

INFORMED CONSENT IN THE AOTEAROA NEW ZEALAND CONTEXT

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Psychologists are in very privileged positions; we use our clinical, community, academic, and research skills to support individuals, families, and communities, often during extremely vulnerable times in their lives. Psychologists have specific duties and responsibilities to not only offer a competent and ethical service, but to ensure that clients have been engaged in an open and honest process of gaining informed consent before a psychological service is offered, and either accepted or declined by the client (Knapp, Gottlieb, & Handelsman, 2015; Nagy, 2011).

Appelbaum, Berg, and Lidz (2001) noted three ways of thinking about informed consent: as a specific rule to govern practice, as an autonomous authorisation tool, and as a shared decision-making process. Gaining informed consent is a process that may take different forms. Beginning at the start of the psychological relationship, informed consent may be revised during the relationship, culminating in a shared understanding and agreement that the psychologist takes responsibility for documenting.

Fink, Hall and Prochazka (2012) note that while informed consent may be practically applied, it may never reach its theoretical ideal (Fink et al., 2012). In the same vein, the New Zealand Psychologists Board's *Guidelines on Informed Consent* (2016) states that defining informed consent is relatively easy; however, transforming this into ethical action is more complex and may require "attention and sensitivity to a number of factors which can potentially compromise the client's ability to consent in an informed manner" (p. 4).

Aotearoa New Zealand Context

The importance of gaining informed consent is well documented in several relevant publications involving psychologists working in this country: the *Code of Ethics for Psychologists Working in Aotearoa New Zealand* (2002) (the Code of Ethics); The Health Practitioners Competency Assurance Act (2003), the *Code of Health and Disability Services Consumers' Rights* (1996) (HDS Code) and the New Zealand Psychologists Board's *Guidelines on Informed Consent* (2016).

The Code of Ethics is the most important regulatory document for our profession and its purpose is to "unify the practices" of psychologists and guide "ethical decision making" (p. 1) while also acting as a source of information for consumers of psychological services. The Code of Ethics clearly articulates that "obtaining informed consent from those with whom they are working is a fundamental expression of respect for the dignity of persons and peoples" (Principle 1.7; p. 10). Under this principle, psychologists are obliged to negotiate and obtain informed consent, and to recognise that we have increased responsibilities for protecting and promoting the rights of those who have less power and are more vulnerable.

Informed consent is a process rather than a one-off event that should only occur when the client or the client's representative has received relevant information in a form he or she can understand. Saks and Golshan (2013), from a psychoanalytic perspective, suggest that informed consent may not even be possible as it may be very difficult for the patient to absorb the information and weigh up the risks and benefits in a meaningful way. Psychologists must negotiate these complexities each time they offer their services or skills to clients.

The Health Practitioners Competence Assurance Act 2003 (the HPCA Act) seeks to protect the public by appropriately regulating health professionals (Ministry of Health, 2014). Important key protections are in place, with provisions that ensure health practitioners under the Act are registered and practise within their scope; that their regulatory bodies are responsible for certifying their practitioners, and that restricted activities are only

allowed to be performed by registered practitioners. The HPCA Act mandates the New Zealand Psychologists Board to register psychologists and assure the public that psychologists are fit to practise and provide high quality and safe services.

The Health and Disability Commissioner's Code of Health and Disability Services Consumers' Rights Regulation (HDC; 1996) is defined as "a tool for the empowerment of all health and disability services consumers in New Zealand" (Health and Disability Commission, 1999, para 1). Our medico-legal situation in Aotearoa New Zealand is unique in that consumers have rights by law. Service providers including psychologists have duties and responsibilities, both to inform consumers of their rights and to ensure that they can exercise these rights (Health and Disability Commission, 1999). Within this Code, consumers have the right to be fully informed (Right 6) and to make an informed choice and give informed consent (Right 7). They are "presumed competent to consent, unless there are reasonable grounds for believing that the consumer is not competent" (HDC, 1999, Right 7 (2)). In cases of diminished competence, consumers retain their rights to the extent appropriate to their level of competence. Providers may provide services if it is in the consumer's best interests and reasonable steps have been taken to gain their views and the views of others interested in their welfare (Right 7 (4)). Consumers have the right to refuse services and withdraw their consent (Right 7 (7)). Psychologists should be familiar with all 10 rights of consumers and duties of providers that are described under the HDC Code.

The New Zealand Psychologists Board's *Guidelines on Informed Consent* (2016) have been developed "to support psychologists in providing competent and ethical practice by translating or expanding on the Code in relation to more specific aspects of their professional behaviour" (p. 3). In adopting these guidelines, the Board was clear that while they have the least authority of any of the regulatory documents, "a disciplinary or review body may use the guidelines in evaluating a psychologist's knowledge and competency" (p.3). It is therefore essential that psychologists refer to these guidelines to ensure they are following "best practice".

