

The Right to Respect for Autonomy Part II

Dain van der Reyden. Nat Dip OT, BA, LLM (Med Law)

Senior Lecturer – Department of Occupational Therapy, University of KwaZulu-Natal

ABSTRACT

This paper, the second in a series, approaches patient autonomy from an occupational therapy practitioner perspective. The Occupational Therapy Codes of Ethics as well as the Health Professions Council Guidelines for good practice are briefly reviewed, rights identified, limitations to autonomy discussed and practical implications and explicit guidelines for practice, as relevant to different areas of practice, proposed.

Key words: Patient autonomy, ethics, legislation, patient's rights, occupational therapy

Introduction

This second paper of the series looks at patient/client autonomy from a practical occupational therapy perspective.

A literature search of professional occupational therapy journals, books and dissertations revealed a dearth of literature with specific guidelines, particularly with reference to the South African situation, hence the need for this paper.

Having considered the relevant legislation and the Health Professions Council of South Africa (HPCSA) - Rules in the previous article¹, the focus here will be on professional ethical codes and how these require practitioners to address patient/client autonomy. The paper briefly deals with limitations to autonomy and implications for practice and proposes practical guidelines for implementation.

Autonomy as addressed in the Occupational Therapy Codes of Ethics

For the purpose of this paper, the Codes of Ethics of the World Federation of Occupational Therapists (WFOT)², as well as the American Occupational Therapy Association (AOTA)³, the British Association of Occupational Therapists (BAOT)⁴, Australian Association of Occupational Therapists (AAOT)⁵ and the Occupational Therapy Association of South Africa (OTASA)⁶ were reviewed. The WFOT Code was reviewed as that upon which the codes of WFOT member countries are based. The American, British and Australian Codes were reviewed as representative of countries with substantial numbers of Occupational Therapists⁷ and which were readily accessible. The HPCSA guidelines⁸ were reviewed as applicable to an excess of 125,000 health care practitioners registered with the HPCSA, these guidelines although originally compiled for the Medical and Dental Professions Board, have largely been revised to be applicable to all practitioners registered with the HPCSA.

The Codes of Ethics were reviewed in terms of the extent to which each fulfilled the basic requirements for adequately addressing the issue of autonomy. These requirements were compiled from literature and case law as discussed in Part I¹.

To effectively address the issue of autonomy such documents should mention:

- the patient / client's *right* to autonomy (self-determination)
- the *role* of the patient / client in planning and implementation of intervention and termination thereof (see Note 1)
- the right to *information* of disorder; nature and purpose of proposed intervention; possible outcomes of participation and refusal, both positive and negative; risks; alternative options; cost and time requirements
- the right to medical and *occupational therapy information*, occupational therapy files, investigation and assessment reports and discharge information.
- the right of *informed consent*
- the right of *refusal of intervention*

Note 1: The term intervention is used as a more encompassing concept and includes treatment except where the context clearly indicates that treatment of a patient is referred to.

- the right to withdraw consent given at anytime
- the right to seek a *second opinion*
- the right to *continuity of care* (not to be abandoned)
- *confidentiality* -the need to safeguard information disclosure
- the need to *safeguard records*, files, electronic data
- rights in terms of *participation in research*.

The rights mentioned are further underpinned by the National Patients Rights Charter⁹ and entrenched through the adoption of the Constitution¹⁰. The Charter provides a baseline against which to judge standards of care and additionally mentions a right to choice of health services and the right to lodge a complaint and receive a response to such complaint.

The WFOT Code of Ethics² describes the appropriate conduct for occupational therapy practitioners in all member countries and for all fields of practice. Standards of practice are accordingly based on guidelines contained in the Code which comprises five sections, covering responsibility towards the patient/client, colleagues, self-development and the profession. The different sections refer to personal attributes, responsibility to the recipient of the occupational therapy services, conduct within the occupational therapy as well as the multidisciplinary team, developing professional knowledge and promotion of the profession.

Autonomy is referred to under the section of responsibility towards recipients of occupational therapy services and states that the consumer's personal preferences and ability to participate should be taken into account when planning service provision. It does not, however, fulfil even two of the ten requirements for adequately addressing patient autonomy as set out above and seems weakly paternalistic at best. Confidentiality, interestingly, is stated as an absolute (guaranteed) and specifies that no personal information will be passed on without the patient's consent. Again, this seems quite limited as harm or danger to a third party is not mentioned. The right of the patient not to be discriminated against on any grounds is however spelt out in detail. The Code of Ethics is very brief and rather simplistic, probably to allow for interpretation by member countries.

