

The right to respect for autonomy

Part I — What is autonomy all about?

Dain van der Reyden, LLM

Nat Dip OT (PTA), DipEd Voc Ther (PTA), BA (UNISA), LLM (Med.Law)(UKZN)

ABSTRACT

This paper seeks to clarify the nature, extent and significance of a patient's right to respect for autonomy from the practitioner. It is one of two articles and attempts to contextualise patient autonomy within a legal, bioethical and professional perspective. The Bill of Rights contained in the Constitution of the Republic of South Africa (108 of 1996), the Mental Health Care Act (17 of 2002), the National Health Act (61 of 2003) the Promotion of Access to Information Act (2 of 2000) as well as the rules of Professional Conduct as stipulated in the Health Professions Act (56 of 1974) are discussed as relevant to patient/client's right to respect for autonomy and inherent within that right, the right to informed consent, confidentiality, refusal of treatment, a second opinion, access to personal information and to be treated with respect and dignity. Common and case law are addressed briefly together with the bioethical principle of 'respect for autonomy.' Commentary is given on each of the Acts with a view to professional practice implications.

Key words: patient autonomy, ethics, legislation, occupational therapy, patient rights

Introduction

The concept of autonomy has been integral to the debate of what constitutes humankind since the time of Plato and Aristotle¹ with rationality being the thread running through scholars' thinking. The concept of patient autonomy however only gained recognition during the 1950s, together with a greater sense of the need for truth and justice in patient care². This concept is fundamental to an understanding of the ethical and legal obligation of respect for the autonomy of the patient/client. Inherent in this obligation is the right to informed consent, confidentiality, refusal of treatment, a second opinion, access to personal information and to be treated with respect and dignity. This paper attempts to clarify the concept of patient autonomy within a legal and ethical context and provides some insights of relevance to daily practice.

Several factors significant to the profession, make it necessary to examine the issue of patient/client autonomy more closely. These include managed health care, consumer rights movements, and in particular disability rights movements³, the Bill of Rights of the South African Constitution⁴, health professional practice requirements, recent South African Legislation^{5,6}, the emergence of alternative health care options, easy access to health information and a strong client centred approach to intervention.

On investigation the concept of autonomy, particularly from a legal perspective, has proved to be more complex than it would seem from superficial review. Its significance lies in the fact that it impacts on every facet of practice and that attitudes and behaviours which previously were ethical aspirations are now legal requirements.

As occupational therapists we need to gain a fuller understanding of the concept and implications of the ethical principle and the professional duty of **respect for patient/client autonomy** and must become more aware of factors limiting or impacting on such autonomy. The practitioner should not only accommodate respect for patient/client autonomy within daily practice, but also be able to facilitate the development of such capacity in order to enhance all interventions.

This paper together with part 2 (to be published later), seeks to examine patient autonomy within the context of occupational therapy in South Africa. It briefly reviews autonomy from a bioethical, and thereafter from a legislative and common law perspective. Relevant codes of ethics are examined and limitations to autonomy considered, particularly with regard to the opportunities and limitations created for practice.

Patient/client autonomy must firstly be placed within the framework of the *practitioner-patient relationship*, the nature of which is largely determined by the relational model adopted, as this defines the way in which the autonomy of the patient/client is viewed and accommodated. The deliberative model as proposed by Emanuel and Emanuel⁷ seems to be the most appropriate. In contrast to the paternalistic medical model, it adequately accommodates the nature and practice of our profession. It presupposes ongoing interaction, communication and negotiation between the practitioner and the patient/client in an ongoing relationship in which patients/clients will be free to critically assess, change or affirm their values and preferences, and based on these, make decisions in keeping with their life choices. The role of the practitioner, on the other hand, is seen as that of integrating relevant information, and through discussion of such information and related values, guidelines and recommendations, to help empower the individual to make appropriate decisions.

What then is autonomy all about?

