Chapter 1: Truth Telling

1.1 Introduction

Truth telling forms part of the contemporary medical-ethical debate concerning the right of the patient to know and the duty of the doctor to inform. 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 (Hébert, *et al.* 1997:225). This idea differs greatly from the paternalistic mode of doctor-patient interactions such as that of 1803 when Thomas Percival wrote: "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" (Leake 1989: 189). This strongly paternalistic model continued in medical practice for centuries.

The movement from a strongly paternalistic model to one of (at best) weakly paternalistic has led to better communication between patient and doctor in the western world. The attitudes of patients toward truth telling generally gained worldwide momentum in an open debate in the 1990's (Surbone 2006:945). Yet questions remain and there is variation in the application of truth telling globally which appears to have a cultural influence (Asai 1996; Blackhall 1995).

1.2 Views of professional bodies on truth telling

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

the treatment, except when direct communication to them may cause harm (Da Silva, *et al.* 2007:280). This promotion of truth telling is emphasized in the revised list of medical ethics principles by the American Medical Association that unequivocally recommend that relevant information be made available to patients (Corrao, *et al.* 2004:176).

In South Africa, the guidelines for good practice in the health care professions as set by the Health Professions Council of South Africa (HPCSA) clearly describe the role of physicians and all other health care professionals regarding the right of patients to information concerning them. The Council states in the guidelines that patients have a right to information about the health care services that are available to them (HPCSA: 2007). The information must also be presented to them in a way that is not complicated e.g. described in purely medical or scientific terms for their understanding and use. In the same vein, the South African Medical Association (SAMA), a body that looks at amongst other things the professional standards and ethics of doctors, stresses the role that practitioners have to play concerning the respect of the right to information given to patients (SAMA 2000). The credo of the members of SAMA requires that doctors strive to respect the right of their patients to full information concerning their condition in order to make informed decisions in accepting or refusing a proposed treatment. Clearly, patients are the ones who should decide and make choices about their own lives while doctors have to accept and resist the feeling of paternalistic attitudes and therefore prevent the promotion of the belief that ‘doctors know better’ and are the only ones to make decisions concerning their patients’ care (ibid).

1.3 Patients' and doctors' viewpoints

Regardless of one's personal belief, it is essential for physicians to understand that they are dealing with individuals that are autonomous and rational beings who are capable of deciding on matters concerning their own health.[1] It is thus 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 to do so. And while a physician may learn and hold this ideal, the influence of ethical values on the physician must be considered. For instance, a report from Good, *et al.* (1990:72) provides an example that gastroenterologists from Southern and Eastern Europe are less likely than their North American colleagues to reveal the true facts of the case to their patients.

When patients are not made central to the truth telling process, there is the risk of underestimating their true expectations, opening doors for doubt and negative feelings within these patients. Higgs (2006:90) translates this sentiment in a single sentence stating that 'fear of the unknown was the worst disease for many patients and yet direct information seemed too hard to obtain'.

The views of patients about their attitudes to truth telling with regard to cancer diagnosis were already sought in the 1950s (Tuckett 2004:501). Indeed, Kelly and Friesen (1950), Bowen (1955), as well as Aitken-Swan and Easson (1959) have shown in their early work that patients were glad and preferred to know their diagnosis about cancer. When one looks at the progression of the attitudes of doctors in truth telling about cancer, the figures could appear shocking to many. In an early survey of 444 doctors by Fitts and Radvin (1953:901) asking doctors if

1 In this research report, I am concerned with adult competent patients, one which are capable of making their own voluntary choices. Excluded fro this research report would be those individuals who are incompetent e.g. children, patient in comatose states, etc.

they would disclose a diagnosis of cancer, the majority would not do so, with more than 50% saying that they would not and 12% saying that they would never disclose. With time, the number changed gradually to a point that 30 years later about 98% of doctors in the survey that looked at the attitudes of physicians toward the use of deception in resolving difficult ethical problems were in favor of telling the patient her or his diagnosis (Novack, *et al.* 1979:897).

Today, several studies have been conducted in relation to truth telling and many of these studies focus on the attitudes or roles of physicians in informing patients of their conditions, especially concerning seriousness of their illness (Surbone 2006:944; Morita 2006:1; Wang, *et al.* 2004:53; Surbone, *et al.* 2004:165).

Some studies have looked at patients' attitudes towards truth telling in clinical practice. Hérbert, *et al.* (1997:225) emphasized the purpose of truth telling in their views on bioethics for clinicians. They state the truth telling process does not only enable patients to make informed choices regarding their health care but most importantly, it allows them to know their situation. This empowers the patient so she or he can make informed choices concerning her or his life or death. There is also a strong suggestion that physicians should include patients in any team that is supposed to make decisions concerning their diagnosis and treatment. Moreover, they should satisfy the need of patients regarding their wishes to be informed (Sullivan, *et al.* 2001:192).

However, differences between attitudes of patients in the Western world and those in other geographic locations have also been described. While expectations to know the truth from their doctors are high in the Western world, even for severe conditions, these expectations were found not to be of the same degree in countries like

Saudi Arabia and Japan (Wang, *et al.* 2004:53-54). Despite the discrepancy between the Western world and countries in other geographic locations, most studies indicate that patients still prefer to know the truth about diagnoses and prognosis of diseases including those patients suffering from cancer (Ozdogan 2006:1114; Higgs 2006:93; Higgs 2005:437; Wang, *et al.* 2004:53; Tuckett 2007:500; Sullivan, *et al.* 2001:193; Hérbert, *et al.* 1997:227).

Chapter 2: Ethical issues related to Truth telling

2.1 Autonomy in truth telling

The ethical basis of this study is firstly centered on the autonomy of the patient. The term “autonomy” brings with it an ethical principle that means self-determination of and self-governance over one’s actions (Tuckett 2004:505). The notion of self-governance is associated not only with the freedom of the individual but also includes wishes for her or his future life (Baron and Kim 2003:1821). Truthful disclosure is to the patient nothing less than the rightful way of determining a course of actions and control of her or his life plan. In the patient-physician relationship, a major consideration for the physician should always be to ensure that the innate imbalance of power between them is balanced. This means that power should be shared and if this is achieved, then the ground is laid for ensuring that the patient receives the most benefit and exercises her or his autonomy to the optimal degree (Brody 1997:78). Withholding the truth diminishes the autonomy of the patient and in the same time shows lack of respect for the patient as a person. An important aspect of autonomy is the ability of the patient to forfeit her or his right to truth telling (Tuckett 2004:506). When a competent patient requests not to be told, doctors can only abide by this ‘negative’ duty and respect the explicit request of the patient, except, of course, where not knowing could result in or perpetuate harm to others.

Making medical decisions in the current medical world depends greatly on the respect for an adult competent patient’s autonomous choices (Morita 2006:1). The consideration of such patient autonomy should be directly linked to truthful disclosure of information. While doctors have

some authority in deciding what to say, how to say what and when to say it, they should refrain from being paternalistic during the truth telling process. Failure to do so may result in conflict between embracing strong paternalism and preserving patients' autonomy. Indeed, Sullivan, *et al.* (2001:192) state that the conflict between benevolent paternalism and the preservation of a patient's autonomy as expressed by physicians are in fact increasing, leading to regularization of ethical issues such as autonomy and informed consent in an effort to bring the patient to the centre of the truth telling process.

This is made explicit by Morita, *et al.* (2006:1) who state that physician-patient communication has become characterized by the autonomy of the patient that is institutionalized in legal procedures that include informed consent and disclosure of information. However, not everything that surrounds the process of truth telling should be subject to regulation. Respecting patients' autonomy should not always be prescribed by law. Medical ethos on the respect of individuals' autonomy may be enough to guide disclosure of information to patients; even those suffering from cancer (Wang 2004:53).

The reality, however, is somewhat different. A recent Japanese survey by the Ministry of Health and Welfare for instance showed that only 20% of patients who died from advanced and lethal cancers were told the truth about their condition (Morita, *et al.* 2006:1). Such data suggests that doctors have exercised their duty in a paternalistic approach in this particular group of patients regarding the seriousness of these patients' illness. On the other hand, it may have occurred because of patients' choice.

Here it should be said that autonomy coupled with beneficence would make it a prerequisite that patients are actually informed. Patients should have the right to the complete truth because such information would provide them with enough power to decide on their life and any treatment plans (Surbone 2006:946). Furthermore, telling patients the truth will foster trust in the medical staff and make patients feel the respect owed to them as individuals because they are individuals in their own right (Hébert 1997:225). Moreover, in situations where physicians feel that disclosure may not benefit patients, the honesty expressed during communication should be of a level that approaches the maintenance of autonomy and freedom of choice (Higgs 2006:94).