It should be noted that some WFOT member countries have developed standards of practice¹¹, which *inter alia* more fully address issues of patient autonomy.

From the review of different countries' codes of ethics it is evident that each deals with issues slightly differently but strong commonalities do exist. For example, the WFOT Code covers relevant aspects but, as mentioned, only in general statements, whereas the AOTA Code³ which was found to be the most comprehensive of all the codes consulted, contains provisions and statements which adequately reflect the required conduct of practitioners in terms of patient autonomy. The BAOT⁴ code is reasonably adequate, but leaves implementation to the discretion of the occupational therapist. The Australian Code of Ethics⁵ mentions autonomy in its introductory statement as a basic bio-ethical principle. It further stipulates the safeguarding of information related to patients and clients beyond the necessary sharing of information with professional colleagues. By implication, informed consent is not required

for discussion within a team context. Autonomy is again referred to as a patient/client right with an explanation that this right implies their active participation in decision making. The OTASA⁶ code which was more recently extensively revised now fulfills most of the criteria listed earlier.

The HPCSA Code of Ethics⁸ published as “Guidelines for Good practice in Health Care professions” is contained in 17 different booklets which provide detailed consumer friendly guidelines. These booklets originally compiled for Doctors, Dentists and Medical Scientists have largely been revised for use by all health care professions registered with the HPCSA. Booklets 1, 10 and 11 are relevant to this paper as each makes specific reference to one or more aspects of Autonomy, indicating areas for attention and guidelines for practise. Booklet 3 contains the Patients’ Rights Charter which underscores the HPCSA as well as legislative provisions regarding autonomy.

Autonomy is described in principle in Booklet 1, General Ethical Guidelines for Health Care Professions as one of 13 core values and standards. The definition of which reads to “honour patients’ rights to self determination or to make their own informed choices living their lives by their own beliefs values and references”⁸ (1 item 1.2) (Note 2).

This booklet briefly addresses informed consent, access to information, respect for dignity and privacy and confidentiality – topics which are integral to the concept of autonomy and are discussed in detail in booklets 10 and 11 (see Note 2).

Booklet 10 – Seeking Patients’ Informed Consent: The Ethical Considerations, provides considerable detail. The provisions contained in this booklet confirm the legal right of the patient to know about his/her condition as well as any intervention and therefore also the responsibility of health care practitioners to ensure that such information is provided honestly and comprehensively and that consent is obtained. It makes it clear that the practitioner providing treatment or undertaking an investigation is responsible for providing the information. The booklet details the information to be provided, as discussed in paper 1 of this series¹ and outlines the limitations of the practitioner clearly (Items 5.3.1.3 to 5.3.1.7).

It further states that care needs to be taken to give information in keeping with the wishes and level of understanding of the patient and the level of risk of the procedure. More medically related aspects such as subsidiary treatment (e.g. pain relief) monitoring of the condition and side effects as well as possible student involvement are mentioned as required information. Where treatment is provided in stages, this must be clearly explained, also the possibility of other problems arising whilst dealing with the presenting problem. Patients/clients furthermore have a right to know the reasoning or justification leading to a particular decision. It also mentions the patient/client right to change his/her mind at any time and emphasises the voluntary nature of consent (item 5.3.1.3).

The booklet reflects a respect for the dignity of the individual and an empathetic approach to the patient/client which is evident in the options of being accompanied by a relative or friend, being able to tape record a consultation, being provided with information on counselling services/ support groups, receiving information in an incremental fashion, or in written format as and when needed. The need to enable adequate decision making where such capacity is not consistent, and involvement of other team members in discussions to enhance this process is also addressed (item 5.3.4).

It should be noted that Children over the age of 12 years may, as provided for in the Children’s Act (38 of 2005), with sufficient demonstrated maturity, decide on all forms of medical procedures and treatment. A child of any age may however consent to termination of pregnancy (item 9.5) as stipulated in the Choice of Termination of Pregnancy Act (92 of 1996).

Other aspects of note to the practitioner are stipulations with regard to the application of the “best interests” principle (item

10); application to a court of law where an individual’s capacity to consent is questioned (item 11); the need to respect express consent (prior expressed opinion) (item 12); the need to comply with statutory requirements (item 13), implied consent (item 14) and the need to review consent, should circumstances (e.g. time lapse/developments) indicate (item 15).

The provisions about screening and testing (item 16) apply particularly to occupational therapists working within school settings. Informed consent needs to be obtained for all screening, and follow up plans/services need to be clearly explained.

