The Duty of States to Give Sufficient Recognition to the Right to Health

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Modern human rights, as they have developed since World War II, have several characteristics that are imperative to how they are viewed. They are universal, indivisible, interdependent and interrelated. That is, they are held by all people by virtue of the fact that they are human, and apply to all people everywhere. Not all human rights are absolute. That is, some are considered “qualified rights” which may be subject to lawful interference. In the Papua New Guinea (PNG) context, interference will be lawful if it is prescribed by law consistent with the national Constitution and necessary to protect either the rights of others or for other considerations, such as national security, public order or public health. In the ending of life context, the weight that should be given to the consent to, and refusal of, treatment in circumstances where the decision will lead to the death of a patient is debated. This leads to another concern which is the way in which the prerequisites for a refusal of treatment (or valid consent) have been construed. The requirements of competence, voluntariness and information-giving arguably come under more intense scrutiny where the ramifications of the decision have such grave consequences. This paper considers consent as a reflection of the ethical principle of respect for personal autonomy that is often expressed in the law as the principle of self-determination. It also reviews the experiences of healthcare professionals who guide an informed consent process made by individuals, spouses, family members and advisors for the loved ones whose sickness, injury or geriatric age prevent them from having decision-making capacity. The last part summarizes the understanding of the nature of the procedure, benefits and risks which are important to informed consent and offers suggestions as to how the situation can be remedied.

Keywords: constitution, human rights, qualified rights, right to die, PNG

Introduction

The authority to make medical decisions used to lie squarely in the hands of physicians. However, complex social changes have resulted in acceptance of the idea that the patients have a right to know about their health, to know about available diagnostic and treatment options and their risks and probable benefits, and to choose among the alternatives.

For many commentators, shared decision-making is not so much an alternative model but a way of
achieving a more meaningful consent (Gutheil, Bursztajn, & Brodsky, 1984; A. P. Minei, Kaipu, & J. M. Minei, 2020). Developing effective informed consent documents requires thoughtful consideration of the language of patient, family members and others as well as the social and cultural context of the local setting. In resource poor settings where illiteracy rates and lack of medical education are high, challenges associated with comprehension of informed consent documents may be exacerbated. According to one healthcare worker,

The consent form is written in high school grade 10 reading level, too high a literacy level for the parents and is written in English. According to another, the form was too lengthy and rendered it misleading. A third recommended “[to] keep the process on the actual consent forms as simple as possible … so as not to frighten people.” (A. P. Minei, Arafia, Kaipu, & J. M. Minei, 2020, p. 9)

Translation of consent forms from one language to another adds an additional layer of complexity to the preparation of the consent forms. A healthcare professional should be conversant or familiar with the people and what goes on in the local setting. Medical doctors, nurses, social workers, and the clergy have traditionally been the main players in helping care for people near death, but psychologists are increasingly using their expertise to help people have a so-called “good death” or perhaps the more accurate “least bad death”.

Trust is an essential aspect of communication during the consent process and influences decisions regarding participation to making a decision. Levels of trust vary considerably depending upon an individual’s or a community’s past experience with research and factors associated with social status and power. Socio-economic background, residence, gender, age, and education both express and reinforce differences in the relative power of individuals during the consent discussion. Individuals are more likely to experience trust when the person seeking their consent shows respect for their cultural beliefs, language, perceptions of risks, and social and political history. Several healthcare professionals emphasized:

The importance of being aware of language, culture and literacy when interacting with patients. Respondents noted that some patients required the input of patients’ families or other trusted sources prior to consenting to participate in treatment or a procedure. This was particularly true for non-English speaking patients. (A. P. Minei et al., 2020, p. 9)

This is the situation that occurs among families in PNG where decision(s) are made by spouses, family members or clan elders because sickness, injury or geriatric age of persons prevent them from having decision-making capacity.