Personal autonomy refers to the personal rule of self that is free from interference by others and from personal limitations that prevent meaningful choice⁸. Mappes and DeGrazia⁹ characterise an autonomous person as someone who is capable of making rational and unconstrained decisions and being able to act accordingly. Being autonomous furthermore implies the ability to make decisions in keeping with personal goals, acting in a responsible way to achieve goals, delaying gratification and changing behaviour to achieve a desired end. Effective rational thinking, therefore, presupposes a number of abilities⁹, including the ability to formulate and prioritise, or even abandon or modify goals; plan the best means to realise goals and act effectively in doing so.

The capacity to make autonomous decisions does not however necessarily imply that a person will govern him/herself, and such capacity may be constrained temporarily by factors such as illness, ignorance, coercion or limiting conditions.

Importantly, actions can be autonomous by degrees, as related to different levels of understanding and freedom from constraint as well as the context within which the decision needs to be made. A person can therefore only be autonomous to the extent to which s/he is able to reason rationally, is free of external constraints and has access to relevant information and options.

Autonomy - a bioethical perspective

Beauchamp and Childress⁸ define autonomy within one of a

set of four clusters of principles, each of which corresponds to fundamental obligations to the patient. These are the familiar principles of respect for autonomy, non-maleficence, beneficence and justice. The principle of respect for autonomy is articulated as requiring the health professional not to interfere (respectful action) with the effective exercise of the autonomy of the patient/client and presupposes an acknowledgment of the patient/client's capacity and right to make decisions about his/her life and to act accordingly. It furthermore encompasses the concept of enabling persons to act autonomously.

Ethical theories provide the practitioner with a framework within which to make decisions and justify actions.

The approach of the occupational therapist to a patient/client is further determined by the ethical theory subscribed to and the degree of paternalism practised. From personal observations occupational therapists seem to subscribe to a pragmatic mix of deontological (what is the right thing to do)⁸, utilitarian (what is the best for the majority)^{8,9} and virtue (to be good)⁹ ethical theories as, for example, would be evident in the equitable distribution of limited resources. Clinical ethical reasoning thus reflects a rather eclectic approach to resolving ethical dilemmas and, on further scrutiny, has interestingly been found to have a strong feminist¹⁰ ethical bias.

It is also deemed necessary for personal virtues to be inculcated and cultivated over time⁸. What is felt to be 'intuitively right' is more often than not based on virtue developed by socialisation into the attitudes, norms and practices of the profession⁸. A combination of such virtue, training, positive role models and clinical experience would almost inevitably lead to respect for the autonomy of the patient/client. It is also true that the nature of occupational therapy intervention would make it very difficult to build up the kind of relationship needed for effective intervention without the appropriate values and attitudes (virtue) on the part of the therapist. This moral goodness would however need to be underpinned by prescribed principles, rules, guidelines⁸ and behaviour to be really effective.

Autonomy — a legal perspective

It is necessary briefly to explore the nature of the relationship between ethics and the law. According to Dickens¹¹, the law is described as the minimal ethic which prescribes what people must do or not do. What is lawful may however not be ethical and what is considered ethical may in fact not be lawful. Dickens notes that disobedience of the law in certain instances may be ethically justifiable as would be the case in active euthanasia for a person who is terminally ill and experiencing excruciating pain with no prospect of recovery or relief. The law may reflect ethical principles¹¹ such as non-maleficence and can furthermore prohibit certain behaviours such as assault and murder, compel obedience and advance ethical values of care and protection. It, however, does not allow for choice, as is the case with ethical responsibilities. The law ultimately determines the behaviour and attitude required of the health worker towards his/her patients/clients, current legislation^{5,6} being explicit about the rights of the patients and the responsibilities of the practitioner.

A number of pertinent Acts (laws) have been approved by Parliament and have been published (promulgated) in the Government Gazette. The provisions of the Acts are contained in numbered paragraphs called Sections (S) or subsections (s).

With the promulgation of the Bill of Rights, which is contained in the Constitution of the Republic of South Africa Act 108 of 1996⁴, a new era of human rights awareness dawned. The Constitution is then also the yardstick against which all other legislation and policy is measured and ensures that all Acts promulgated embraced human rights, thus necessitating, in the context of this paper, closer scrutiny. The Constitution⁴, the Mental Health Care Act⁵, the National Health Act⁶, the Promotion of Access to Information Act¹² and the Health Professions Act¹³ will be considered

with reference to the relevant sections, after which common law and legal capacity will be briefly addressed.