Interestingly the booklet makes specific mention of the International Classification of Diseases and Health related problems (ICD) 10 coding and of the legislative requirement to supply codes as required to medical aid schemes to ensure payment. However, in doing so, it allows for a breach of the individual’s right to confidentiality. It is clear that the patient/client needs to consent to the disclosure of this information. (item 18)

Practitioners registered with the HPCSA, may in the interest of optimal healthcare and with consent of the patient share information, (item 18.2) with practitioners registered with another Health Professional Council.

Booklet 11 titled “Confidentiality: Protecting and providing information”, is in keeping with the provisions of the National Health Act (18 of 2003) and describes when and how disclosure may be justified. It emphasises the critical importance of both maintaining confidentiality and making disclosure only where absolutely necessary. It clearly outlines the process and precautionary measures to be taken before disclosure may be made.

Having briefly discussed various codes and their implications for practice, limitations to Autonomy need some consideration before looking at practical guidelines and implications for occupational therapy.

Limitations to Autonomy

For the occupational therapy practitioner to adequately address issues around patient/client autonomy, she/he must firstly be cognisant of those factors which may and often will impact on the exercising of autonomy by the patient/client as well as of those incidences or circumstances in which the restriction of autonomy are justifiable and even necessary.

As the process of giving informed consent occurs within a health worker – patient/client relationship it is necessary to briefly consider this relationship. Marincowitz¹² describes a “mutual – participation model” as the most appropriate. The principles underlying this model reflect those of the deliberative model¹³ as mentioned in Paper 1¹. He however goes further to describe factors essential for mutual participation. These include the establishment of mutual trust and respect, acknowledging and dealing with factors such as own immaturity, limited training, skill or knowledge or even time on the part of the practitioner, also a fear of loss of control or power. Differences of social standing or cultural beliefs, or worldviews are also seen to be possible limiting factors. He further found that a patient/clients perception of being considered an “expert” in terms of his/her own illness increased willingness to participate. His literature search also revealed that factors such as a higher socio-economic status, better education, enough knowledge, being well enough to participate, or even when a person felt that she/he was getting worse, facilitated such mutual participation.

Several factors^{14, 16} may contribute to the limitation of autonomy and may be either of an external or internal (personal) nature. External factors such as *coercion to act* (or not) in a certain way; *removing the option of choice* or the opportunity to exercise that choice, for example by not having the treatment of choice available, will limit self determination. Other external factors mentioned are the *unavailability of information*, *lack of knowledge* of the practitioner, *deception or purposeful withholding of knowledge* by a practitioner, and thereby placing a constraint on autonomous decision making. Scarce resources and managed health care practices, which strictly prescribe treatment, may on the other hand limit the opportunity for a person to act autonomously.

Note 2: Due to the inconsistency in the terminology used to indicate sections, subsections, paragraphs or sub paragraphs across the different booklets, the term item and relevant numbering is used for ease of reference throughout.



It should be remembered that the patient/client may decide to limit or even abdicate his/her right to own autonomy, and may give permission and instruct the practitioner to do whatever she/he deems appropriate and thereby submit to the "superior" knowledge of the practitioner, thus essentially accepting a "paternalistic approach"¹⁴. In occupational therapy it may happen that due to language barriers, time restraints and an inherent paternalistic approach that the practitioner just "presents" the patient/client with treatment which is accepted without question. The practitioner, however, also needs to retain his/her own clinical autonomy, and may refuse to perform an action which is not professionally acceptable or in the patient/client's best interests¹⁴.

Diminished ability to reason and make decisions would clearly be a major limitation. It is however important to note that certain factors may impact on rational thinking and cause decisions made under these circumstances to be less than rational. As would for example be the case with mental incapacity.

Ackerman¹⁵ identifies several social and psychological impediments, such as demands of the illness or loss of function; fear or pain, which can lead to withdrawal and refusal of treatment; anxiety, which exacerbates reactions to proposed intervention also the patient/client's personal goals and social impediments, including attitudes of caregivers. In terms of the latter, we have only to consider the negative impact of overprotection of family members to realise how disempowering this may be. Social impediments could however also be of a religious or cultural nature especially where there is a disjunction of values, belief systems and practices between the practitioner and the patient/client. Therapists deal with this situation probably on a daily basis, and seem to cope better where a positive attitude towards diversity is adopted, where differences are not only acknowledged but also embraced and every effort is made to communicate effectively and learn about the everyday realities of the other person. Childress and Siegler¹⁴ additionally list limitations caused by the law, being patients of the state e.g. prisoners and those manifesting with disorders such as substance abuse.