**Shared Health Care Decision-Making**

In this sense, the patient’s consent is still necessary but, instead of disclosing the relevant information and abandoning patients to their decisions, medical professionals work through them with their patients (Bridson, Hammond, Leach, & Hester, 2003). Once parties arrive at a mutually acceptable treatment option, the patient’s state of mind will be one of consent and the care professional should be aware of this. Once the procedural requirements of consent are satisfied, the intervention would be morally and legally justified. A healthcare worker commented:

… there’s a little bit of a clash between the, maybe, Western medical idea about, you know, that the patient is the one that always needs to be informed and is always empowered to make the decision to consent? Um, there were occasions when, um, a patient comes to the health centre consistently with their husband or their partner … and that’s the person that they kind of rely on to be the interface between them and the medical system. And if I had, you know, excluded that person and just talked to the woman … like, that kind of, I, um, don’t feel like she would have been comfortable, you know, saying yes. So I would, um … you know, I would … approach, I would speak to … to both of them, and show the consent form to both of them. (R. T. Brown et al., 2002, p. 536)
This view of shared decision-making reflects the relevance of the doctor-patient relationship explored in this paper.

**Medical Decision-Making Capacity**

Decision-making capacity is often referred to by the legal term “competency”. It is one of the most important components of informed consent. Decision-making capacity is not black and white. That is, a patient may have the capacity to make some decisions, but not others. The components of decision-making capacity are as follows:

1. The ability to understand the options;
2. The ability to understand the consequences of choosing each of the options;
3. The ability to evaluate the personal cost and benefit of each of the consequences and relate them to your own set of values and priorities;
4. If you are not able to do all of the components, family members, court-appointed guardians, or others (as determined by state law) may act as “surrogate decision-makers” and make decisions for you.

To have decision-making capacity does not mean that the patient will always make “good” decisions, or decisions that his or her doctor agrees with. Likewise, making a “bad” decision does not mean that patient is “incompetent” or does not have decision-making capacity. Decision-making capacity, or competency, simply means that he or she can understand and explain the options, their implications, and give a rational reason why he or she would decide on a particular option instead of the others. Nowadays, many regard traditional practices based on the theory that “doctor knows best” as unacceptable and paternalistic (Childress, 1982).

The society recognizes that patients or their surrogates have a right to decide, in consultation with the physicians, which proposed medical interventions they will or will not accept. Decision-making power or authority is increasingly seen as something to be shared by equal partners in the physician-patient or physician-surrogate relationship. For many patients and family members, personal values affect healthcare decisions, and physicians have a duty to respect the autonomy, rights, and preferences of their patients and their surrogates (Beauchamp & Childress, 1989). A nurse commented:

> There are a couple of the calls we made … through [the] interpreter, you know, that it was very hard. You know, they, didn’t want to talk to us, and when they did, they truly want other family members’ input and I don’t think it was because they didn’t understand; it’s because they truly felt they couldn’t make that decision on their own. (R. T. Brown et al., 2002, p. 536)

Informed consent is at the heart of shared decision-making; this is a recommended approach to medical treatment decisions in which patients actively participate with their doctors. A second staff member noted:

> Some of the older women wanted their daughter’s or younger sibling’s input. A couple of them said, “I need my husband’s input…. So, they would say, ‘You know, I think I understand you, but, would you explain it to my daughter, to see if it’s something I should do?’” (R. T. Brown et al., 2002, p. 536)

The doctrine reminds people to respect people by fully and accurately providing information relevant to exercising their decision-making rights. Experts (Appelbaum, Lidz, & Meisel, 1987) on informed consent include at least the following elements in their discussions of the concept:

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1 Patients must have adequate information if they are to play a significant role in making decisions that reflect their own values and preferences, and physicians play a key role as educators in this process. A patient must give informed consent; it has been called the most important legal doctrine in patient’s rights. It is required not only in life-or-death situations but also in clinic and outpatient settings as well. A healthcare worker discloses the information required and in the language the patient understands, and from that informed consent process flows.
1. Provision of information: Patients should have explanations, in understandable language, of the nature of the ailment or condition; the nature of proposed diagnostic steps and or treatments and the probability of their success, the existence and nature of the risks involved; and the existence, potential benefits, and risks of recommended alternative treatments (including choice of treatment).