2.2 Impact of informed consent

In practice, the respect due to the patient as a person and particularly the autonomy of a patient is expressed at best in the informed consent process. According to McQuoid-Mason and Dada (1999:135) consent is considered to be informed when it is given with the patient having a substantial knowledge regarding the nature and effect of the act consented to. There is therefore an obligation on the doctor to inform the patient of the risks related to the proposed act in the language that the patient understands. Only when obtained in the manner described above from a competent person who acts freely will the informed consent translate to the expression of the patient's autonomy or self rule (van Bogaert and Ogunbanjo 2006:62).

Of the several functions of the informed consent, the promotion of individual autonomy should be exercised in all patients without preferences. Levine (2003:198) emphasizes the promotion of

autonomy saying that all patients are entitled to the same degree of thoroughness of negotiations for informed consent, as are participants in clinical / scientific research.

One should notice that discussions related to truth telling frequently arise together with discussions on the requirements of informed consent. Competent adult patients as it has been accepted, have a moral and legal right to refuse medical interventions without their informed and voluntary consent (Mappes and Degrazia 2006:64). For patients to give informed consent and exercise their right to self-determination relevant information should be made available to them and most of the time physicians are the ones in a position to supply this kind of information. In fact, in the list of requirements for an informed consent to be valid, Beauchamp puts 'disclosure of information' such as explanation and recommendation of the planned intervention and its consequences at the top of the six requirements (van Bogaert and Ogunbanjo 2006:62). Therefore, informed consent requires relevant information on the part of doctors and other health professionals that explain to the patients about a proposed procedure or treatment prior to obtaining the consent of the patient on whom the procedure or treatment will take course (Veriava 2004:312).

The guidelines for good practice of health care professions in South Africa enhanced the link between truth telling, autonomy and informed consent succinctly. They state: "seeking consent of patients to disclosure is part of good communication between health care practitioners and patients and is an essential part of respect for the autonomy and privacy of patients" (HPCSA 2007). The guidelines stipulate that health care practitioners must make sure that the amount of information given to patients is enough to base their decision on,

whilst also providing them with the reasons for the disclosure and the likely consequences of doing so.

Although the debate surrounding informed consent brought about a repeated and approved claim that ‘full informed consent’ is a goal that we can never achieve, we must at least strive toward it (Freedman 2003:203). While striving toward this goal and despite strong evidence of the acceptance of the notion of informed consent, some cultural resistance to truth telling during the process of informed consent is still present in both physicians and patients in some places of the globe. In Italy for instance, a conspiracy of silence often took place until recently and it was considered legitimate to conceal both the diagnosis and prognosis to seriously sick patients in an attempt to maintain hope (Surbone, *et al.* 2004:166).

Chapter 3: Legal issues related to Truth Telling

3.1 Legal implications

Certainly, patients have a right to be informed about their conditions and the related therapeutic measures to improve their health. In situations where a person's life or health is in serious danger due to injury or in an emergency or simply that such a person is unable to communicate, doctors may decide to start treatment without informed consent. However, if such a person can communicate and insists on giving consent only if the diagnosis and/or treatment plan was explained to her or him, the doctor in this situation has the duty to do so to avoid making the consent illegal (McQuoid and Dada 1999:136).

Therefore, no professional act may be undertaken without first seeking consent to avoid opening the doors to potential legal cases. In fact, the Common Law recognizes the principle of the right to bodily integrity against invasion by others, hence medical procedure that is undertaken without the patient's consent may open doors to lawful arrest (Mason and Laurie 2006:349). Legally speaking, consequences of such unauthorized bodily invasion may include civil actions for damages and criminal liability for assault. In general, the law defines circumstances in which a patient may seek reparation for damages when she has been wronged or harmed as a result of failure to negotiate adequate consent (Levine 2003:198). In court, findings in favor of the informed consent from competent patients have been based on the right of the individual to self-determination (Young 2005:445). Because of this right to self-determination, it becomes understandably clear that competent patients may seek protection against interference with their bodies in the doctor-patient relationship. The intention of the practitioner should

therefore not always be read as good to the patient since any lack of respect of the autonomy of the patient constitutes nothing less but an assault. Failure to obtain proper consent has been treated as a battery action in some jurisdictions and the law of battery makes it wrong to touch or treat a person prior to getting consent from the concerned individual. The harm attached to the act becomes irrelevant as what matters most is the touching without consent which makes the whole situation erroneous.

In South Africa, protection and exercise of the right to information for patients are well expressed in the law by simply looking at the hierarchal structure of the law. From the Constitution, the supreme law of the country, through acts such as The National Health Act or The Health Professions Amendment Act, down to policies such as those used in the HPCSA or those applied in National Patients' Rights Charter, there is a vertical authority relationship of accountability and responsibility between these levels.
Section 12 of the Constitution (Act 108, 1996) announces the right of individuals to freedom and security, as well as the right to bodily and psychological integrity. This means that a person who is able to make informed decisions about her health also has the right to seek protection against interference by doctors in matters concerning her health. However, this section of the Constitution should not be looked at in isolation. It should always be read together with section 36 for better understanding and interpretation of the law. In this section 36, the constitution states that whenever reasonable and justifiable, there may be some limitation of the right of the individual.

Both the National Health Act and Health Professions Amendment Act reinforce the right of patients to information. In fact, the National Health

Act requires health care professionals to inform patients of any condition or disease from which they are suffering (HPCSA 2007). Doctors are requested to do so in a manner that is easy to follow and use and this should include information concerning the patient's diagnosis, prognosis, treatment options, and outcomes of treatment and potential side effects (ibid). While the Act requires providing patients with basic information about their treatment plan, it also puts a considerable onus on physicians as it requires that they should respect the wishes of any patient who asks not to be given detailed information. The Health Professions Amendment Act states that among its other functions, the HPCSA should control and exercise authority in all matters concerning diagnoses and treatment. The HPCSA should also exercise its power and responsibility in the best interest of the public, in accordance with National Health policy as determined by the Minister of Health. The above strongly suggests that there is no better path of protecting and exercising the right of patients to information (Act 29, 2007). The Act goes further in its legal vision of protecting patients by stating that the HPCSA must ensure that 'doctors' behave in a manner that is inline with the Constitution in that they must respect the right to human dignity, bodily and psychological integrity and equality. If they do not, disciplinary action must be taken against them. If a health care worker were to make medical decisions based on own convictions, she should reconsider and think otherwise.

At the policy level, the law remains enforced with all its vigor. The National Patients' Rights Charter specifies without ambiguity that it is the right of every citizen to participate in the development of health policies and that everyone has the right to participate in decision making in matters affecting one's health (2008). Not only does the Charter promote partnership between doctor and patient, it also highlights the power given to individuals to act as autonomous

individual beings. Furthermore, the Charter stipulates that in matters relating to access to healthcare, information given to patients, should be in the language that they understand best. This is not merely a respect of patients' autonomy, but rather a strong signal that patients are empowered by the law, and doctors should accept their right and thereby promote the notion of informed decision making.

3.2 Practical situations

Practical legal cases in relation to fault to inform patients or from failure to obtain consent exist and the following cases will be used to illustrate this situation.

In the case of *Castell* v *De Greef* (Veriava 2004: 312), emphasis was put on the obligation of the doctor to warn a patient of the risks of a procedure. This case concerns a plaintiff who underwent a mastectomy to reduce the risk for breast cancer with an unsuccessful result; the permanent damage to her left breast needed numerous corrective surgical procedures. The plaintiff claimed that she was not warned of complications and stated that if they were disclosed to her prior to surgery, she would have decided not to undergo the procedure. The evidence however did not support the allegation as the court found that she had been fully aware of the risks of the operation. This case stresses the role of "material risks" in informing a reasonable person to a point that she could not claim not having being informed.

VRM v *the HPCSA* (Veriava 2004:309) is an interesting case. This is a Court of Appeal case from [patient] VRM after the HPCSA Committee of Preliminary Inquiry found no wrongdoing on the part of VRM's doctor who tested her blood for HIV without obtaining a valid informed consent. The appellant stated, similar to her deposition to the

Committee of Preliminary Inquiry that Dr Labuschagne did not counsel her prior to testing her blood for HIV nor did he offer her counseling after the result came back positive. She was informed only when she delivered a stillborn child a month later. The court fundamentally considered the dispute on the issue as to whether Dr Labuschagne informed VRM that her blood was to be tested for HIV putting an emphasis on the fact that it would not be proper to do so without informing VRM of the purpose of the test. Although the court declined to pronounce on the conduct of Dr Labuschagne, it found nonetheless that the Committee of Preliminary Inquiry misjudged its powers and overstepped the bounds of its discretion. The court therefore found that further inquiry was required to resolve the dispute. This case brings some light on what could be considered as a breach of the truth telling process.