This chapter uses a hypothetical case study format to engage the reader in a discussion about how psychologists in Aotearoa New Zealand can action both the theoretical and practice-based principles of informed consent as it applies to assessment, treatment, and research practices when working with infants, children, adults, and their families/whānau in Aotearoa New Zealand. The chapter should be read in conjunction with both the Code of Ethics and the New Zealand Psychologist's Board *Guidelines on Informed Consent* and with reference to Te Tiriti o Waitangi/Treaty of Waitangi.

Case Study

Aroha is a 15-year old Māori girl, who is 8 months pregnant. She has been given an urgent appointment at the local Child Adolescent Mental Health Service (CAMHS), following reports by her care and protection social worker that she has been behaving oddly (staying in her room, staring into space, and both visually and verbally responding to nonvisual stimuli). Aroha arrives with her social worker and a residential house mother as a support person. As you briefly greet Aroha, she appears tentative and distracted. The social worker introduces herself and explains she is there to support Aroha and to ensure that the unborn infant is safe. She also informs you that Child, Youth and Family (CYF), have custody and guardianship of Aroha and will likely take responsibility for the newborn infant. As you lead Aroha into the clinic room, you are aware that the social worker and the house mother are also following you into the clinic room.

Defining the Client

Psychologists are required to name an identified client whenever they are engaging in service delivery. Fisher (2009) stated that while traditionally pressure has been on psychologists to name "the client", "primary client" and other "third parties" who may be involved, such thinking obscured the real ethical questions about psychologists' obligations to each of the parties involved in a case. He argued that psychologists have the responsibility for "protecting the rights of everyone involved—those who request services; those who receive services; those who participate as collaterals in the services provided to others; 'outsiders' who provide information; and others to whom information is disclosed, etc." (p. 1). While Knapp and VandeCreek (2003) identified that in couple or family work, the psychologist's focus is to "clarify their roles and their relationships with all parties" (p. 148), a more pragmatic approach is needed.

Fisher (2009) states that each party has a right to receive, in advance, an explanation of the psychologist's role; a clarification of the nature of the relationship; an explanation of rights; a discussion of probable uses of the services provided and the information obtained. Additionally, each party can expect an explanation of limits of confidentiality, including how each party's confidentiality may be affected by the third party's involvement.

According to the Code of Ethics, psychologists must "clarify and make explicit their role and responsibilities with the person(s) with whom they are working" (p. 24). This process includes an explanation of who you are, your qualifications, and what the assessment process will entail, as well as obtaining explicit informed consent for any psychological services provided. As documented in the Health and Disability Commissioner Act (1994), it is the duty of the health professional to inform the client clearly and honestly, with the expectation that the following information be included in discussions with the consumer:

- the likelihood of success of the various options
- their likely effects and any associated physical, emotional, mental, social, or sexual outcomes
- the consequences of not accepting the proposed treatment
- the costs of treatment and any financial interest of the provider.

Following the informed consent-seeking process where the health professional explains their opinion and the recommended options, the client has the fundamental right to choose the option they prefer and a right to seek a second opinion.

In the above case study, several people emerge as parties involved: Aroha, who is being brought for psychological assessment; the social worker, who has statutory responsibility for Aroha and is requesting the mental health assessment; and the house mother, who is a support person for Aroha and her unborn child.



Guidelines

1. Be clear with each party about who you are as a psychologist, clearly articulate your qualifications including your scope of practice, your registration status, and your experience in the area.
2. Clearly articulate the purpose of your involvement with each party, what, if any notes will be taken, how they are stored etc. according to agency policy.
3. Inform each party of the limits to confidentiality and the process that will be taken should confidentiality need to be broken.
4. Other considerations may include a discussion of the therapy/treatment options available; costs of treatment; how clients can choose to end services; and how to make a complaint or give feedback more formally.

As you, the psychologist, enters the clinic, you begin by introducing yourself, your qualifications, experiences, role in the agency and general agency consent processes (limits to confidentiality, note-taking process, how the client can ask to see someone else etc.). Then others are invited to introduce themselves. When it is Aroha's turn, she is shaky and very nervous; although she is able to introduce herself, she does so briefly and then looks away. As psychologist, you ask Aroha if she has any questions about the process today and she responds by asking if she can wait until her mother gets there.