2. Assessment of the patient’s understanding of the above information;

3. Assessment, if only tacit, of the capacity of the patient or surrogate to make the necessary decision(s);

4. Assurance, insofar as is possible, that the patient has the freedom to choose among the medical alternatives without coercion or manipulation.

The goals of this consent process include the development of the patient’s comprehensive understanding of the clinical situation, and the timely exercise, by the patient, of active choices regarding the circumstances (Lidz, Appelbaum, & Meisel, 1988). This paper addresses the essential need for new and effective strategies to increase knowledge and information to improve the current understanding of healthcare professionals and others of the duty of states to give sufficient recognition to the right to health.

**Right to Refuse Treatment**

Healthcare providers should engage in the process of informed consent with patients before undertaking any medical treatment. The patients who are judged by healthcare providers to have decision-making capacity have the moral and legal right to refuse any or proposed medical intervention unless they have diminished decision-making capacity or must undergo legally authorized “involuntary” treatment. This is because the competent patients’ autonomy ordinarily extends to the refusal or discontinuation of their own life-sustaining treatment (Capron, 1978). This is true even if the patient chooses to make a “bad decision” that may result in serious disability or even death.

To document that a patient has been given the option of obtaining a recommended treatment or test and has chosen not to, he or she may be asked to sign an Against Medical Advice (AMA) form to protect the health care provider from legal liability for not providing the disputed treatment. Refusing a test, treatment or procedure does not necessarily mean that the patient is refusing all care. The next best treatment should always be offered to anyone who refuses the recommended care. If, because of intoxication, injury, illness, emotional stress, or other reason, a healthcare provider decides that a patient does not have decision-making capacity, the patient may not be able to refuse treatment. (Capron, 1978, p. 1498)

The law presumes that the average reasonable person would consent to treatment in most emergencies to prevent permanent disability or death. Advance directives and living wills are documents that you can complete before an emergency occurs. These legal documents direct doctors and other healthcare providers as to what specific treatments you want, or do not want, should illness or injury prevent you from having decision-making capacity.

**Problems with the Concept of “Consent” by Proxy**

Healthcare providers have adapted the concept of consent to paediatrics many of whom believe that a child’s parents or guardians have the authority or “right” to give consent by proxy. Most parents seek to safeguard the welfare and best interests of their children with regard to healthcare that leads to proxy consent which seems to work reasonably well. However, the concept has issues over one’s self, that is, the person who consents or responds based on unique personal beliefs, values and goals. Proxy consent possesses serious problems for paediatric healthcare providers. Such providers have legal and ethical duties to their child patients
to render competent medical care based on what the patient needs, not what someone else expresses. Although
impasses regarding the interests of minors and the expressed wishes of their parents or guardians are rare, the
paediatrician’s responsibilities to his or her patient exist independently of parental desires or proxy consent
(Weir, 1984).

**Parental Permission and Shared Responsibility**

Decision-making involving the healthcare of young patients should flow from the responsibility shared by
physicians and the parents. The healthcare workers seek permission of parents before medical interventions
except in emergencies when parents cannot be contacted. Usually, parental permission articulates what most
agree represents the “best interests of the child”. However, this standard of decision-making does not always
prove easy to define. In developing countries, there are especially many religious, social, cultural and
philosophical positions on what constitutes acceptable child rearing and child welfare. The law generally
provides parents with wide discretionary authority in raising their children (Holder, 1985). Nonetheless, the
need for child abuse and neglect laws and procedures makes it clear that parents sometimes breach their
obligations towards their children. Healthcare professionals in providing services to children have to carefully
justify the invasion of privacy and psychological disruption that come with taking legal steps to override
parental prerogatives.

**Older Children and the Concept of Assent**

Decision-making involving the health care of older children and adolescents should include to the greatest
extent feasible, the assent of the patient as well as the participation of the parents and the physicians.
Paediatricians should not necessarily treat children as rational, autonomous decision-makers, but they give
serious considerations to each patient’s developing capacities for taking part in decision-making, including
rationality and autonomy. When the physicians recognize the importance of assent, they should empower
children to the extent of their capacity (King & Cross, 1989). In situations where the patients are not and do not
solicit their agreement or opinion of parents, involving them in discussions about their healthcare may foster
trust and better physician-patient relationship, and perhaps improve long-term health outcomes.