Clearly, guidelines on the management of HIV testing exist and doctors should at best follow these procedures although they do not amount to rules and regulations that form part of the Law. The claim by Dr Labuschagne that he had decided not to inform VRM because she was one month away from delivery and he wanted to preserve her best interest from a psychological point of view demonstrates once again how paternalistic doctors can be. By deciding to test her blood, he started a process that required close communication, honesty and full disclosure. VRM, being a competent adult, should have been the one to decide what was best for her, not Dr Labuschagne. Doctors should always start with an assumption that most patients are able to handle bad news. As long as this is not a starting point, those who promote non-disclosure will feel they are in a comfort zone. If the blood test, as was in this case done through a valid informed consent process, dispute concerning the conduct of the doctor would not have been an

issue. This is because a valid consent would in the first place have required Dr Labuschagne to provide VRM with relevant information about the purpose of the test, its advantages and disadvantages, e.g. the impact of a positive result on her pregnancy status and all the pre and post-test counseling that was necessary.

This last case amply stressed the lack of respect of the autonomy of the patient when doctors feel that they can “play God” and decide what is best for patients without their input.

In a similar American case, Schloendorff *v. Society of New York* Hospitals, Justice Cardozo voiced the need to respect patients’ autonomy when he stated in his judgment that surgery ought not to have been performed on the patient as he agreed to let the doctor examine his abdomen under anaesthesia but had specifically refused an operation. The judge declared the following:

> *… every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient’s consent commits an assault, for which he is liable in damages* (Cardozo in Young 2005:445).

The central place of this judgment of 1914 to self-determination of patients has played a major role for the development of informed consent as a legal element. However, later cases have placed emphasis on the disclosure of information to the patient and making her or his consent a truly informed one.

The judgment that should be considered as embedding the notion of informed consent as a medico-legal practice is the case of *Salgo v.*

Leland Stanford Jr University Board of Trustees. This case underlines the requirement of legal duty of disclosure (ibid: 446). It is a case where a patient was debilitated with paralysis of the legs after a procedure. Although the direction given to the jury was involved considering some use of discretion by the physician to minimize alarming information from the patient, the case shed light on the extent and nature of disclosure for consent to be informed. This case tells us that patients should know the risks involved with procedures they may undergo even if this risk is negligible.

While general opinion would consider that such negligible risk and very rare complications of a procedure may be kept silent, the court does not think the same. When considering comparative law, in the UK, in a landmark case of *Canterbury v. Spence*, Judge Robinson once more voiced the notion of autonomy as accentuated by the self-determination of a patient (Mappes and Degrazia 2006: 102). The complainant in this case, a 19-year-old man by the name of John W. Canterbury presented with paraplegia following a back operation. He was not informed of the risks associated with the operation by his physician, William Thornton Spencer. Doctor Spencer actually testified in his defense against the case brought by Canterbury against him and the hospital. He stated that telling the patient of the 1 percent risk was not good practice as this might discourage patients from undergoing needed surgery. However, Judge Robinson argued that it was only up to an adult patient with sound mind to decide what should be done to her or his body.

The court made it clear that no physician can remain silent on the premise that information may push patients to decide otherwise for therapy that the physician perceives as necessary. These cases with

their court outcomes still signal that informed consent can probably not be obtained to its fullest. However, that should not determine how to disclose information on diseases or procedures to be undertaken on competent patients, as they are the best persons to decide on their well-being and what to do with their bodies.

Similar court cases exist in South Africa as well, but going into a detailed discussion of each one is beyond the scope of this research. A few relevant cases are however listed below:

- *Castell v De Greeff, 1994 (4) SA 408 (C)*
- *C v Minister of Correctional services, 1996 (4) SA 292 (T)*
- *Jansen van Vuuren v Kruger, 1993 (4) SA 842 (A)*
- *Broude v McIntosh and Others, 1998 (3) SA 69 (SCA)*
- *Jacobson v Carpenter-Kling, unreported 1998, Transvaal Provincial Division of the High Court*
- *Pop v Revelas, 5 August 1999, High Court of South Africa (Witwatersrand Local Division)*

Chapter 4: Methods

4.1 Objectives

The objectives of this study were four fold:

1. To explore the preferences of patients attending the outpatient clinics at the Johannesburg General Hospital regarding the practice of truth telling.

2. To explore the attitudes of patients attending the outpatient clinics at the Johannesburg General Hospital regarding the practice of truth telling.

3. To assess differences among patients attending different clinics such as medical, surgical and oncology.

4. To identify the characteristics of patients who do not want the truth about their conditions and or their treatment plan as opposed to those willing to do so.

4.2 Study design

This was a cross sectional descriptive method of investigation utilizing a self-administered questionnaire. Data was derived from information from patients attending the adult outpatient clinics at the Johannesburg General Hospital.

Questionnaires were distributed to patients in different areas of the hospital that host these clinics. We distributed these questionnaires in the oncology; medical; surgical and nuclear medicine units on a daily basis for about ten working days.

A color scheme was used on questionnaires to distinguish these clinics from each and other. Patients were given the questionnaires in the outpatient clinics if they were able to read and write (this is not restricted to literacy as patients may have disabilities such as cataract or severe arthritis that will restrict them from reading or writing).

The questionnaires were in three different languages (English, Afrikaans and Zulu) because the majority of patients attending the Johannesburg General Hospital mainly communicate with health care professionals in these languages (Appendix).

Posters with information concerning this study were displayed at the clinics. Nursing staff at the clinics were approached to help in distributing the information sheets and the questionnaires to the patients.

I personally distributed these documents in the Surgical Outpatient Clinic and the Nuclear Medicine Unit (which was considered as a mixed clinic because patients attending the nuclear medicine unit are referred from almost all the disciplines in the hospital).

A box was placed at a designated corner in the clinic and patients were requested to return the questionnaires by placing them inside the box, whether or not they had completed them.

4.3 Study population and sampling

To be statistically significant, we needed at least a hundred replies per clinic for 400 responders. We distributed 600 questionnaires (150 per clinic) and received 465 responses.

4.3. 1 Inclusion criteria

- Only patients attending one of the described outpatient clinics and aged at least 18 years and grouped in five different categories (Appendix)

- Patient who were able to read and write

- Patient who voluntarily agreed to participate

4.3.2 Exclusion criteria

- Patients who were not able to read and write

- Patients attending clinics others than the ones described above

- Patients who did not wish to participate

4.4 Ethical issues

Being a self-administered questionnaire, there was no need for written informed consent, as completion of the questionnaire implies implicit consent. Posters and sheets to inform patients prior to completing the questionnaires were available.

Permission was obtained from the Johannesburg General Hospital management (office of the CEO) (Appendix) to distribute questionnaires to patients attending the selected outpatient clinics and the study was submitted with success to the Human Ethics Committee (Medical) of the University of the Witwatersrand for review and ethical approval (Appendix).

To avoid any concerns regarding healthcare compromise, all patients were requested to return their questionnaires whether

completed or not in a box placed at the clinic. In this way, their identities with regard to non-participation were protected.

4.4.1 Confidentiality

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

4.4.2 Data management and analysis

Percentage of preferences is measured from patients who were willing to know about their conditions and/ or treatment plans and the ones who are not.

To establish differences between clinics and to detect associations among variables measured in a categorical scale (gender, age, education and preference) a Chi-square test was used and a Fisher exact test when necessary with the level of significance at 0.05. Data were analyzed using SAS software version 9.1 (SAS Institute Inc., Cary, NC).

Chapter 5: Results

5.1 Preferences and percentages

We have used a tabular format to list the questions submitted to participants and describe the percentages in relation with demographics and opinions of participants.

Chi-square was used to test the significance of the above-mentioned relation and whenever necessary the Fisher's exact test was of use to measure the statistical significance of this relation.

Four hundred and sixty five (465) participants completed and returned the questionnaires from four different out patient clinics, namely the oncology, surgical (general surgery and orthopedics), medical (gastro, renal and general internal medicine) and the Nuclear Medicine Unit that represents the mixed out patient clinic.

Demographics of participants can be seen in Table 1 and Tables 5 A-D shows demographics of participants in each out patient clinic.

There were 298 females (64.50%) and 164 males (35.50%) participants divided in 5 age groups, 10.97% from group one (1), 15.70% from group two (2), 20.65% from group three (3), 20.88% from group four (4) and 31.83 from group five (5). The results indicate that about three-quarters (73.34%) of participants were 41 years or older (Table 1).

More responses were from the oncology out patient clinic (29.46%) followed by surgical, medical and nuclear medicine out patient clinics with 26.45%, 22.80% and 21.29% of the responses respectively (Table 1). The number of responders was significantly high from oncology as compared to other out patient clinics (p=0.0001).

