did not appear significantly to influence the participants' opinions concerning disclosure and non-disclosure ($p>0.05$) (Tables III, IV, V and VI), except for education with regard to the right of patients to disclosure ($p=0.0430$) (Table V).

Discussion

Truth telling in clinical practice has been subject to considerable debate and will probably continue to be scrutinised for many years to come. Of participants in this study, 86.3% indicated that they

Table IV. Characteristics of the participants according to preference for disclosure or non-disclosure of treatment details

	Disclosure *N* (%)	Non-disclosure *N* (%)	*p*-value
Age (yrs)			
18 - 30	50 (11.2)	1 (0.2)	
31 - 40	68 (15.2)	1 (0.2)	
41 - 50	90 (20.2)	4 (0.9)	0.0692
51 - 60	93 (20.8)	0 (0)	
>60	130 (29.1)	9 (2.0)	
Gender			
Female	280 (63.2)	8 (1.8)	0.3346
Male	148 (33.4)	7 (1.6)	
Education			
Primary school	52 (11.8)	3 (0.7)	
High school			
Without matric	187 (41.1)	6 (1.4)	
With matric	117 (26.6)	4 (0.9)	0.2812
Graduate			
College	48 (10.9)	0 (0)	
University	15 (3.4)	2 (0.4)	
Postgraduate	6 (1.4)	0 (0)	

Table V. Characteristics of participants according to their opinions on patients' right to disclosure

	Disclosure *N* (%)	Non-disclosure *N* (%)	*p*-value
Age (ys)			
18 - 30	50 (11.1)	1 (0.2)	
31 - 40	70 (15.5)	1 (0.2)	
41 - 50	92 (20.3)	0 (0)	0.7219
51 - 60	93 (20.6)	1 (0.2)	
> 60	141 (31.2)	3 (0.7)	
Gender			
Female	289 (64.4)	3 (0.7)	0.4369
Male	154 (34.2)	3 (0.7)	
Education			
Primary school	53 (11.9)	1 (0.2)	
High school			
Without matric	163 (36.5)	33 (7.4)	
With matric	122 (27.3)	0 (0)	0.0430
Graduate			
College	51 (11.4)	0 (0)	
University	15 (3.4)	2 (0.4)	
Postgraduate	6 (1.3)	0 (0)	

would prefer to be told about their condition. This finding is similar to the results of studies that looked at patients' attitudes towards being told the truth about cancer and the clinical care of terminally ill patients.[8,9] The high percentages in our study could possibly be explained by increased patient awareness of truth telling due to improved media coverage and television and radio programmes focusing on health issues. This attitude toward truth telling was noted across all age groups and in both genders and was not influenced by level of education, although education was the sole factor that significantly influenced participants' opinions on the right of patients to disclosure.

Table VI. Characteristics of the participants according to their opinions on the duty of the doctor to disclose all information

	Disclosure ***N* (%)**	**Non-disclosure** ***N* (%)**	***p*-value**
Age (yrs)			
18 - 30	50 (11.0)	1 (0.2)	0.9094
31 - 40	71 (15.6)	1 (0.2)	
41 - 50	92 (20.2)	1 (0.2)	
51 - 60	92 (20.2)	2 (0.4)	
> 60	140 (30.8)	4 (0.8)	
Gender			
Female	289 (63.9)	4 (0.9)	0.1959
Male	154 (33.9)	5 (1.1)	
Education			
Primary school	52 (11.5)	2 (0.4)	0.2339
High school			
Without matric	193 (42.9)	6 (1.3)	
With matric	124 (27.5)	0 (0)	
Graduate			
College	50 (11.1)	0 (0)	
University	16 (3.5)	1 (0.2)	
Postgraduate	6 (1.3)	0 (0)	

Our data did not support previous findings that younger and better educated patients would be more likely to want to know the prognosis of a serious condition.[5,8,10]

The percentage of participants who would prefer not to be told the truth was small but significant (13.7%). This finding is in accordance with the literature, as others have reported the existence of a small proportion of patients whose wishes not to be informed must be respected.[11]

In contrast to the study by Wang *et al.*, in which about one-third (37.4%) of participants indicated that they would prefer relatives not to be informed of a cancer diagnosis,[8] our results showed a higher percentage of participants (87.8%) who would want their relatives to be informed of their condition. In the oncology outpatient clinic specifically, the majority of participants (90.2%) supported disclosure to relatives.