**Patient’s Refusal to Assent (Dissent)**

There are situations where a patient would persistently refuse to assent (that is dissent) which maybe
ethically binding. In PNG, this seems quite common in the village settings where the patients will refuse
because of other social, cultural and customary factors. This seems clear in the context of research, particularly
that which has no potential to directly benefit the patient (Leikin, 1983). A patient’s reluctance should also
carry considerable weight when the proposed intervention is not essential to his or her welfare and/or can be
deferred without substantial risk. Healthcare personnel should respect the wishes of patients who withhold or
temporarily refuse assent in order to gain a better understanding of their situation or to come to terms with fears
or other concerns regarding proposed care. Coercion in diagnosis or treatment is a last resort (Shield & Baum,
1994).

King and Cross (1989) asserted that the authority for the healthcare decisions is usually left to the
physicians and parents and this tendency diminishes the moral status of children. There is a real need to care for
children, to provide for measures to solicit assent, and to attend to possible abuses of power over the children
when ethical conflicts occur. This is particularly important regarding the initiation, withholding, or withdrawing
of life-sustaining treatment (Leikin, 1983). There are examples of ways to resolve conflicts, and these include
additional medical consultation(s); short term counselling or psychiatric consultation for patient and the family; case management or similar multidisciplinary conferences(s); and or consultation with individuals trained in ethics or a hospital-based ethics committee. If attempts fail and no agreement is reached, then parties can seek formal legal adjudication where necessary.

The traditional notion of informed consent clearly applies to patients who have reached the legal age of majority, except when the patient has been determined to be incompetent. The laws have designated two settings in which minors have sole authority to make healthcare decisions. First, certain minors are considered “emancipated” and treated as adults for all purposes. Second, many states give decision-making authority (without the need for parental involvement) to some minors who are otherwise un-emancipated but who have certain medical conditions such as sexually transmitted diseases, pregnancy, and drug or alcohol abuse (Sigman & O’Connor, 1993). The situations in which minors are considered to be totally or partially emancipated are defined by statute and case law and may vary from state to state (Tsai et al., 1993). Legal emancipation recognizes a special status (e.g., independent living) or serious public and or individual health problems that might not otherwise receive appropriate attention (e.g., sexually transmitted disease).

**Human Rights**

Human rights have been defined in numerous ways throughout history. Simple definitions include:

1. The recognition and respect of people’s dignity;
2. A set of moral and legal guidelines that promote and protect a recognition of our values, our identity and ability to ensure an adequate standard of living;
3. The basic standards by which we can identify and measure inequality and fairness;

The United Nations was founded in 1945, its purposes being to provide a platform for dialogue amongst nations, to maintain international peace and to promote cooperation in solving international economic, social and humanitarian problems (European Court of Human Rights, 2003). In 1948, the United Nations General Assembly adopted the Universal Declaration of Human Rights (UDHR). The UDHR recognizes that “inherent dignity and the equal and inalienable rights of all members of the human family is the foundation of freedom, justice, and peace in the world.” In the preamble, governments also commit themselves and their people to strive by teaching and education to promote respect for the rights and freedoms set out in the UDHR, and by progressive measures, national and international, to secure their universal and effective recognition and observance. The UDHR, combined with other international covenants including International Covenant on Civil and Political Rights (ICCPR) and International Covenant on Economic, Social and Cultural Rights (ICESCR), form what is commonly referred to as the International Bill of Human Rights. These have been joined by over 100 other human rights instruments (UNHR, 2014). The Rights as are contained in the UDHR, include:

   Article 1. All human beings are born free and equal; …

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2 Definition: emancipated minors include those who are: (i) self-supporting and or living at home; (ii) married; (iii) pregnant or a parent; (iv) in the military; or (v) declared to be emancipated by a court.