All participants had some level of formal education and just more than two-thirds (71.24%) of them attended at least a high school (secondary school).

The duration of illness for all participants ranged from 1 month to 432 months (median 26) and Table 4 shows the duration of disease in each of the selected out patient clinics.

The majority of participants stated that the doctor had told them about what was wrong with them (92.90%). Almost all participants thought that patients have the right to know about their condition (98.28%) and also that the doctor has the duty to inform patients of their condition (98.02%) and the information about the condition should be in detail (98.21%) (Tables 2 & 3).

If they were suffering from a “bad” condition, a higher percentage of participants (86.28%) would want to know about their condition while a small but significant percentage (13.72%) would not want to know. When this group was asked on their preference to disclosure if their condition were to be serious, the participants in this small group were equally divided (50.0% each) in supporting disclosure and non-disclosure (Table 3).

The majority of participants (96.64%) also preferred to know about information relating to their treatment in detail and a high percentage (87.83%) would want their family members to be informed of their condition. The majority of this last group would want the information to their family members be given to them in detail (96.38%) (Tables 2 & 3).

When we looked at the group of participants who did not want to be informed of their “bad” condition (13.72%), we found that the majority felt that patients had the right to disclosure (93.44%). Moreover, respondents felt that doctors had the duty to disclose information concerning the condition to patients (93.55%).

About a fifth of participants (19.15%) were not satisfied with the information given to them by their doctors and 70.93% of them did request doctors to provide more information but only few of them (40.0%) were satisfied with the additional information that they received from their doctors.

More than half of 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 (57.14%) or related to their treatment (58.83%).

A considerable percentage of participants (23.73%) felt that in general doctors do not disclose all necessary information regarding the condition and treatment of their patients (Table 2).

5.2 Characteristics of participants

Table 6 represents the characteristics of participants by knowledge of their condition (what was wrong with them) and only gender was a significant factor (p=**0.0176**) while age (p=0.2672) and education (p=0.4509) did not influence the opinions of participants on the knowledge of their condition.

Table 7 shows the characteristics of participants by preference to disclosure and non-disclosure of a “bad” condition and table eight (8) presents the characteristics of participants by preference to disclosure and non-disclosure of details of the treatment.

Tables 9 and 10 present the characteristics of participants by preference to the right of patients to disclosure and by preference to the duty of the doctors to disclosure of all the necessary information concerning the condition and the treatment of patients. The frequency of age, gender and education did not indicate a significant level of difference in opinions of the participants concerning disclosure and non-disclosure (p>0.05) (Tables 7, 8, 9 &10), except for education with regard to the right of patients to disclosure (p=**0.0430**) (Table 9).

Forty nine of all the participants (10.53%) put down comments at the end of questions in the space allocated to them following a statement ‘feel free for any comment’ in the questionnaire (Appendix). After analysis of the 49 comments, we were able to group them in seven (7) different patterns. Only two (2) patterns could be directly linked to the truth telling process. They include comments on disclosure of information and the need for more information from twelve (12) participants, and the need for more time during doctor-patient

communication from five (5) participants. The remainder of the comments was either related to praise of the job done or pure complaints on the logistics or financial structures as well as on medical complications with no direct link to disclosure. For the purpose of this report, four (4) of these comments were randomly selected to illustrate the patterns of comments directly linked to truth telling:

Comment 1: "*I suggest that doctors should have time to inform patients of their condition and feel free to tell patients step by step of their condition. They must have time to listen to patients and answer their question and give advices when it is necessary*". A female graduate aged between 41 and 50 years.

Comment 2: "*The reason for not fully advising all detail is apropos to not fully examining patients themselves at all times. They seem too rushed compared to specialist physicians*". An over 60-year-old male with matric.

Comment 3: "*Some of the doctors do take time to explain. They are the older doctors. The younger doctors' especially in out patients need to take time to listen to patients*". A female participant aged between 51 and 60 years who did not complete matric.

Comment 4: "*I feel that it is important for doctor to discuss the condition of the patient so that they know what is wrong with them, and also explain the medication that they give, how it works and how it will help them because the elderly patients don't understand as the younger ones do. And most of the elderly patients forget what to do so they have to be reminded how to take their medication. Also the doctors must have more patience with elderly people. Thank you. Please keep*

up the good work you are doing. Remember GOD has given you a gift to care for the sick, and you have taken an Oath to care for the sick and those in need. GOD Bless you". An over 60-year-old male with a primary school level of education. [2]

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2 While comment four (4) addresses specifically issues concerning vulnerability, vulnerability *per se* was not the focus of the comments reviewed.

TABLE 1. Demographics characteristics (n=462)

PATIENT		n	%
Gender*:	Female	298	(64.5)
	Male	164	(35.5)
Age (years):	18 – 30 (G1)	51	(10.97)
	31 – 40 (G2)	73	(15.7)
	41 – 50 (G3)	96	(20.65)
	51 – 60 (G4)	97	(20.86)
	> 60 (G5)	148	(31.83)
Education**:	Primary school	58	(12.64)
	High school		
	- without Matric	202	(44.01)
	- with Matric	125	(27.23)
	Graduate		
	- from College	51	(11.11)
	- from University	17	(3.70)
	Post Graduate	6	(1.31)
Clinic:	Oncology	137	(29.46)
	Surgical	123	(26.45)
	Medical	106	(22.8)
	Mixed	99	(21.29)

* 3 participants did not indicate their gender

**** 6 participants did not indicate their level of education**

G1 - 5: age groups

TABLE 2. Responses of Patients to main questions (n=465)

QUESTION	ANSWER	n (%)
Did your doctor tell you what is wrong with you?	Yes	432 (92.90)
	No	33 (7.10)
Were you satisfied with the information given to you?*	Yes	363 (80.85)
	No	86 (19.15)
You need information concerning your bad condition in details**	Yes	390 (86.28)
	No	62 (13.72)
You need information concerning treatment in detail***	Yes	431 (96.64)
	No	15 (3.36)
You want your family to be informed of your condition†	Yes	397 (87.83)
	No	55 (12.17)
You feel that patients have the right to know about their condition††	Yes	446 (98.67)
	No	6 (1.33)
You feel that doctors must inform patients of their conditions†††	Yes	446 (98.02)
	No	9 (1.98)
You feel that doctors do inform patients of all necessary information regarding their conditions⊥	Yes	344 (76.27)
	No	107 (23.73)
You feel that doctors do inform patients of all necessary information regarding their treatment⊥⊥	Yes	344 (76.27)
	No	107 (23.73)

*: 16; **: 13; ***: 19; †: 13; ††: 13; †††: 10; ⊥: 14; ⊥⊥: 14 = Number of patients who did not respond to a question, or did not indicate their preference.

TABLE 3. Responses to sub–questions

QUESTION	ANSWER	n (%)
If you were not satisfied with information given to you, did you ask for more?	Yes	61 (70.93)
	No	25 (29.07)
Were you then satisfied?	Yes	20 (40.00)
	No	20 (60.00)
You do not need information in detail even if your condition is serious?	Yes	29 (50.00)
	No	29 (50.00)
Do you want your family to know about your condition in detail?	Yes	373 (96.38)
	No	14 (3.62)
Do you feel that doctors must inform patients of their condition in detail?	Yes	439 (98.21)
	No	8 (1.79)

TABLE 4. Duration of disease at time of questionnaire completion.