This interaction highlights other parties who may need to be considered in the process of gaining informed consent. Aroha's whānau, given that she is an indigenous Māori youth, will also play an important role in supporting Aroha to feel more comfortable in the assessment process and in therapy and recovery. In the Code of Ethics, the declaration clearly documents that "in giving effect to the Principles and Values of this Code of Ethics there shall be due regard for New Zealand's cultural diversity and in particular for the provision of, and the spirit and intent of, the Treaty of Waitangi" (p. 1). Each of the four principles identified requires that psychologists are informed about the Treaty of Waitangi and have training in appropriate ways to show respect in their practice for the dignity and needs of Māori.



Guidelines

1. Respect Aroha's wishes to have her mother present, as this is a culturally appropriate practice, and it is her right to be supported.
2. Discuss this with the other parties involved.
3. Provided there are no imminent safety concerns, rebook the assessment for a time when her mother can be present.

The Client is Under State Guardianship

The Care of Children Act (2004) makes the “best interests and welfare of the child” paramount in any legal dealings. Although entering into a professional relationship with a psychologist may not be a legal issue, referring a child into services may require some legal mandate when the child's legal status no longer sits with the parents but instead sits within a legal entity. Aroha's care sits under the guardianship of the Chief Executive of Child, Youth and Family, under section 67 of the Children, Young Persons and their Families Act (1989). However, the general principle of the Act is that “wherever possible, a child's or young person's family, whānau, hapū, iwi, and family group should participate in making decisions affecting that child or young person” (sec 5(b)). Additionally, “consideration should be given to the wishes of the child or young person, so far as those wishes can reasonably be ascertained” (sec 5(d)).

Psychologists are guided by the Code of Ethics, which states that “in any work where children/young persons are involved, psychologists recognise that the interests and welfare of children/young persons are paramount and therefore given precedence over other considerations” (1.5.1; p. 7). However, psychologists are also cautioned to discriminate between the needs and the wishes of the child/young person, which must be taken into account along with wider social and general welfare issues. Therefore, it would be both reasonable and respectful of Aroha's wishes to allow the assessment to take place when her mother is also available, provided there is no imminent need to urgently assess her mental health.

Age and Competency of the Client

Legally, a psychologist may meet a young person (under the age of 16), without parental authority or knowledge if that young person is believed to have sufficient understanding to make their own informed decision (Rucklidge & Williams, 2007). Under the HDC Code (1996), there is a presumption that all consumers of health and disability services, regardless of age, are competent to make an informed choice and to give informed consent unless there are reasonable grounds for thinking otherwise. Under the HDC Code, children are subsumed within the category of “consumer” without reference to age or capability, and therefore, as consumers, they are presumed to be competent unless and until assessed and determined not to be (Rucklidge & Williams, 2007). The HDC Code functions on the basis that the ability to consent to treatment is not secured to age and it is the functional level of competency that determines whether a child or young person (or any other consumer) is able to make an informed choice (Rucklidge & Williams, 2007). Furthermore, if the child refuses a treatment that is not required because there is no immediate urgency, then as long as the child is deemed competent, the clinician must accept the child's decision.

When considering whether a child can give informed consent, the Ministry of Health's document *Consent in Child and Youth Health* (1999) notes a “clear trend away from age-related thresholds and, instead, [a focus] on the competence of the individual child to consent to participating in a health service” (p. 50). Nevertheless, there are some guidelines listed on the Health and Disabilities Commission website (<http://www.hdc.org.nz>) on how providers can ensure that their services are more appropriate for children and youth. These include seeing the child in the context of their whānau/family, and using plain language and other props or resources to help with understanding conversations about consent and confidentiality.

When working with children and young people, the clinician is responsible for assessing the individual's level of competency with respect to the particular service being offered (Rucklidge & Williams, 2007). It is worth asking; is this particular child or young person competent to make an informed choice about whether to consent

to or refuse the particular service which is being suggested? Sometimes it will be obvious that the child is not competent, for example in the case of an infant or a very young child. As children grow older, however, they may well be competent to consent, even when quite young, especially if the procedure or treatment is relatively simple. This question also takes account of these circumstances. The legalistic view is that consent is a global and principally an enduring trait (Rucklidge & Williams, 2007). In practice, the ability to consent, for children in particular, is affected by many situational variables and may change over different disorders or treatments, and over time (Miller, Drotar, & Kodish, 2004).

In an English case (*Adult: Refusal of Medical Treatment*, (1994) 1 WLR 290) Fordham, (1994) the Court had determine whether “a mental patient was competent to withhold his consent for treatment” (p. 129). The Court established a useful three-stage test for competency for consent to treatment. In that case, the Court concluded that a person is competent if he or she:

1. can comprehend and retain the necessary information about the procedure or treatment, and
2. is able to believe it, and
3. is able to weigh the information, balancing risks and needs and so arrive at a choice.