According to Mappes and DeGrazia¹⁶, the limiting of liberty is justifiable only in those incidences when a person's liberty (autonomy) could/should justifiably be restricted. Some of the principles mentioned are to prevent harm or offence to others; to prevent a person from acting immorally; to prevent harm to the individual him/herself, and/or to ensure benefit to the individual or otherwise to ensure benefit to others. These restrictions are clearly outlined in for example the Mental Health Care Act.

Of these, curtailment of a person's liberty to prevent or avoid harm to others is certainly the most, and according to Mill¹⁷, the only, justifiable incidence. Application of liberty limiting principles could also be seen as the perpetuation of a *paternalistic approach*, which however benevolent has long been integral to the application of the medical model and still evident where the patient/client is not given substantial information or the opportunity to truly participate in decision making.

The question to be asked is when if ever paternalism could possibly be justified. It is widely recognised that the paternalistic model of care is justified during emergencies when a delay may cause irreversible harm to the patient. Mill¹⁷ stressed 'diminished autonomy' (lack of required ability for effective deliberation) as justifiable cause. Herein however lies the dilemma, in that determination of capacity to make decisions would in fact be a matter of judgement of someone else, which of necessity could be subjective and prone to generalisation, as, for example, when using diagnosis as a criterion.

Whilst 'strong' paternalism should undoubtedly be avoided by practitioners, 'weak' paternalism is more acceptable and would seem to be justified but only under two conditions¹⁴. These are described as, firstly, when intervention is responsive to the welfare of an individual whose autonomy is severely diminished, or, secondly, when temporary constraint is necessary to prevent a person from acting in such a way that will presumably be irrational and self-harming. It should be mentioned that weak paternalism is not seen to show a lack of respect for a person's individual autonomy, but aims

to protect and diminish harm. This approach is supported by the Mental Health Care Act¹⁸ as relevant to the service user admitted as an assisted or involuntary patient.

Every effort should be made by the practitioner, regardless of the current capacity of the patient to enable him/her to become more autonomous and facilitate this capacity by empowering, teaching, giving support and encouraging practice; and creating an environment conducive to exercising this right. This should also be seen as an ongoing process with the practitioner continuously attempting to enable the individual to act autonomously, by simply providing information and opportunity for choice.

It is necessary to mention the possible impact of *limited* resources for health care provision on the autonomy of the individual. It is common knowledge that resources for health care are severely limited in South Africa and, even more so, from experience, resources for rehabilitation. Despite policy documents such as the Integrated National Disability Strategy (INDS)¹⁹ and its companion documents on implementation, resources and facilities for rehabilitation remain inadequate. A situation which is further exacerbated, according to colleagues, by short hospital stays, discharge before adequate rehabilitation has been completed, or in some cases, even started.

The practitioner may be faced with the dilemma that lies in providing a service within economic and resource constraints, and situations in which she/he seems to have increasingly less control over who, when and how often to treat. A managed health care system may be particularly problematic in this respect. Cassidy²⁰ identified the increased role of the hospital administrators in clinical decision-making, curtailing of duration or frequency of treatment offered, or early discharge of patients, as factors related to resource allocation and possible limitation of treatment, despite the need and desire or even decision of the patient.

It is clear from the above, factors impacting on autonomy are virtually endless, this needs however to be kept in mind when dealing with patient/clients.

Practical Implications and Guidelines for Occupational Therapy

Practical implications

Clinical reasoning, a critical component of day to day practice, has only become prominent since the late eighties in occupational therapy literature. It is described by Neuhaus²¹ as being 'a model that aims to shift autonomy, control and responsibility from the professional back to the patient'. It is reflected in the values held by practitioners and by intervention characterised by collaborative efforts, mutually determined goals and, above all, unquestionable consideration of the wishes of the patient.

The values a person holds determine motivation and behaviour, strongly influence decision-making and determine attitudes. It therefore goes without saying that the values held by the occupational therapy practitioner will largely determine professional conduct in general and consideration for patient autonomy specifically. The core values as articulated by the HPCSA⁹ are applicable to all categories of occupational therapy practitioners and include respect for other persons, integrity, truthfulness, compassion, tolerance, justice and community. Underlying these values, as indicated by the descriptive statements in the documents, are sensitivity to social needs, respect for different religions or cultural beliefs, being impartial and fair and contributing to society.