	Median	(Range)
Patients from study group	**26**	**(1 – 432)**
Oncology Clinic	**15**	**(1 – 360)**
Surgical Clinic	**27**	**(1 – 400)**
Medical Clinic	**60**	**(1 – 432)**
Mixed Clinic	**60**	**(5 – 228)**

TABLE 5. Demographics and characteristics per Outpatient Clinic

A. Oncology

		n	%
Gender:	**Female**	**108**	**(80.60)**
	Male	**26**	**(19.40)**
Age (years):	**18 – 30**	**10**	**(7.30)**
	31 – 40	**14**	**(10.22)**
	41 – 50	**34**	**(24.82)**
	51 – 60	**27**	**(19.71)**
	> 60	**52**	**(37.98)**
Education:	**Primary school**	**14**	**(10.29)**
	High school:		
	- without Matric	**60**	**(44.12)**
	- with Matric	**35**	**(25.74)**
	Graduate:		
	- from College	**21**	**(15.44)**
	- from University	**5**	**(3.68)**
	Post Graduate	**1**	**(0.74)**

TABLE 5. Demographics and characteristics per Outpatient Clinic

B. Surgical

		n	%
Gender:	**Female**	**68**	**(55.28)**
	Male	**55**	**(44.72)**
Age (years):	**18 – 30**	**17**	**(13.82)**
	31 – 40	**20**	**(16.26)**
	41 – 50	**24**	**(14.51)**
	51 – 60	**21**	**(17.07)**
	> 60	**41**	**(33.33)**
Education:	**Primary school**	**21**	**(17.80)**
	High school:		
	- without Matric	**50**	**(42.37)**
	- with Matric	**26**	**(22.03)**
	Graduate:		
	- from College	**11**	**(9.32)**
	- from University	**9**	**(7.63)**
	Post Graduate	**1**	**(0.85)**

TABLE 5. Demographics and characteristics per Outpatient Clinic

C. Medical

		n	%
Gender:	**Female**	**60**	**(56.60)**
	Male	**46**	**(43.40)**
Age (years):	**18 – 30**	**12**	**(11.32)**
	31 – 40	**20**	**(18.87)**
	41 – 50	**16**	**(15.09)**
	51 – 60	**25**	**(23.58)**
	> 60	**33**	**(31.13)**
Education:	**Primary school**	**14**	**(13.21)**
	High school:		
	- without Matric	**47**	**(44.34)**
	- with Matric	**31**	**(29.25)**
	Graduate:		
	- from College	**11**	**(10.38)**
	- from University	**1**	**(0.94)**
	Post Graduate	**2**	**(1.89)**

TABLE 5. Demographics and characteristics per Outpatient Clinic

D. Mixed Clinic

		n	%
Gender:	**Female**	**62**	**(62.63)**
	Male	**37**	**(37.37)**
Age (years):	**18 – 30**	**12**	**(12.12)**
	31 – 40	**19**	**(19.19)**
	41 – 50	**22**	**(22.29)**
	51 – 60	**24**	**(24.24)**
	> 60	**22**	**(22.22)**
Education:	**Primary school**	**9**	**(9.09)**
	High school:		
	- without Matric	**45**	**(45.45)**
	- with Matric	**33**	**(33.33)**
	Graduate:		
	- from College	**8**	**(8.08)**
	- from University	**2**	**(2.02)**
	Post Graduate	**2**	**(2.02)**

TABLE 6. Characteristics of the patients by knowledge or ignorance of their condition

	KNOWLEDGE (n)	IGNORANCE (n)	P-value
Age (years):			
18 – 30	**46**	**5**	
31 – 40	**64**	**9**	
41 – 50	**92**	**4**	**0.2672**
51 – 60	**91**	**6**	
> 60	**139**	**9**	
Gender:			
Female	**283**	**15**	**0.0176**
Male	**146**	**18**	
Education:			
Primary school	**54**	**4**	
High school:			
- without Matric	**187**	**15**	
- with Matric	**119**	**6**	
			0.4509
Graduate:			
- College	**47**	**4**	
- University	**14**	**3**	
Post Graduate	**5**	**1**	

TABLE 7. Characteristics of the patients by preference for disclosure or non-disclosure of a less desirable condition

	DISCLOSURE (n)	NON-DISCLOSURE (n)	P-value
Age (years):			
18 – 30	**46**	**5**	
31 – 40	**65**	**6**	
41 – 50	**80**	**14**	**0.1615**
51 – 60	**84**	**10**	
> 60	**115**	**27**	
Gender:			
Female	**248**	**40**	**0.9473**
Male	**139**	**22**	
Education:			
Primary school	**48**	**7**	
High school:			
- without Matric	**165**	**29**	
- with Matric	**106**	**17**	
			0.9007
Graduate:			
- College	**45**	**6**	
- University	**14**	**3**	
Post Graduate	**6**	**0**	

TABLE 8. Characteristics of the patients by preference for disclosure or non-disclosure of treatment details

	DISCLOSURE (n)	NON-DISCLOSURE (n)	P-value
Age (years):			
18 – 30	**50**	**1**	
31 – 40	**68**	**1**	
41 – 50	**90**	**4**	**0.0692**
51 – 60	**93**	**0**	
> 60	**130**	**9**	
Gender:			
Female	**280**	**8**	**0.3346**
Male	**148**	**7**	
Education:			
Primary school	**52**	**3**	
High school:			
- without Matric	**187**	**6**	
- with Matric	**117**	**4**	
			0.2812
Graduate:			
- College	**48**	**0**	
- University	**15**	**2**	
Post Graduate	**6**	**0**	

TABLE 9. Characteristic of the patients' opinions on the right of patients to disclosure

	DISCLOSURE (n)	NON-DISCLOSURE (n)	P-value
Age (years):			
18 – 30	**50**	**1**	
31 – 40	**70**	**1**	
41 – 50	**92**	**0**	**0.7219**
51 – 60	**93**	**1**	
> 60	**141**	**3**	
Gender:			
Female	**289**	**3**	**0.4369**
Male	**154**	**3**	
Education:			
Primary school	**53**	**1**	
High school:			
- without Matric	**193**	**3**	
- with Matric	**122**	**0**	
Graduate:			**0.0430**
- College	**51**	**0**	
- University	**15**	**2**	
Post Graduate	**6**	**0**	

TABLE 10. Characteristics of the patients' opinions on the duty of the doctor to disclose all information

	DISCLOSURE (n)	NON-DISCLOSURE (n)	P-value
Age (years):			
18 – 30	**50**	**1**	
31 – 40	**71**	**1**	
41 – 50	**92**	**1**	**0.9094**
51 – 60	**92**	**2**	
> 60	**140**	**4**	
Gender:			
Female	**289**	**4**	**0.1959**
Male	**154**	**5**	
Education:			
Primary school	**52**	**2**	
High school:			
- without Matric	**193**	**6**	
- with Matric	**124**	**0**	
			0.2339
Graduate:			
- College	**50**	**0**	
- University	**16**	**1**	
Post Graduate	**6**	**0**	

Chapter 6: Discussion and Conclusion

6.1 Clinical experience

Truth telling in clinical practice has been subject to debate and will most likely continue to be scrutinized for a long period to come. Our study found that 86.28% of participants preferred to be told about their condition. This finding is similar to the results of studies that looked at the attitude of patients toward truth telling of cancer (Wang, *et al.* 2004:53) or the approach to the clinical care of the terminally ill patients (Shen 1984:351). The high percentage in our study could possibly be explained by the increased awareness of truth telling due to improved media coverage and communication of health issues on television and radio programs. This positive attitude toward truth telling was noted across all age groups and gender and was not influenced by the level of education of the participants in the study. Even when the group of participants with the lowest education level (primary school) was assessed separately, a similar percentage to the group as a whole (87.20%) was noted to show preference to disclosure of a “bad” condition. However, education was a sole factor that influenced participants’ opinions with regard to the right of patients to disclosure.

Our data did not support previous findings that younger and higher educated patients would likely be the ones wishing to know their diagnoses for a bad condition (Blackhall, *et al.* 1995:820, Meyza 1997:468, Wang 2004:57). All these previous findings are from patients that were suffering from cancer. Moreover, when we looked at the percentage of participants from our study selected from the oncology out patient clinic, we found a similar percentage willing to know about

their condition (87.41%) regardless of age, gender or the level of education.

The percentage of participants who preferred not to be told the truth was small but significant (13.72%). This finding is in accordance with the literature that a significant but small group of patients whose wishes not to be informed must be respected (Higgs 2006:93). However, the percentage of this group of patients not wishing to be informed was almost twice the percentage found in the study of Wang, *et al.* (2004:57) in patients with cancer. However, if we considered only the participants from the oncology out patient clinic, the percentage of those not wishing to be informed remains quite similar to the percentage found in Wang *et al.* 's (ibid) study (12.59%).

Contrary to the study by Wang, *et al.* where about one-third (37.4%) of participants did not prefer that relatives be informed of a cancer diagnosis, our results showed a higher percentage (87.83%) of participants wishing that their relatives be informed of their condition. Our study was in agreement with the findings of the study on truth telling and patients' diagnoses where 85.0% of patients who were attending an acute care hospital have indicated their preference for disclosure to relatives (Sullivan, *et al.* 2001:193). Looking at participants from the oncology out patient clinic alone, the majority of participants (90.23%) would also want their family members to be informed of their condition and thereby support disclosure to relatives.

Furthermore, our study also looked at the attitude of patients towards the preference of disclosure of information regarding treatment. The Code of Medical Ethics stresses that the patient has the right to decide jointly with the physician on the preferred type of treatment (Wang, *et*

al. 2004:57). In addition, the National Health Act in South Africa stipulates that health care practitioners must inform patients of the range of diagnostic procedures and treatment options generally available to them; in addition, patients also have a right to information of treatment options, its outcomes and side effects (NHA: 2007). In the study cited above, (Sullivan, *et al.* 2001:193) found that 95.0% of patients experienced a better outcome of the course of disease if they were involved in their treatment. Similarly, our study found that the vast majority of participants showed preference to disclosure of treatment in detail (96.64%). This preference to disclosure of information of treatment did not differ among participants attending various out patient clinics; 97.71% from the oncology clinic, 95.73% from surgical, 96.08% from medical and 96.88% from the mixed out patient clinic.