Although the majority of participants felt that patients had the right to disclosure, a significant number (13.7%) indicated that they did not need to know about their condition. While patients have the right to be informed, we should not forget that they also possess the right to choose non-disclosure.[8] The small but significant percentage of participants in our study who expressed a preference not to be informed is consistent with current literature indicating that a small group of those who wish not to be informed exists and must be respected.[8,11] What seems controversial, however, is that the majority of those participants who supported non-disclosure still felt that in principle patients had the right to know about their condition (93.4%). The reasons for this conflicting opinion will not be known unless direct interviews are conducted with this subgroup of participants.

Currently, the key issue in the topic of truth telling is whether philosophy should be applied in the practice of medicine, and a range of patient views in this regard have been quoted in the literature. The public impression that doctors prefer to conceal information may be justified. As Higgs put it, although for many patients fear of the unknown outweighs their actual physical disease, direct information nevertheless seems hard to obtain.[11] The day-to-day impression is that doctors are too busy to talk to their patients, and when they are not too busy they still seem to be withholding information in order to maintain hope and avoid creating unnecessary anxiety in an attempt to do no harm.

Our study shows rather an encouraging picture in that the majority of participants indicated that they had been told about their condition, although a significant proportion was not satisfied with the information received.

In truth telling, the physician-patient relationship is of paramount importance in building mutual trust, which could have direct implications on the management and outcome of treatment.

It is essential that physicians start by accepting the centrality of the patient, and more importantly acknowledge the fact that they are dealing with autonomous beings who are capable of making their own decisions about what is best for them. Furthermore, decisions regarding the patient's management and preferences should come from the patient him- or herself. Taking this perspective would avoid most unnecessary hiccups, as patient and doctor will be in a close partnership with the best interests of both at heart, and where both are seen as equal.

A key issue remains, concerning the understanding of what actually constitutes the truth. In the physician-patient relationship, there is a need to move away from viewing the truth as the opposite of lies or simply a sum of correct statements to seeing it as the situation in which a physician-patient relationship becomes an entity that depends on mutual responsibilities.[6] The relationship should be based on openness and willingness to establish a social contract between the two partners, i.e. doctor and patient. The relationship that is to be established should therefore be based on mutual rights and rules.[6]

A paternalistic attitude of the doctor in the physician-patient relationship erodes the capacity of patients to think and decide for themselves. In extreme situations, this attitude sometimes violates the rights and dignity of the patient. It also creates the impression that the physician, as the only one with knowledge and power, can decide and dictate in a vertical and authoritative way of communication. This attitude has no place in our health care environment, as supported by the findings of the present study that almost all participants (98.7%) indicated that they felt patients had the right to disclosure on information concerning their condition.

When therapeutic privilege is cited by those who support paternalistic attitudes, a counter-argument is that physicians who favour this view and such behaviours truly try to control patients, because they consider themselves as guardians with special knowledge justifying their decision when and to whom to reveal the truth.

It is imperative that doctors understand that patients are autonomous beings and that respecting their autonomy means that they should be informed. While in some circumstances there may be exceptions to the doctor's obligation to tell the truth about diagnosis and prognosis, these do not give doctors the excuse not to be open and share with their patients in a manner that is acceptable to both parties.

Secondly, in the attempt to minimise harm and seek a better outcome for the patients, doctors need to accept that the best judge of the patient's best interest at all times is the patient him- or herself.[12]

Again, the figures from our study are clear. An overwhelming majority of participants (96.6%) supported the disclosure of information relating to their treatment. There should therefore be no hesitation in considering them as partners in the attempt to achieve better treatment outcome.

While it is true that truthfulness can do harm, as 'what one does not know cannot hurt', an important consideration is the manner in which the truth is conveyed to a patient. Here, several factors should be considered, such as: (*i*) the time of giving the information, particularly for bad news; (*ii*) the environment in which the information is given; (*iii*) the manner in which information is given; (*iv*) the words chosen to convey the information; and most importantly (*v*) the attitude of the bringer of the bad news.

Conclusion

This study confirms the current worldwide awareness of patients regarding their right to information concerning their condition or their treatment, probably resulting from improved media coverage of medical issues. As in other studies, a high percentage of participants also supported disclosure to family members.

The majority of participants in our study supported the right of patients to disclosure, while the vast majority also felt that doctors have a duty to inform patients of their condition. There was, however, a significant percentage of participants who felt that the information given to them was not satisfactory, even when they had requested more. This implies that there is a need to look at the way information is given to our patients and find ways to improve it.

It is worth noting that there was a small but significant group who did not want to be told their diagnosis, even if they acknowledged the right of patients to make choices with regard to disclosure of information.

We can conclude that patients attending Johannesburg General Hospital are given information about their condition. The problem, if any, resides in the quality and the quantity of information given.

It would be most interesting in a future study to do direct interviews with patients, which might assist in understanding patient perceptions.

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