First and foremost, respect for autonomy implies a respect for the *rights* of patient/clients. Respecting a patient/client's right to autonomy is easily understood and accepted on an abstract level, but less so in a practical, clinical situation where the decision or wishes of the individual may be contrary to that which the practitioner believes to be in the best interest of that person; or where resources do not allow much needed intervention. Although it is fairly unthinkable that any occupational therapy practitioner would deny the patient/client's right to self-determination, it would be equally naive to think that this principle is implemented in all situations. The practitioner is however expected to demonstrate such

respect within a 'deliberative', participatory patient/client-practitioner relationship^{12,13}, negotiating with and enabling the patient/client to select goals for and methods of intervention. Should this not be possible, the practitioner should make every attempt to obtain informed consent, to the extent to which this is possible for the individual and to determine goals of intervention, together with the patient/client and his/her guardians.

It is thus a matter of debate whether the principle of autonomy is in fact applied as stringently as required within day-to-day practice. Challenging situations may arise due to diagnosis and level of performance as reflected in the ability to think rationally and the changed life situation of the patient/client due to illness or injury. Other challenges may arise due to procedures and commonly held, albeit misguided ideas of the practitioner him/herself. Such habits and ideas may include believing that when individuals attend treatment, they necessarily consent to all aspects of treatment; or that, because other practitioners do not consult with guardians, that this is not necessary. That a guardian's informed consent is not required when a referral is made by a third party such as a teacher; or that the brief information provided at the commencement of therapy is adequate; or even that colleagues have an automatic right to the reports of other colleagues.

Guidelines for Practice

These are discussed as relevant for procedures or situations and include aspects such as: assessment; provision of information and obtaining consent; record keeping; non professional staff; practice in the school system; cultural and religious diversity and mental health care users.

Assessment

- First and foremost, the practitioner should assess the patient/client's current level of rational thinking and decision-making. It is also essential to specifically identify and carefully record the factors which impact on the patient/client's autonomy e.g. Intervention should then actively address the factors identified, and should be an ongoing process with ongoing evaluation and modification.
- The practitioner must accept responsibility, as part of treatment, to enhance capacity and facilitate the empowerment of the patient/client and his/her care providers function to an optimal level.

Providing information and obtaining informed consent

- The aspects listed earlier in the paper regarding the provision of culturally appropriate patient/client information should be followed strictly.
- It may be helpful for the practitioner to draw up a checklist to ensure that all aspects have been covered.
- The practitioner is also required to obtain information on alternative treatments/intervention in order to provide the individual with the best possible information.
- Where indicated, the practitioner may prepare user friendly brochures / hand-outs to provide the necessary information. Should brochures or pamphlets be used, the practitioner must ensure that the content has been fully understood and assimilated.
- Information should be provided in a suitably private, comfortable environment conducive to sharing of information.
- Sessions to obtain informed consent should form an integral part of all interventions and time(s) scheduled for this purpose.
- In cases where the individual's ability to understand or assimilate information is limited, ongoing, incremental efforts should be made to enable such a person (and care providers) to understand.
- All information must be in an understandable mode and language and exclude professional jargon. Where necessary, the services of an interpreter should be used.
- The signing of a consent form is recommended but must go hand in hand with detailed input and deliberation. The information may however need to be repeated periodically throughout intervention to ensure adequate understanding.

Patient / client records and reports

Reports are included in the discussions about autonomy as maintenance of confidentiality of personal information is integral to the concept of autonomy.

- Reports should be factual, accurate, honest and contemporaneous.
- Information provided should be fairly presented, substantiated and appropriate to the request made.
- Reports should be labelled confidential and locked in a cupboard or cabinet used for this purpose.
- The practitioner should ensure that information is only provided to other parties where consent has been obtained to do so, when this is absolutely necessary, such as when the behaviour of an individual poses a real and serious threat to an identified third party, or when legally obliged to do so.
- The safe custody of personal information should be ensured. Reports may for instance not be faxed to a general office but preferably to the person, who has a legitimate reason to access the report which should be collected, receipt acknowledged and safe keeping ensured.
- Electronic or other transmission of information should be properly monitored and all equipment be kept in a secure area, the practitioner must ensure that appropriate arrangements are made for safe keeping.
- It should be noted that express consent needs to be obtained from the patient/client for publication of case studies and/or photos even when the practitioner is of the opinion that the patient/client can not be identified.
- Of note is the specification that an individual may object to disclosure at any time, such wishes need to be recorded and respected.
- Information required in the public domain (e.g. communicable diseases) may need to be anonymous except where reporting is a statutory requirement (e.g. suspected child abuse).
- Any forms completed by the practitioner in relation to an insurance contract between the patient and an insurance company must be disclosed to the patient as is the case in life insurance.
- In medico legal situations where the occupational therapist acts as an expert witness for the insurance company, she/he is not acting as the 'therapist' of the plaintiff, she/he is contractually bound to the insurance company to furnish whatever information is gathered from the plaintiff, relevant to the dispute, but not duty bound to disclose such information to the plaintiff. The plaintiffs lawyers' are however entitled to obtain that information from the lawyers of the insurance company.