This study was primarily about preferences and attitudes of patients towards truth telling. While doctors did not participate in the study, an indirect implication to truth telling could be derived from some of the opinions expressed by participants, such as those contributing the knowledge of their condition as a direct result of being informed by their attending doctors. Furthermore, the ability of participants to clearly express satisfaction and dissatisfaction to the information received from their doctors enhances the possibility of the indirect implications of truth telling.

The majority of participants in this study indicated that they have been told about their condition (92.90%) and this percentage shows a degree of openness towards disclosure of information to patients by the doctors who work in the Johannesburg General Hospital. However, when participants were asked if they were satisfied with the information given to them a considerable percentage (19.15%) disagreed and

about two-thirds of them indicated the need to have requested for more information, but only 40% of them were satisfied with this additional information.

These figures may indicate a need for doctors in our institution to revisit the manner in which they inform patients of their condition and perhaps more importantly try to incorporate a simple question such as ‘are you satisfied with the information?’ as a means of assessing the satisfaction of patients. This kind of question could allow doctors to understand the position of patients and provide more information whenever required. The findings of our study somehow echo the results of the study by Sullivan *et al.* who found that about a quarter of the physicians in their study stated that they only inform their patients about 50.0% to 90.0% of the time (2004:196). Although medical ethos would require that all patients be informed, the practical scenario has been quiet different as there will always be a number of those who will claim that they were not informed. In studies that were conducted in the past thirty years, about 20.0% of patients would deny being told even if they were given information (Higgs 2006:93).

Three situations usually attempt to explain this position; pure forgetfulness from patients, a lack of skill of the informer and lastly an element of denial when patients cannot accept the validity or reality of what has been told to them. More interestingly, the same studies have demonstrated a curious double standard from doctors in that most of them wish to be told the truth themselves, but, at the same time, those same doctors said that they would not speak openly to their patients. These attitudes make truth telling a process which may never be achieved in full.

Interestingly enough, in the literature the percentage of patients who would deny being informed, resemble the percentage of participants in our study who felt that doctors do not disclose all necessary information concerning the condition and treatment of patients (23.73%), although the majority of participants have indicated that they were told of their condition (92.90%). The element of satisfaction with the quality and quantity of information given to patients could possibly influence their opinions regarding their acceptance of disclosure. In our study, 19.15% of participants were not satisfied with the information given to them concerning their condition and more than half of these participants felt that doctors do not disclose all sufficient information related to the condition (57.14%) or the treatment (58.33%) of the patients.

6.2 Right to disclosure

Undoubtedly, patients have the right to be informed of their condition. Both the Code of Medical Ethics (Wang, *et al.* 2004:57) and both the National Health Act (Pretoria 2007) and the Bill of Rights in the constitution (Act 108, 1996) support the right of patients to be informed. In our study, almost all participants felt that patients have the right to know about their condition (98.67%) with an emphasis on the duty of the doctors to inform them in detail (98.21%). These figures correspond to the findings of Schreiber in a study that looked at preference to direct disclosure of radiological findings to patients (1996:1091). In that study, 99.0% of the 261 patients responded positively in a survey that used questionnaires and wanted to be told of their results directly by radiologists to know what the findings were. In our study, variables such as age, gender or education did not affect the opinions of participants with regard to their preference to the right to disclosure.

Reasons to support the high level of awareness to the right to disclosure cannot be stated, as the study did not look into it. However, Surbone, *et al.* think that participation in clinical trials promotes awareness as trials have made breast cancer patients aware of choices they had (2004:167). In a large institution like the Johannesburg General Hospital, similar reasons should not be ignored. One should also keep in mind the increasing role of media, looking at the number of programs that deal with medical issues.

Finally, like everywhere in the world, we see in the streets of our big cities and in front of our courts, many activists who draw thousands of people into campaigns to claim the right to treatment for HIV infection and these gatherings offer a platform to educate patients on their rights. Although the majority of participants felt that patients had the right to disclosure, a significant number (13.72%) of all participants have 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 (Wang, *et al.* 2004:57). The small but significant percentage of participants in our study who expressed their right not to be informed fall in line with current literature which states that a small group of those who wish not to be informed exist and must be respected (ibid; Higgs 2006:93). The percentage of participants who wish not to be informed in the promotion of non disclosure did not change when considered from within participants from each out patient clinic, 12.59% in oncology, 10.17% in surgical, 15.38% in medical and 17.89% in mixed.

What seems controversial however is that the majority of these participants who supported non-disclosure still felt that patients had the right to know their condition (93.44%).The reason for this conflicting

opinion of preference will not be known unless direct interviews are conducted with this subgroup of participants.

6.3 Respect for autonomy

6.3.1 Background

The issue of truth telling forms part of the contemporary debate on patients' right to know and doctors' duty to inform. After the distressingly sad stories that were heard in the Nuremberg trials, effort was directed towards better communication between patient and doctor (researcher and participant), mainly to make sure that the patient or research participant is informed and voluntarily consents to a treatment or procedure. The principle of beneficence alone was not enough to protect individual from harmful procedure (Surbone 2006:945).

In reality, those concerns started to influence the practice of medicine only in the years 1970 to 1980 as the notion of "autonomy" of patients became the leading principle in Western bioethics and information rendering (Surbone, *et al.* 2004:166). It is however, in the 1990's that truth telling attitudes and practices were starting to be openly discussed outside of the Anglo-American context (Surbone 2006:945). It is only from this period onward that physicians were put to the test to disclose more frequently.

Currently, the key issue in the topic of truth telling would be to know if philosophy should be applied in the practice of medicine. Different tales from patients with different outcomes exist. The public impression -may be justified- that doctors prefer concealing information. As Higgs (2006:90) puts it in a more understandable way, that though fear of the unknown is mostly the actual disease above all physical disease for

many patients, direct information seems so hard to obtain. This comes from the day-to-day impression that doctors are too busy to talk to their patients. And when they are not too busy, they still seem to be keeping information 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 they has been told of their condition, although a significant proportion was not satisfied with the information received. Satisfaction with the information brings in a different dimension to the process of truth telling. The picture becomes rather gloomy in situations whereby news to be told is not good. The case of the elderly woman described by Higgs (2006:90) actually says it all. She in fact learned to expect from doctors, silence at the best, and deception at the worst. Her sentiments are perhaps supported by doctors themselves as Higgs (ibid: 433) described the feelings and statement of a young doctor who just broke bad news to a patient and muttered as he was walking away from a crying patient that he did not surely sign up for a kind of dreadful job. Hoffman, *et al.* (1994:598) enhance that feeling by stating that every physician “hates” to convey bad news and particularly to tell a patient that she might have cancer. The direct implication of the scenario can easily create a picture of a young doctor who would most likely, in future similar situations, prefer to control the information by being quiet, or simply let someone else deal with it.

Moreover, when one considers the chain of events that such attitudes may produce, particularly if everybody would prefer someone else to break the bad news, or in worst-case scenario everyone keeping quiet, potential consequences can only be imagined. Doctors in our environment should perhaps be reassured with the findings of our

study indicating that patients in high percentages (86.28%) would like to know about their condition.

6.3.2 Physician-patient relationship

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

It is essential that physicians first start by accepting the centrality of the patient, and more importantly acknowledge the fact that they are dealing with autonomous beings that are capable of making decisions about what is best for them. Furthermore, a need for the best outcome concerning the patient's management and preferences should come from the patients themselves. If looked at from this perspective, most of unnecessary hiccups could be avoided as patient and doctor will be in a relationship that may be categorized as a close partnership with the best interest of both at heart, and where both are seen as equal.

Actually, there is no need for physician-patient relationships to differ from other relationships between human beings in the society in general. If exception should be granted to the so-called "special relationship" then principles that guide morality and ethics should be applied on an equal basis. The attitudes that treat them as two separated extremities with the knowledge in the field of medicine and the other being that of seeking help as an uninformed person, should move away from the traditional web of thinking when dealing with truth telling.

A key issue remains concerning an understanding what actually constitutes the truth. In the physician-patient relationship, there is a

need to move away from taking the truth as the opposite of lies or simply a sum of correct statements but rather as a situation in which a physician-patient relationship becomes an entity that depends on mutual responsibilities (Da Silva, *et al.* 2007:281). The relationship should be based on openness and willingness to establish a social contract between the two partners notably the doctor and the patient. The established relationship should therefore be based on mutual rights and rules (ibid). Accordingly, it also becomes important for special responsibilities on the part of the doctor in establishing a true relationship of trust between her and her patient. However, here the debate on when and how to tell the truth resurfaces.