Constitution of the Republic of South African Act 108 of 1996⁴

It would seem that virtually the entire *Bill of Rights*, contained in chapter 2 of the Act, provides for respect of the individual and his/her choices; in other words, the person's autonomy. The Rights of significance to this topic are defined in the sections as set out below:

- ❖ The Right to **freedom and security** of person, which includes the right to bodily and psychological integrity and consequently the right to make decisions about intervention or refusal thereof [Section 12(2)]
- ❖ The Right to **privacy** which includes the right to confidentiality of communication [Section 14(d)]
- ❖ The Right to **freedom of religion**, belief and opinion which requires the practitioner to respect such practices and consequent choices [Section 15(1)]
- ❖ The Right to an **environment** which is not harmful to their health or wellbeing [Section 24(a)]
- ❖ The Right to **access to health care services**, which also implies the right not to utilise such services, as well as having such services reasonably available [Section 27(1)]
- ❖ The Right of **children to an identity, basic nutrition, care, protection and respect** for their rights [Section 28(1)]
- ❖ The Right to **access** of information held by another person (eg, health practitioner) that is required for the exercise or protection of any rights [Section 32(1)(b)].

Mental Health Care Act 17 of 2002⁵

The Mental Health Care Act similarly has several provisions which directly address issues of autonomy. This is reflected in the use of terminology (mental health care users) as well as the inclusion of Chapter 3 which specifically deals with rights and duties relating to mental health care services.

- ❖ Section 8 (1) provides for respect for **human dignity and privacy**, whereas Section 9 provides for consent to care, treatment and rehabilitation and admission to health establishments. Services may, according to this section, only be provided with the **consent of the patient**, except when such care is authorised by a court of law or where the mental state of the person could cause death or irreversible harm to the health of the user or others, or may cause serious damage to or loss of property. The Act makes it very clear that the person with a mental illness should be encouraged and helped to make decisions about, and be involved in, all aspects of care or rehabilitation.
- ❖ **Confidentiality** is dealt with in Section 13 (1), (2) and specifies that a person or health establishment may not disclose any information which a mental health care user is entitled to keep confidential in terms of any other law, and describes conditions under which confidential information may be disclosed.
- ❖ Interestingly, Section 14, makes provision for the right of persons with mental illness to enter into **intimate relationships** on condition that such a person is able to consent to such a relationship, behaviour which was previously frowned upon, and might have serious repercussions.
- ❖ The patient's right to information is furthermore enforced by the provisions of Section 16 which provides for the issuing of a **discharge report** to the user, whilst Section 17 stipulates that users must be **informed of their rights prior to care or treatment**. This serves as a directive to all practitioners.
- ❖ Sections 25, 27 and 38 are relevant as they deal with **admissions** to mental health care facilities and specifically the issue of informed consent to care, treatment and rehabilitation. In the case where the patient, admitted under Section 27 (assisted care, treatment and rehabilitative services) who,



from observation and information obtained, has recovered the ability to make informed decisions; such a patient should, according to Section 31, be asked whether s/he is willing voluntarily to continue with care, treatment and rehabilitation - a situation which in the past was virtually unheard of. A similar provision (made in Section 38) is for persons admitted as involuntary mental health care users - to be dealt with as Section 25 (voluntary mental health care users) admissions when recovered.

Both Sections 31 and 32 are important as the Act makes provision for care, treatment and rehabilitation (including occupational therapy) **without consent** for the person who is incapable at the time to consent. It, at the same time, provides that should the patient regain the ability to make such decisions, consent should be sought.

Attempting to obtain informed consent is therefore an ongoing responsibility and process regardless of the section of the act under which the patient was admitted in the first instance.

National Health Act 61 of 2003⁶

The National Health Act (Chapter 2) strengthens the provisions of the Mental Health Care Act, as it not only provides for rights and duties of users of health services, but also contains rights of health care providers. It comprehensively deals with issues around patient/client's right to respect for autonomy.