Non-professional staff within the occupational therapy department / practice

- Staff who work in an occupational therapy department (e.g. receptionist, administrator) are obliged, as 'servants'²² under the supervision of the practitioner, to uphold the ethical principles and rules as instructed by the practitioner.
- The occupational therapy practitioner is vicariously liable for the actions of persons who are employed to assist with administration or occupational therapy service provision. This means that auxiliary as well as administrative staff must be required to maintain confidentiality of information about individuals who attend or have attended that particular practice / department. Auxiliary staff are further obliged to perform professional acts as delegated by the occupational therapist.
- It is suggested that a contract be drawn up with such persons, in which they commit to respecting and upholding basic patient rights, and particularly confidentiality.
- It is also suggested that provision be made to ensure that personal information is obtained in private. Staff training is recommended.

Therapists practising within a school system

- It is recommended that the practitioner has *face to face* contact with the parent / guardian of the child, minimally at the



commencement and termination of the interventions. Due to the nature and complexity of the information to be discussed every attempt should be made to ensure this. An initial meeting is necessary to obtain and provide relevant information and ensure informed consent.

- The authority of the parent / guardian cannot be ignored and Intervention should be planned and executed in consultation with everyone concerned with the child's welfare including the parent and the teacher and possibly the referring health professional. As set out above, the parent / guardian, has legal rights which must be respected. It is in the child's interests for parents / guardians and others to be cognisant and supportive of the intervention received.
- A statement in the child's school 'homework' book is unacceptable as the only contact with the parent /guardian, for example indicating that "therapy" has commenced or been terminated. Even where a parent has signed a form giving the school blanket permission to refer their child for therapy, this is at best only a referral.
- Regular progress reports also need to be provided.
- The disclosure and distribution of documentation about the child (e.g. assessment reports) may only be given to other health professionals or teachers with the express permission of the parent/guardian. The parent / guardian should however be made aware timeously of the extent and nature of sharing of information which may need to take place amongst team members to ensure effective intervention. A contract with the parent /guardian at the commencement of treatment, in which permission is given to the practitioner for submission of assessments and other relevant reports to appropriate professionals, would cover this.
- Consent is required from the parent/guardian for "screening" of children in school for example to identify learning problems.

Cultural and religious diversity

Although the profession accepts the autonomy of the patient/client as paramount, it is also necessary to consider the particular cultural and religious background of the individual and how this may impact on autonomy, decision-making and behaviour.

Although the diversity of world views and belief systems held by the South African society makes it unwise to generalise it would seem that western philosophy is more likely, considering documentation from our regulating body as discussed earlier, to value attributes such as personal autonomy, self-consciousness, rationality and freedom of choice, and the burden of moral liability and responsibility on the shoulders of the individual. In contrast, African²³ views of the person would seem to rather emphasise interdependence amongst people, and embodies a deferential approach to nature and all living things. In practice, this may lead to a system of consensus for resolving interpersonal and community disagreements and for decision-making. It should also be kept in mind that western approaches may be more technologically and economically driven, African philosophy more egalitarian, with less notion of individual ownership of property and thus self-determination.

- In practice this means that the occupational therapy practitioner needs to respect and take cognisance of the cultural and religious background of the patient/client. For example expecting a person to take decisions without consulting family members, community elders and/or religious leaders may be inappropriate and stressful for the individual.
- The practitioner is minimally required to enquire whether the patient/client would prefer to be assisted by other person(s) in the process of gaining information and giving consent. Such a request should be respected and actively facilitated by the practitioner.