Often, the question is not *if the truth should be told but what would the justifications be to tell a lie* (Higgs 2006:91). The issue of doctors being part of common society comes in sharply here, in that, general morality should guide them and they should avoid considering themselves as part of a separate entity with their own rules. Should the question arise as to whether doctors have a special dispensation from principles that usually guide the conduct of the public?

The answer is that the feeling among the community of doctors is that they are granted that special cover in some situations. If fact, the statement of Lawrence Henderson (cited in Higgs 2006:91). supports this view when saying:

> *…it is meaningless to speak of telling the truth, the whole truth and nothing but the truth to a patient…because it is…a sheer impossibility…Since telling the truth is impossible, there can be no sharp*

distinction between what is true and what is false…"

In opposing Henderson's statement, Higgs believes that the concept of truth, which is abstract and of course difficult to grasp, should be better assessed by an element of intention, to tell the truth or to lie (2006:92). In fact, the words of Sissela Bok should resonate in everyone's mind when the question of intention has been brought to challenge the measure of truth or lie. She argued that the moral question of whether someone is lying or not is not settled by establishing the truth or falsity of what she says but in assessing whether she intends her statement to mislead (ibid). Once again, the findings of our study convey to doctors in our institution a signal that the majority of patients would like to know the truth about their condition and treatment plan. These findings therefore inform a direct plea to doctors to choose the truth to guide their interactions with patients.

6.3.3 Paternalism

The 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 a unilateral view that the physician is the only one with knowledge and power to decide and dictate in a vertical line and authoritative way of communication (Da Silva, *et al.* 2007: 280). This view should find no place in our environment as supported by the findings of our study that almost all participants (98.67%) indicated that they felt patients had the right to disclosure on information concerning their condition.

When therapeutic privilege is cited by those who support paternalist attitude, a counter argument is that physicians who favor this view and

such behaviors truly try to control patients, because they consider themselves as special guardians with knowledge and can simply decide when and to whom to reveal the truth (ibid: 281).

It is imperative that doctors understand that patients are autonomous being and that respecting their autonomy means that they should be informed. While exceptions may be accepted in some circumstances in diagnosis and prognosis, they do not limit doctors for being open and sharing with their patients in a manner which is acceptable to both parties.

Secondly, in the effort to minimize 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 her or himself (Higgs 2005:435).

Again, the figures from our study are clear. Participants in an overwhelming majority (96.64%) supported the disclosure of information relating to their treatment. There should therefore be no uncertainly in considering them as partners for better treatment outcome. Furthermore, the National Health Act is more than clear regarding information concerning treatment to the primary beneficiaries, who are the patients themselves (NHA 2007).

Paternalism is often used in countries where families play a central role in the life of individuals and control communities' values. In such situations, the word 'autonomy' is really perceived as being synonymous with the need for isolation of the person concerned in lieu of the freedom of the person (Surbone 2006:945). The direct consequences of this different perception is that families and doctors will most likely try to 'control' the patients by assuming protective roles and will withhold information and medical truth that they judge to be potentially painful for the patient. Viewed from a Western medical

perspective, these attitudes affect and restrict patients' rights to knowledge and freedom of choice in management decisions regarding their own health. However, when taken from a communitarian perspective, where the autonomy of an individual is not emphasized, the community's values take priority. These differences serve to influence a physician's role in truth telling.

From a Western perspective, it is in the *task* of telling that, at least as postulated by Higgs (2006: 93), that doctors have traditionally misunderstood the wishes of his or her patients. It appears that just as doctors do not want to give bad news similarly, patients do not want the bad news presented to them in a detached manner. Therefore, it falls upon the doctors to choose what if any information should be kept to protect themselves from both the pain of telling and for the blame that may be put on them as the ones who broke the bad news (ibid). The whole issue here remains to define clearly, if doctors are allowed to withhold information in specific occasions thus acting in a paternalistic way. If they do withhold information, it may be taken as if they consider their patients as incompetent individuals who cannot understand their situations and *de facto* cannot decide what is good for them. On the other hand, the situation is not so clear-cut.

While it is true that truthfulness can truly do harm as 'what one does not know can not hurt', an important consideration is the manner in which the truth is conveyed to a patient. Here, several factors should be considered such as 1) the time of giving the information, particularly for bad news, 2) the environment in which the information is given, 3) the manner in which information is given, 4) types of words used, and most importantly 5) the attitude of the informer of the bad news.

While acceptance exists for doctors to be exempted from the society's general requirement for truthfulness, there are also statements saying that not telling the truth is the same as telling a lie (Higgs 2006:94). And it seems as if those primarily opposed to keeping the truth secret, at least in some occasions, give the impression of accepting that somehow there are circumstances whereby truth may be withheld. They do so in statements that request strong justification for a lie and suggest that lying must be a last resort (ibid: 95).

6.3.4 Conclusion

Truth telling in clinical practice seems to offer ways for quality debate. It can be consolidated by ways of creating a concrete partnership between doctor and patient, the two individuals engaged in a bond that should result in a good outcome to the ultimate satisfaction of both parties.

Our study confirms the current worldwide awareness of patients regarding their right to information concerning their condition or their treatment most likely resulting of improved media coverage of medical issues. As in others 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. 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 level of information given to them was not satisfactory, even when they requested for more. This brings a need to look at the way information is given to our patients and seek ways on how this can be improved.

We also found, in accordance with current literature, that there was a small but significant group who did not wish to be told their diagnosis. If we understand and respect the autonomy of our patients regarding their right to disclosure, then it should not be difficult to crossover to the other side and respect the right of those who choose non-disclosure. It remains however amazing to note that almost all participants, including the group that chose non-disclosure, felt that patients had the right to be informed at the same time that doctors had the duty to inform them.

Even in the small group of patients that did not want to be informed, there was obvious recognition of the right of patients to making choices with regard to disclosure of information.

We can conclude that contrary to our perception, patients attending the Johannesburg General Hospital are given information about their conditions. The problem, if any, resides in the quality and the quantity of information given. As suggested by the findings of our study, about a fifth of participants were not satisfied with the information given to them. More importantly, when they requested more information, less than half were satisfied with the additional information they received.

Recommendations from this study are as follows:

It will be interesting to conduct a similar study to assess the preferences and attitudes of doctors in our environment and another study in surrounding hospitals in our province. Where we could not find reasons for conflicting opinions, it would be preferable to undertake a direct interview with patients.

It would be interesting to note results of qualitative research in this arena. This would assist in understanding patient perception.

While the majority of patients were made aware of their medical condition, a significant percentage was not satisfied with the information given to them. Based on this, it is recommended that programs to enlighten health practitioners be established where non-existent or reinforced where already underway.

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Appendix

English version

Information leaflet

Patients seen at the University Hospital in Johannesburg: their views on Truth-Telling

Hallo,

Introduction:

I am Professor Willy Vangu and I am conducting this research. The research is part of the requirement for a master degree Bioethics and Health Law. This research is in the form of a survey on patient-doctor communication in this hospital. We are trying to learn about how much information is given to patients attending this hospital and what and how much you as a patient would want to know from your doctor.

Invitation to participate:

We are inviting you to take part in this survey by answering a set of questions.

What is involved?

This is a questionnaire regarding information given by doctor to patients and information requested by patient from doctors. You are requested to select a simple “yes” or “no” to questions that should not take more than 10 minutes of your time.

Risks

This is a survey that requires only answering questions without a risk to participating.

Benefits

There is no direct benefit to you in participating in this survey. However, answering this questionnaire may help doctors understand the needs of patients regarding information about their condition and treatment.

Participation is voluntary but you are required to return this questionnaire even if you do not complete it. This is to protect you from being identified as a non participant. However, please be reassured that you will not be penalized if you do not fill the questionnaire.

Confidentiality

This is an anonymous survey that does not require your personal information.

Contacts

Should you require information regarding this study, please feel free to contact me at 011 488 3608.

Should you have any concern as a participant, please contact Prof Clinton Jones from the Research Ethics Committee that has approved this study at 011 717 1234

Thank you

Willy Vangu

Thank you for taking time to answer these questions

Your gender: Female □ Male □

Your age group: 18-30 □
31-40 □
41-50 □
51-60 □
Over 60 □

Your education: Primary school □
High school □ with matric pass □ no matric □
Graduate □ from College □ from University □
Postgraduate □
Other (specify):……..