❖ The user's right to **full knowledge** is unequivocally outlined in Section 6 and requires that the health care provider inform the user of his/her health status (unless such disclosure would be contrary to the best interest of the user), the range of diagnostic procedures to be undertaken, and treatment options generally available to the user, benefits, risks, costs, consequences generally associated with each option and the user's right to refuse health services. This right to knowledge is strengthened by Section 8 (2) (b), which states that a user, who is able to understand, should be informed, even if such a person lacks the legal capacity to give informed consent.

According to this Act, a health service may not be provided to a user without the **user's consent** (Section 7 (1)), unless the user is unable to give consent due to incapacity, incompetence or age, or where a delay or failure to treat could lead to death or irreversible damage to his/her health.

Importantly, the autonomy of the user is further acknowledged by specifying (Section 8) that the user should be given the opportunity to participate in any decision affecting his/her personal health and treatment.

❖ **Confidentiality** is dealt with in Section 14 and stipulates how all information related to a person's health status, treatment or stay in a health care establishment should be dealt with. These provisions are similar to those of the Mental Health Care Act (Section 13 (1) (2)).

The Promotion of Access to Information

Act 2 of 2000¹²

This Act is of relevance to this paper in that it makes specific provision for access to health and other records, as well as mandatory disclosure of information.

❖ Records from both private (in terms of Sections 30 and 61) and public bodies (in terms of Section 11) **may be accessed**. Requests do, however, need to comply with certain requirements and/or procedures such as a formal application using a format as approved by the profession. The category of 'private body' makes provision for health practitioners in private practice as well.

❖ Occupational therapists should note that this Act defines **record** as being *any recorded information* regardless of form or medium, under control or in possession of the public or private body, whether or not it was created by that private/public body. This would thus include patient/client records or files.

❖ It should be noted that where the individual tasked with granting a request for access to information is of the opinion that *disclosure may cause serious harm to the mental or physical health or wellbeing* of the person requesting the information, such individual should consult a health practitioner. Should the health practitioner deem the information to be of a nature to cause serious harm (as mentioned), access to this information (records) can only be given if adequate provision has been made for counselling to avoid such harm prior to, during and after disclosure.

❖ In cases where a public or private record contains information that reveals evidence of either a substantial contravention of the law, or a failure to comply with the law, or otherwise evidence of an imminent and serious risk to the public, disclosure is mandatory. Public interest (need for the public to know) in the disclosure of the record must however be considered to clearly outweigh the harm which may befall the individual about which the disclosure is to be made.

It is evident from the above that recent legislation leaves no doubt as to the significance of and the obligation of practitioners to uphold the right of the patient to respect for autonomy.

Health Professions Act 56 of 1974 as amended¹³

A generic set of ethical rules of conduct compiled by the Health Professions Council of South Africa (HPCSA) applies equally to all health professionals registered with the Council. They were approved by the Department of Health and promulgated in 2006¹³. All occupational therapists, occupational therapy assistants and technicians are legally bound to register with the HPCSA. The rules and regulations of the HPCSA, as the statutory body, apply equally to all the categories named above. The Ethical and Professional Rules form part of the regulations formulated in accordance with powers delegated to the HPCSA by the Health Professions Act 56 of 1974 under Section 49 (1), and are therefore discussed under this section of the paper.

It is of interest to note that of the 27 Rules formulated, only five refer directly to the relationship of the patient and the health practitioner. These rules make either direct or indirect mention of the rights of the patient, as well as the practitioner's concomitant responsibilities, and therefore merit brief discussion. The five rules mentioned refer to supersession, impeding a patient, confidentiality, retention of human organs and issuing certificates.

The retention of human organs will not be discussed as it is of academic interest only to occupational therapists.