Providing services for mental health care users

The care, treatment and rehabilitation of the mental health care user challenges the principle of autonomy, due to the mental incapacity which may occur. Within many long-term institutional

settings, patients are often referred for occupational therapy under a 'blanket' referral system, which means that everyone in a ward is 'sent to' occupational therapy. Should somebody be unwilling to join the others, he may be allowed to remain in the ward. This may be detrimental to his/her condition. For example, many psychiatric symptoms cause patients to be unwilling or reluctant to participate in treatment. An example is the person (diagnosed with a major depression) who has extremely low motivation and believes that everything is futile, coupled with high levels of fatigue. In this case, it would mean that if the patient were given a choice of participating in treatment, the answer would more likely than not be in the negative, should this be accepted it would re-enforce the inactivity cycle which is known to exacerbate the condition. This dilemma is faced on a daily basis by occupational therapists and is usually overcome through meaningful occupation and making therapy "overt".

The Mental Health Care Act¹⁸ constitutes a notable shift away from previous discriminatory practices towards a more rights-orientated approach; although mentioned earlier, certain sections relevant to occupational therapy practice merit further attention.

- Services must, for example, *intrude only as little as possible*, to give effect to appropriate care, treatment and rehabilitation, and thus implies retaining the users independence as far as possible.
- The concept of autonomy is alluded to in section 10 (3) which states that policies and programmes which *promote mental health status* must be implemented, an aim to which occupational practitioners can contribute maximally.
- Section 17 of the Act which should be read together with section 9, determines that *every* healthcare provider *must*, wherever possible, before administering any care treatment and rehabilitation services *inform* the user in an *appropriate manner* of his or her rights. The provision for assisted care or involuntary care does, however, not absolve the occupational therapy practitioner from providing such information and this should be done as soon as the user's condition is stabilised and the person becomes amenable to treatment. The provision of information must thus be seen as an ongoing process in which the extent and content of information provided is likely to differ during different stages of the treatment and rehabilitation process.
- The nature of the occupational therapy intervention and the extent of the interaction make the occupational therapist ideally suited to report to the health team on the recovering patient's capacity to give informed consent.
- Section 32 makes provision for care, treatment and rehabilitation services without consent for those individuals who are incapable of making an informed decision on the use of these services. This means that the occupational therapist may thus not withhold treatment on the basis of the user's refusal, but should use all his/her skills, together with the team, to ensure participation in appropriate intervention. The apparent tension between the ethical principle (respect for autonomy) and the act is addressed by stipulating incremental increase of provision of information and consent sought.
- The autonomy of the mental health care user is again acknowledged in section 35, which allows for an appeal to be made against the head of a health establishment on *involuntary* care, treatment and rehabilitation. The occupational practitioner should be aware of this provision and help to facilitate such an appeal, by providing detailed information about the person's capacity for understanding and decision making.

Conclusion

In conclusion, the occupational therapy practitioner is ethically bound and legally obligated to respect the patient/client's autonomy. In a nutshell this means the practitioner should:

- Provide relevant and comprehensive information in understandable language and format, and that risks are clearly identified.

- Ensure that each patient/client is properly informed of his/her rights.
- Ensure patient/client understanding and create opportunities available to discuss debate and negotiate nature and extent of intervention.
- Actively address barriers to autonomy.
- Respect diversity, cultural and religious beliefs and values.
- Ensure that informed consent is obtained, and accept that this is an ongoing process, even when initially difficult.
- Ensure that informed consent is obtained for large group screening.
- Actively involve the patient/client and his/her care providers in all planning and decision making and genuinely respect and accommodate their wishes.
- Actively contribute to and facilitate the development of autonomy, be this through direct service provision (empowerment) or through the adaptation of the physical or social environment in which the individuals resides.
- Keep information confidential, when acquired both in and outside of therapeutic situations. Such information should only be disclosed with patient's/client's consent. Should it be absolutely necessary, in the interests of avoiding real danger to a third party, to disclose information, this can only be done with the utmost care and, as a last resort and if at all possible, with the consent of the individual.
- Safeguard all files and documentation and ensure safe custody of information.
- Provide access to information in occupational therapy files as requested through appropriate channels.
- Facilitate requests for a second opinion.
- Accept a patient/client's refusal for intervention except in cases where the individual is incapable of making a rational informed decision.
- Protect the individual with diminished autonomy from inappropriate paternalism, exploitation and abuse.

Practitioners should thus not only take cognisance of these obligations but actively seek to ensure their implementation as part and parcel of everyday ethical professional practice.