Please, select the appropriate answer

How long you have been a patient with the current condition?:

…….weeks, ……months, ……. Years

Did your doctor tell you what is wrong with you? yes□ no□

If yes, in details□ general terms□

Were you satisfied with the information given to you? yes□ no□

If no, did you ask for more? yes□ no□

If yes, were you satisfied? yes□ no□

You need information concerning your bad condition in details yes□ no□

If no,
Even if your condition is serious, you don't need to be told yes□ no□

You need information concerning treatment in details yes□ no□

You want your family to be informed of your condition yes□ no□
If yes, in all the details yes□ no□

You feel that patients have the right to know about their condition yes□ no□

You feel that doctors must inform patients of their condition yes□ no□

If yes, in all details yes□ no□

You feel that doctors do inform patients of all the necessary information with regard to their condition yes□ no□

You feel that doctors do inform patients of all the necessary information with regard to their treatment yes□ no□

Feel free to add any comment

Thank you once more for answering this questionnaire

Afrikaanse weergawe

Inligtingsblad

Menings oor ware inligting vanaf pasiënte by Johannesburgse Universiteits Hospitaal.

Hallo,

Inleiding:

Ek, Prof. Willy Vangu is tans besig met navorsing vir ‘n Meestersgraad in Bioetiek en Gesondheids Wet. Hierdie navorsing is gedeeltelik in die vorm van ‘n vraelys rondom pasiënt – dokters kommunikasie. Die bedoeling is om uit te vind hoeveel inligting die pasiënt van sy geneesheer verlang.

Uitnodiging om deel te neem
U word uitgenooi om deel te neem by hierdie vraelys.

Wat dit behels
Hierdie is ‘n vraelys rondom inligting wat dokters aan pasiënte verskaf en inligting wat die pasiënt van sy dokter verlang. U word versoek om ‘n eenvoudige “ja” of “nee” te kies en dit behoort u nie langer as tien minute te neem nie.

Risiko
U deelname behels geen risiko nie

Voordele
U deelname bevat geen direkte voordele nie, maar hierdie vraelys mag dokters help om beter te verstaan wat pasiënte se behoeftes rondom inligting oor hulle siekte en behandeling is.

Vrywillige Deelname
Deelname is vrywillig, maar u is verplig om hierdie vraelys aan ons terug te gee, al het u dit nie ingevul nie. Dit is om u identiteit te beskerm sou u verkies om nie deel te neem nie. Nietemin kan u verseker wees dat u nie gepenaliseer sal word sou u verkies om nie deel te neem nie.

Vertroulik
Hierdie vraelys is vertroulik en bevat geen persoonlike inligting nie.

Kontakte
Indien u meer inligting verlang omtrent hierdie studie, voel gerus vry om my te kontak by 011 488 3608.

Sou u enige bekommernisse as pasiënt mag hê, staan dit u vry om Prof. Clinton Jones wat hierdie studie goedgekeur het te kontak by die Research Ethics Committee by 011 717 1234

Baie Dankie
Willy Vangu

Dankie vir u deelname aan hierdie vraelys

U geslag: Vroulik Manlik

U ouderdomsgroep
18–30
31-40
41-50
51-60
Over 60

U opvoeding
Primêr
Sekondêr Matriek
>Matriek
Tersier Kollege
Universiteit
Nagraads
Ander (spersifiseer)…….

Kies asseblief die toepaslike antwoord
Hoe lank is u ‘n pasiënt met u huidige siekte

…….weke ……..maande
…….jare

Het u dokter u vertel wat is fout met u? Ja
Nee

Indien wel in detail alg.
Terme

Was u tevrede met die inligting Ja
Nee

Indien nie, het u meer inligting versoek Ja
Nee

Indien wel, was u toe tevrede Ja
Nee

Benodig u inligting omtrent u siekte toestand in detail Ja
Nee

Indien nie, selfs as die toestand ernstig is, verkies u om dit nie te weet nie Ja
Nee

U verlang inligting i.v.m u behandeling in detail	Ja Nee
U verwag dat u familie ingelig word omtrent u siekte	Ja Nee
Indien wel, in detail	Ja Nee
U voel pasiënte het die reg om te weet van hulle siekte	Ja Nee
U voel dokters is verplig om pasiënte van hulle siekte in te lig	Ja Nee
Indien wel, in detail	Ja Nee
U voel dat dokters al die inligting van hulle siekte aan pasiënte verskaf	Ja Nee
U voel dat dokters al die inligting van hulle behandeling aan pasiënte verskaf	Ja Nee

Weer eens dankie dat u die vraelys voltooi het

Isizulu

Ipheshana lolwazi

Iziguli ezibonwa e University Hospital yase Johannesburg: imibono yazo ngokukhulunwa kweqiniso.

Sanibona,

Isiqalo:

Igama lami ngingu Professor Willy Vangu ophethe lolucwaningo. Ucwaningo lolu luyingxenye yezi fundo zami ze master degree Bioethics and Health Law. Lolu cwaningo lubheka ukuxhumana ngenxoxo phakathi kwadokotela nesiguli sakhe. Sizama ukufunda ukuthi lungakanani ulwazi olunikwa iziguli ezihamba lesisibhedlela. Nokuthi yini wena njengesiguli ofuna ukuyazi kudokotela wakho.

Isimemo sokuthi uhlanganyele kulolucwaningo:

Siyakumema ukuthi ubeyingxenye yalolucwaningo ngokuthi uphendule imibuzo embalwa.

Emayelana nani?

Lena yimibuzo emayelana no lwazi odokotela abalunika iziguli no lwazi oludingwa iziguli kodokotela. Kudingeka ukhethe impendulo ewu “yebo” noma “cha” yalemibuzo engeke ithathe ngaphezu kwemizuzu eyishumi.

Ingozi

Kulolucwaningo sidinga izimpendulo zakho kuphela. Ayikho ingozi.

Inzuzo

Ayikho inzuzo ezakuwena nqo ngokuphendula lemibuzo. Kodwa ukuphendula lemibuzo kungasiza odokotela baqonde izidingo zeziguli ngolwazi olumayelana nezifo eziziphethe nokwelashwa kwazo.

Ukuhlanganyela kulolucwaningo akuphoqelekile kodwa sicela ulibuyise lelipheshana noma ungaliphendulanga. Angeke uhlawuliswe ngokukhetha ukungabi ingxenye yalolucwaningo.

Ukufihlakala

Lolucwaningo aludingi ukuthi uzazise.

Ukuxhumana nami

Uma udinga ulwazi ngalolucwaningo, ungakhululeka ukungifonela kulenamba 011 488 3608.

Uma kukhona okukuhluphayo ngalolucwaningo, sicela ufonele u Prof Clinton Jones e Research Ethics Committee okunguye ovumele lolucwaningo kulenamba 011 717 12

Ngiyabonga

Willy Vangu

Ngiyabonga ngokuthi uthathe isikhathi sakho uphendule lemibuzo:

Ubulili bakho: Sifazane □ Silisa □

Iminyaka yakho: 18-30 □
31-40 □
41-50 □
51-60 □
Ngaphezu kwa 60 □

Imfundo yakho: Isikole sebanga eliphansi (iPrimary school)□
E High school □ uMatric □ Awunawo uMatric□
Iziqu □ zase Kolishi (College) □ zase Nyuvesi (University) □
Iziqu phezu kweziqu (post graduate) □
Okunye (chaza):…….

Sicela ukhethe impendulo:
Sekuyisikhathi esingakanani uphethwe ilesisifo esikuphethe?:

……amasonto, ……izinyanga, …….. iminyaka

Wakutsela udokotela wakho ukuthi uphethwe yini? Yebo□ Cha□

Uma yebo: Wachaza kabanzi□ Kafishane□

Waneliseka ngencazelo? yebo□ cha□

Uma cha, wacela ukuthi acacise?
yebo□ cha□

Uma yebo, waneliseka? yebo□
cha□

Uyafuna ukwazi noma isimo sakho sibucayi? yebo□
cha□

Uma cha,
Uma isimo sakho sibucayi awufuni ukutselwa yebo□ cha□

udinga ulwazi olubanzi ngokulashwa kwakho yebo□
cha□

Ufuna umndeni wakho waziswe ngesifo sakho yebo□
cha□
Uma yebo, kabanzi na? yebo□ cha□

Uvumelana nokuthi iziguli zinelungelo lokuthi zazi ngezifo eziziphethe
yebo□ cha□

Uvumelana nokuthi odokotela kufanele batsele iziguli ngezifo eziziphethe
yebo□ cha□

Uma yebo, kabanzi na yebo□
cha□

Ubona sengathi odokotela bayazinika ulwazi iziguli ngezifo eziziphe
yebo□ cha□

Ubona sengathi odokotela bayazinika ulwazi iziguli ngokulashwa kwezifo eziziphethe yebo□ cha□

Siyabonga ngokuphendula imibuzo yethu.