Article 2. Everyone is entitled to the same rights without discrimination of any kind; …

Article 30. No person, group or government has the right to destroy any of these rights …

The rights include civil and political rights. The progressive realization of economic, social and cultural rights continues to be an important goal for the 21st century, reflecting the idea that governments have a moral, and often legal, obligation to meet such rights. A “declaration” is not, in most cases, legally binding but carries moral weight because it is adopted by the international community. The term is chosen to indicate that the parties do not intend to create binding obligations, but rather want to declare certain aspirations (see United Nations Treaty Section, Definitions of key terms used in UN Treaty Collection). A “convention” (sometimes referred to as covenant) is a formal agreement between states. It creates binding legal obligations, which come into force upon ratification by a requisite number of states.

Ending of Life

End-of-life that is defined as the period when health care providers would not be surprised if death occurred within about six months is a time when psychologists can treat depression and anxiety associated with pending death, offer grief counseling, help people understand confusing medical terms, and help provide compassionate care for the dying and their loved ones (R. T. Brown et al., 2002).

The ending of life context has in recent time often conflicted with the human rights perspective. Human rights law has proven to be highly relevant to end-of-life decision-making, which is unsurprising given the moral axis of the sanctity of life, respect for personal autonomy, and the relief of personal suffering that has characterized the arguments about decision-making on the ending of life (Kleespies, 2004).

In several countries, the impact of the human rights perspective has proved a significant factor in changes to the legal approach, particularly to that of assisted death. PNG has no human rights legislation but it has adopted the bill of rights like the US, Canada and the UK in its Constitution. There are some sections of the PNG Constitution that have relevance to rights. Healthcare is largely state responsibility but provisions like Section 49 (Right to privacy) do confer legislative powers on the National Parliament with respect to matters relating to health, sickness and hospitals, medical and dental services.

However, the sort of human rights that are brought into focus by the ending of life in the clinical setting are not the sort that PNG would invoke. However, among the indigenous population there are beliefs where a sick patient tells his family relatives and external family or clan elders that he or she is unable to cope with the illness and is willing to die. While the patient undergoes no other medical treatment or procedures, the family members consent to the medical staff or the hospital administration to take the patient out of the medical setting and return the patient to his or her family home to await his or her death. PNG continues to have no entrenched national human rights legislation and so using human rights as a basis for legal arguments will be more difficult given the absence of express legislative or constitutional guarantees.4

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4 This is where informed consent is appropriate in euthanasia. Question which one ponders in his or her mind in this situation is: Is consent to die a treatment by death of the illness? The family members then prepare for his burial place and attend to other familial requirements while awaiting the death of the patient. PNG is a Melanesian country; in Melanesia this practice happens not only in medical settings but also in the villages. This is an unreported issue which may be common to few other cultures. The patient’s or the individual’s wishes are respected and recognized by the healthcare worker and families even though they do not consider it to be in the individual’s interest to do so.
The notion of autonomy is honoured in different ways in all major moral theories in the Western analytic tradition (Hardin, 1989). The courts, on the other hand, have come down hard to enforce patients’ autonomy rights through landmark judgements, thereby enforcing the doctrine of informed consent. The theories and positions taken by the philosophers Immanuel Kant (1993) and John Mills (1991) provide the moral basis, or foundational moral arguments for the principle of respect for autonomy.

Health practitioners and patients should be aware that the law in PNG places great (if not paramount) emphasis upon the health and wellbeing of children. The discussion on euthanasia and the position PNG holds in terms of this subject is unknown but undoubtedly reflects such emphasis. What do the others say, for example, what is the religion’s say on this issue? What are the limits of modern-day consent in culture such as in PNG? The questions have often proven very difficult to resolve. These are issues which we are aware of; however, we have decided to do what we have deemed necessary for present purposes.

There are two distinctions that may shape the law relating to the ending of life in the clinical setting. One is the distinction between the patient who lacks capacity and the patient who has it. The other is the line which is drawn between omissions which lead to a patient’s death, and actions which have the same result. Competent patients have the right to refuse life-sustaining and life-saving treatment. In this respect, the principle of self-determination “trumps” that of the value of life. The right of self-determination does not mean to permit a person to assist another to die, either by facilitating the death or fully bringing it about. In PNG these situations remain captured under the criminal law. Patients who are incompetent to take these decisions may have in fact exercised their advance directive in relation to their medical care or have appointed a substitute decision-maker. Incompetent patients include babies and young children who have never been competent and the test is therefore what is in their best interests.