❖ The rule on **Supersession** (Rule 10), deals with taking over a patient from another practitioner whilst that patient is under treatment from the original practitioner. It states that a practitioner may not take over a patient from another practitioner if s/he is aware that the patient is receiving treatment from the other practitioner, unless *requested to do so by the patient*. It should be remembered that a patient has the right to terminate treatment at any time and seek treatment from another practitioner. In which case, the practitioner who is taking over the patient should, as a matter of courtesy, consult the practitioner originally treating the patient. The rule also states that the original practitioner is obliged to provide the information. What is not stated as such is whether the consent of the patient is required before this may happen. However, reading this rule, together with that of confidentiality (Rule 13) and impeding a patient (Rule 11), it would seem that the patient's consent would first need to be obtained.

Occupational therapists in private practice are at times concerned about the nature and extent of information that may be given to another practitioner. This will obviously depend on the request and consent of the patient. The occupational therapist is obliged to provide information but not to hand over files. Where the patient has not paid for the service provided by

the original practitioner, for example an assessment done, the document remains the property of the original practitioner. A question often asked is whether a patient has the right to his/her occupational therapy files. A patient undoubtedly has a right to information in the file and may be given a copy on request after the proper procedure for request of information has been followed, (the file however remains the property of the therapist).

❖ The rule on **Impeding a patient** (Rule 11) determines that a practitioner may not attempt to stop or dissuade a patient (or his/her guardian) from obtaining a second opinion or from being treated by another practitioner - thereby acknowledging the autonomy of the patient.

❖ **Professional confidentiality** is dealt with in Rule 13 and states that:

"A practitioner shall only divulge verbally or in writing any information which he/she ought to divulge in terms of a statutory provision (eg notifiable disease) or at the instruction of a court of law or where justified in the public interest: provided that other information shall only be divulged with the express consent of the patient or, in the case of a minor under the age of 14 years, with the consent of his/her parent or guardian, in the case of a deceased patient, with the written consent of his/her next of kin or the executor of his or her estate".

It is clear from the rule that confidentiality is not an absolute obligation and that situations may prevail which require the practitioner to breach confidentiality. This should however always be a last resort, and done after very careful consideration and consultation with the patient/client, and only where a third party would be in real danger should the information not be disclosed. An example here would be an individual who is HIV positive, who is putting his partner under real risk of infection.

❖ Rule 16 (1), which deals with the issuing of **certificates and reports**, is also relevant. Section (f) states that a patient needs to give consent for a medical / occupational therapy diagnosis to be indicated on a medical certificate. Section 16 (2) additionally specifies that 'a practitioner shall issue a brief factual report where such a patient requires information concerning him or herself'.

As a companion document, the *General Ethical Guidelines for Doctors, Dentists and Medical Scientists 2000* (12) prescribes a code of ethics applicable to all health professionals, which addresses autonomy and related issues. This guideline contains well-formulated sections on *core ethical values and standards of good practice* and includes a section on autonomy (12). It describes autonomy as honouring patients' rights to self-determination or to make their own informed choices and live their lives by their own beliefs, values and preferences. The section on *duties to patients* (12) includes sections on informed consent and confidentiality and provides clear practical guidelines.

Although, as mentioned, the HPCSA Rules apply equally to all professions, the general ethical guidelines are just that, and while they are accepted as duties, are not as such legally binding. It should also be noted that the Professional Board for Occupational Therapy, Medical Orthotics/Prosthetics and Arts Therapies has not yet developed its own document on general ethical guidelines.

Case law/Common law provisions

Apart from discussing legislation pertaining to patient autonomy, it is also important briefly to consider *common and case law* particularly with reference to the judgement in *Castell v de Greef*¹⁵ as this represents a landmark decision¹⁶ in terms of patient autonomy versus medical paternalism.

The case deals with the issue of consent to medical treatment and the question of whether emphasis should be placed on the

autonomy and right of self-determination of the patient on the one hand, or on the right of the medical profession to determine the meaning of reasonable disclosure on the other.

Two principles are clear from the judgement of this case^{15, 16} and serve to expand on prior discussion.

❖ Firstly that a doctor (practitioner) is obliged to warn a patient of a material risk inherent in the proposed treatment:

"the risk being material if, in the circumstances of the particular case: (a) that a reasonable person in the patient's position, if warned of the risk, would be likely to attach significance to it; or (b) the medical practitioner is, or should reasonably be, aware that the particular patient, if warned of the risk, would be likely to attach significance to it"^{15, 16}.