References

1. van der Reyden D. The Right to Respect for Autonomy – Part I: What is Autonomy all about? *South African Journal of Occupational Therapy*. 2008; 38(1):27-31.
2. World Federation of Occupational Therapists *Code of Ethics*. <<http://www.wfot.org/document.asp>> (31/1/08).
3. Occupational Therapy Code of Ethics. American Occupational Therapy Association Inc. *American Journal of Occupational Therapy*. 2000; 54: 614-616.
4. British Association of Occupational Therapists Code of Ethics, College of Occupational Therapy, *British Journal of Occupational Therapy* 2001; 64 (12) 613-614.
5. Australian Association of Occupational Therapists Code of Ethics. OT Australia 2001. <http://www.otnsw.com.au/download/National-CodeEthics090801.pdf> [28/8/08].
6. Occupational Therapy Association of South Africa Code of Ethics and Professional Conduct (revised July 2005). *South African Journal of Occupational Therapy* 2007; 37:2 16-17.
7. WFOT Survey results - Occupational Therapy Human Resources project. Draft. 2008. admin@wfot.org.au [14/7/08].
8. Health Professions Council of South Africa. Booklets 1-17. *Guidelines for Good Practice in the Health Care Professions*. 2002, largely revised May 2007. Published by HPCSA Pretoria. <http://www.hpcsa.co.za/hpcs/default.aspx?id+152> [14/7/08].
Booklet 1 - General Ethical guidelines for Health Care Professions. Pretoria, 2002.
Booklet 3 - National Patient's rights Charter. Pretoria, 2002.
Booklet 10 - Seeking Patients Informed Consent: The Ethical Considerations (2ed) Pretoria, 2007.
Booklet 11 - Confidentiality: Protecting and Providing Information (2ed) Pretoria, 2007. Items: 9.2.2.2, 9.2.2.3, 9.2.2.4, 9.1.1.3, 1.1.
9. Patients Rights Charter as published by the South African Department of Health, launched in 1999. Available at http://www.doh.gov.za/docs/legislation/patients_rightscharter.html. Also published as booklet 3 of HPCSA guidelines.
10. Constitution of Republic of South Africa. Act 108 A 1996. Sections 10, 12 (2) Butterworths Statutes of South Africa as at 12 Feb 2007.
11. Council of Occupational Therapists for the European Countries. *Standards of Practice*. 1996. <http://www.cotec-europe.org/eng> (31/1/08).
12. Marincowitz GJO. Mutual Participation in the Health Worker-patient Relationship. *SA Fam Pract* 2004;46[4] 30-32.
13. Emanuel EJ, Emanuel LL. Four models of the Physician – Patient Relationships. In: Boetzres E, Waluchan WJ, eds, *Readings in Health Care Ethics*. Broadview Press, 2000 :39 - 41.
14. Childress JF, Siegler M. Metaphors and Models of the Doctor – Patient Relationship : Implications for Autonomy. In: Mappes TA, DeGrazia D, ed. *Biomedical Ethics*. McGraw Hill, Inc. New York, 2001: 78.
15. Ackerman TF. 'Why Doctors Should Intervene' In: Mappes TA and DeGrazia D. Eds, *Biomedical Ethics* 4th Ed. McGraw Hill, Inc. New York, 1996:73-76.
16. Mappes TA, DeGrazia D. General Introduction: In Mappes TA, DeGrazia D, eds. *Biomedical Ethics*. 4th ed. McGraw Hill, Inc. New York, 1996:24-44.
17. Mill JS. Utilitarianism Liberty Essay on Bentham. Warric M. ed. On liberty cited in Mappes TA and DeGrazia D. Eds. *Biomedical Ethics* 4th Ed. McGraw Hill, Inc. New York 1996 :32.
18. Mental Health Care Act 17 of 2002. Butterworths Statutes of South Africa as at 12 February 2007.
19. Integrated National Disability Strategy. Department of Health, Republic of South Africa. White paper. Office of the President; November 1997.
20. Cassidy JC. 'Access to Health Care : A Clinician's Opinion about an Ethical Issue. *American Journal of Occupational Therapy*, 1988; 42(5): 295-297.
21. Neuhaus BE. Ethical Considerations in Clinical Reasoning: The impact of Technology and Cost Containment. *American Journal of Occupational Therapy*. 1988; 42(5).
22. McQuoid-Mason DJ. Legal aspects of medical practice. In: Dada MA, McQuoid-Mason DJ. Eds. *Introduction to Medico-Legal Practice*. Butterworths, Durban. 2001; 22-25.
23. Tangwa GB. The Traditional African Perception of a Person: Some Implications for Bioethics. 2000. *Hastings Report* 30 No 5: 39, 40-43.

This paper was initially prepared as requirement for the LLM[Med Law]. The guidance of Prof J Singh [UKZN] is gratefully acknowledged.

Author's address

Dain Van Der Reyden: reydend@ukzn.ac.za