In overseas jurisdictions where human rights guarantees have been entrenched as part of domestic law, decisions and actions taken in relation to the ending of life have been subjected to more scrutiny, for example, in the UK, Canada and the US. The interpretation has been in some cases to protect a person’s right to make life choices, including choices about the manner and timing of his or her death. In other cases, particularly in relation to incompetent patients, legal arguments have referred to those clauses that protect the right to life, and the right to be free of suffering. Each of those documents contains clauses which have been interpreted as protecting a person’s right to make life choices, including choices about the manner and timing of his or her death.

It is difficult to formulate a definition of euthanasia which is universally acceptable, it is possible to flesh out the contours of the term, and it probably remains the case that, consistent with its origins in the Greek translation of “ethos”, euthanasia refers to an “easy” death which is brought about for the relief of suffering.\(^5\) The law of ending of life applies to competent and incompetent patients. It interferes with a number of legal principles including the law of consent, the criminal law and the civil law. As such, the ending of life is a contextual question and one which must take account of these principles, how the principles have been applied and adopted within the context and the challenging ethical and legal questions that arise.

Our take on this is that perhaps there are two sides of autonomy. The first is that individuals must have autonomy exclusive of others. And the second, for some individuals, family must be involved. Our view on this

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\(^5\) Those factors associated with a “good” death as opposed to a ‘bad’ death have been explored in J. Clark and P. Singer, what is a Good Death? BMJ 309 at 327.
subject is that autonomy of individuals must circumscribe informed consent, for example, remaining pregnant. Numerous ethical and legal issues arise during the periods of preconception, conception and birth. They reflect a deep human sensitivity surrounding factors that precede but affect, or that exist during, the very earliest stages of life.

**State Obligations**

States have the primary obligation to protect and promote human rights. Following ratification of human rights treaties, states parties are required to give effect to these rights within their jurisdictions. The right to health requires progressive realization. States have the legal obligation to protect and promote human rights, including the *right to social security*, and ensure that people can realize their rights without discrimination:

> The obligations of States in relation to economic, social and cultural rights are expressed differently from treaty to treaty. For example, in its Article 2(1) the International Covenant on Economic, Social and Cultural Rights requires States “to take steps” to the maximum of their available resources to achieve progressively the full realization of economic, social and cultural rights. The Covenant also requires States to guarantee the enjoyment of economic, social and cultural rights without discrimination and to ensure the equal right of men and women to the enjoyment of these rights. Other treaties or constitutions word obligations differently and even include specific actions that States must take, such as the adoption of legislation or the promotion of these rights in public policies.

The obligation to achieve progressively the full realization is a central aspect of States’ obligations in connection with economic, social and cultural rights under international human rights treaties. At its core is the obligation to take appropriate measures towards the full realization of economic, social and cultural rights to the maximum of their available resources. The reference to “resource availability” reflects a recognition that the realization of these rights can be hampered by a lack of resources and can be achieved only over a period of time. Equally, it means that a State’s compliance with its obligation to take appropriate measures is assessed in the light of the resources—financial and others—available to it. Many national constitutions also allow for the progressive realization of some economic, social and cultural rights.


Even though States may realize economic, social and cultural rights progressively, they must also take immediate action, irrespective of the resources they have, in five areas: elimination of discrimination; economic, social and cultural rights are not subject to progressive realization; obligation to “take steps”; non-retrogressive measures; and minimum core obligations.

Furthermore, in order to clarify the meaning of States’ obligations, they are sometimes put under three headings: to respect (refrain from interfering with the enjoyment of the right), to protect (prevent others from interfering with the enjoyment of the right) and to fulfil (adopt appropriate measures towards the full realization of) economic, social and cultural rights.

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7 Ibid.
This means the states should take deliberate, concrete and targeted steps forward, using the maximum available resources (financial and others), to achieve the right to health over time.