The reader may question the need to include information regarding material (real) risk, as occupational therapists conceivably do not apply procedures that place the patient/client at risk; it should however be kept in mind that over-servicing or premature termination of treatment may cause risk to the patient, as may application of inappropriate procedures.

❖ The second principle, identified in the case, is that the requirements for consent can only be satisfied if certain requirements are met. These, *inter alia*, include knowledge of, awareness, appreciation and understanding of the nature and extent of the harm or risk; consent to the harm or assumed risk and, lastly, that consent must be comprehensive, which means that it must extend to the entire transaction, including its consequences.

This list is augmented, with some repetition, by that of Van Oosten¹⁶ in his commentary on the case and provides an extensive, but not all inclusive, list of concrete and surrounding circumstances and acts of which the patient needs to be informed. These include:

- ❖ the nature of the disease
- ❖ the nature of proposed intervention
- ❖ the available alternatives
- ❖ the urgency and gravity of the proposed intervention
- ❖ the potential adverse consequences
- ❖ the degree of risk or danger, as well as the frequency of complications
- ❖ the expertise of the practitioner concerned
- ❖ the professional and technical resources
- ❖ the standards of hygiene
- ❖ the degree of specialisation available at the facility.

All of this must however be done with consideration of the patient's personal circumstances. He further mentioned that the practitioner also needs to guard against excessive disclosure of information which could cause unnecessary anxiety or distress and scare the individual away from undergoing needed intervention.

The duty of the health practitioner to disclosure of information essential to the intervention has been found to be irrefutable; also that, based on the right to bodily integrity and moral agency, the individual has the right to information and to decide whether to undergo or refuse treatment.

Legal capacity

In concluding this section of the paper, it is necessary briefly to introduce the concept of 'legal capacity' of a person, as this ultimately determines how the law deals with the person. The law as regards autonomy, centres around the **competency** of the person on the one hand and the protection of persons incapable of protecting their autonomy on the other¹¹.

Legal capacity means that a person can acquire legal rights and can become subject to obligations and legal duties. For example s/he can enter into contracts, sue someone or be sued and execute a will. All persons do not however have similar capacity



to act and persons are thus categorised as either having a full capacity to act (major), limited capacity to act (minors) and no capacity to act (child under seven years and persons with mental illness). No person can however be seen as having *no* legal capacity, but retains rights, duties and capacities, albeit limited and exclusive of certain situations. Dickens¹¹ encouragingly, goes further by stating that modern law is guided by the principle of accommodating only the least invasive inroads into autonomy and specifically mentions that even the adult with impaired mental capacity may still have legal capacity for certain functions, even if not for others.

It is clear from the above that respect for a patient/client's autonomy is no longer an ethical aspiration but a right now firmly entrenched in the law. Furthermore, respect for patient/client autonomy and therefore a person's right to informed consent and confidentiality must essentially form part of day-to-day health professional practice.

From the discussion above it is clear that respect for the autonomy of our patients and hence respect for their human rights is a duty and non-negotiable obligation. This paper has shown that various Acts, HPCSA rules and case law require that health professionals, including occupational therapy practitioners, respect patient/client autonomy and actively facilitate such autonomy.

In summary, the critical components of respect for the patient/client's autonomy are seen as the acknowledgement of:

- ❖ the patient/client's right to self determination
- ❖ the patient/client's right to participate in the planning and implementation of intervention, also the termination thereof
- ❖ the right to, *inter alia*, substantial knowledge of his/her disorder, the intervention, possible outcomes, alternative options and cost and time requirements
- ❖ the right to give or withhold informed consent
- ❖ the right of access to personal health information held either by a private practitioner or institute or a public body (including practitioners)
- ❖ the right to refuse treatment or to terminate treatment
- ❖ the right to a second opinion
- ❖ the right to continuity of care once commenced
- ❖ the right to have personal information safeguarded
- ❖ the right to participate in or withdraw from research projects and not to be placed at risk whilst participating in any research projects.

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reydend@ukzn.ac.za

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