**Obligation to Respect, Protect and Fulfil Right to Health**

Obligation to respect the right to health requires states to refrain from denying or limiting equal access for all persons, including minorities, asylum seekers, prisoners and illegal immigrants, to preventive, curative and palliative health services and abstain from enforcing discriminatory practices as a state policy, and abstain from imposing discriminatory practices relating to women’s health status and needs.

This duty of the states imposes an additional obligation to adopt legislation or to take other measures ensuring equal access to healthcare and health-related services by third parties. States should make sure that third parties do not limit people’s access to health-related information and services. It is the duty of the states to give sufficient recognition to the right to health in their national political and legal systems and to adopt national health policies with detailed plans for realizing the right to health. This obligation also requires the state to take positive measures that enable and assist individuals and communities to enjoy the right to health.

**Conclusion**

This article discussed self-determination and the concept of autonomy and examined the ideas shared by philosophers. The concept of shared healthcare decision-making is being promoted as opposed to the physicians-centred approach to medical treatment. Documentation of informed consent is an important issue for all healthcare professionals, particularly those who work with culturally diverse populations in areas with high illiteracy rates. Informed consent documents should be clear and in simple language. Some answers from our interviews bear out the need for simplicity and clarity of language.

Verbal consent is appropriate when risks associated with treatment are low and the potential harm for patient is unlikely. We say that physicians were more likely to use written consent than non-physicians and that written consent was more likely to be used in areas of high literacy. Moreover, in many cultural settings, agreements based upon trust do not require a signature. In PNG, patients were uncomfortable in signing forms if they were illiterate or did not understand its content. In some international settings, individuals may need to consult with another individual, such as a spouse or head of the household, before consenting to participate. When necessary, healthcare professionals should allow individuals to discuss the consent with others who are important to them.

The justification in obtaining consent from illiterate, sick or aged persons by giving adequate information to the patient, individual and family, familial clan leaders and advisors in addition to observing the process of treatment or not, is ethical. This enables the patient and the family to accept the decision. This paper uniquely shows that attention to the conditions of medical ethical aspects in rural PNG that have varying cultures and dialects is essential. The method could be used in other areas with low literacy rates.

We note that the major challenge of obtaining accurate contact information and reaching patients or individuals has implications for providing quality clinical care as well as for equitable representation in treatment or procedure. Specific to our diverse, low-income population, the following suggested strategies may address the barriers associated to consent: healthcare professionals to modify consent forms to ensure cultural literacy and communication of the appropriate level of risk. Further examination of the effectiveness and appropriateness of consent form language, related to community-based research, is warranted.
We have adverted to the challenges that informed consent itself faces from custom or customary law within the PNG context. Its emphasis on communal interest and welfare often militates against personal autonomy and autonomous decision-making with respect to medical procedures and treatment, let alone the right to assisted death, and the confidentiality of information that ought to remain so between the patient and the physician. To recognize and actualize individual right to health therefore requires surmounting the barriers thrown up by custom or customary law first. This is easier said than done because the indigenous population upholds the rules and practices of custom or customary law as their system of law which demands compliance at the risk of disrupting familial and societal relations and harmony, and the sick and the distressed immediate members of the family do not want this to happen at their most vulnerable time.

In summary, understanding of the nature of the procedure, benefits and risks are important to informed consent. The patient’s right to autonomy should always be respected and steps should be taken to make consent truly informed. We hold the view that there is no absolute right to autonomy or consent. In light of many of the related developments we have canvassed, it is concluded that there are many grey areas in this field of consent law, particularly on the issue of dignified assisted death, which in our view, can be eliminated by pro-active intervention by a concerned professional regulatory body, established and guided by a precise and specifically designed law. Psychologists can contribute to end-of-life care before illness strikes, after illness is diagnosed and treatments begin, during advanced illness and the dying process, and after the death of the patient, with bereaved survivors.

In so saying, we remain mindful of the moral, ethical and religious aspects of the question of assisted death which we believe we have sufficiently covered as warranted by the principal focus of this paper, namely, informed consent.

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