Therefore, age, although important, is only one factor that influences a judgment as to whether a child (or adult in this case), is competent to consent. It is also essential that understanding, maturity, and the best interests of the child are considered along with the complexity and necessity of the service being suggested (Rucklidge & Williams, 2007). It is crucial to consider that any individual's capacity to consent may be affected by drugs or alcohol as well as more obvious factors such as pain, distress, illness, and certain medicines they may have taken (Rucklidge & Williams, 2007).

Although cognitive ability is clearly paramount to level of understanding, it is only one variable of many to consider in the assessment (Rucklidge & Williams, 2007). Formal tests of cognitive ability such as tests of intelligence may be helpful in assessing overall levels of understanding, but they should not be used as the sole criterion for determining capacity to consent. One should also contemplate how risky the procedure is, the maturity level of the child involved, the health problem being treated and the associated risks, and the social and cultural development of the child, and the child's time perception (Rucklidge & Williams, 2007). Also, emotional states such as an anxiety or mood disorder can have an impact on a child's ability to process information (Rucklidge & Williams, 2007). Cognitive ability is also important to consider with older adults.

As society ages, an increasing number of older adults will experience impaired cognitive functioning and thus some reduction in their capacity to be as actively involved in a process of informed consent as they may have been before their cognitive impairments. An ability to exercise decision-making autonomy is a fundamental right in health care, be it in making decisions about assessment, treatment options, or participation in research. Psychologists have been increasingly involved in designing and developing tests to assess a person's cognitive function and therefore capacity to make decisions regarding their own health options. In these circumstances, it has been suggested that psychologists might also obtain surrogate consent (Casarett, Karlawish, & Hirschman, 2003).

Overall, these guidelines are also consistent with the Code of Ethics which, in Practice Implication 1.1.3, directs psychologists to obtain “full and active participation . . . for all persons in decisions that affect them”. In Practice Implication 1.7.3, the Code of Ethics also directs that psychologists, when working with people who are not fully competent to consent to treatment for themselves, should seek informed consent “to the extent that is feasible from the person with limited ability to consent”.

In relation to the case study, young people have rights as clients (Dockett, Perry, & Kearney, 2012), but they are also considered part of a vulnerable population (Rajaraman et al., 2011). Being defined as a child means that it may be determined that they are incompetent to make decisions about their own health journey and that the parent or legal guardian serves as a proxy consentor, making decisions about participation on behalf of the child.

What about if the child is also a mother? As a “soon to be” mother, does her age restrict the rights she has to make decisions for her own child? What then of the rights of the unborn child? In the specialist area of infant mental health, the rights of the infant would certainly be considered and most importantly, that the psychologist is able to hold the infant in mind.



Guidelines

1. As a soon-to-be mother, Aroha has the right to make choices for herself and her infant, if she has capacity and no safety concerns are noted.
2. She has the right to make these decisions in the most supportive environment for her.

Just as you are about to discuss Aroha's desire to have her mother attend the session, the clinic receptionist knocks on the door and informs you that Aroha's mother, Tiana, has arrived and would like to be included in the meeting. The psychologist again checks with Aroha that she would like her mother to be included in the meeting. The social worker interrupts and says that Tiana does not have legal guardianship of Aroha and she is concerned that Tiana may hijack the session. However, it is clear that Aroha would feel more comfortable with her mother present. As you go to the waiting room to meet Tiana, you realise that she has come with other whānau members – an Aunt and an adult cousin. As you greet Tiana she informs you that her Aunt and cousin also want to be included in the session.

Cultural Context

*Tungia te ururua kia tupu whakaritotito to tupu o te harakeke
Set the overgrown bush alight, and the new flax shoots will grow.*

Ikechukwu (2014) describes how different cultural regions around the world approach the concept of informed consent from the “perspectives of their moral and cultural traditions” (p. 2). He further notes that African tradition stresses “communal-determination” rather than self-determination, stating that “community members, family, relatives, clan— continue to regard it as a duty to take care of a sick member ... hence the sick (patient) rarely goes unaccompanied to consult the African traditional medicine doctor . . . in some cases . . . relatives go on the patients behalf” (Ikechukwu, 2014, p. 1).

Tanida (1996) noted that in Japan, morality and doing the right thing as a society is more important than an individual's ethical rights, stating that in Japan “a person does not exist as an individual, but as a member of the family, community or society” (p. 203). Masaki, Ishimoto, and Asai (2014), argued that even though Western concepts have been widely supported in Japan “informed consent is similar to, yet different from, original informed consent that was born in the U.S.” (p. 6.), reflecting the strong mixed influence of Shintoism, Buddhism, and Confucianism that values harmony, avoidance of conflict, and societal group decisions.

Many Fourth World people (a term used to describe indigenous peoples who have stayed on their lands, but had their cultures, histories, and identities subsumed, reshaped and enacted by the colonising powers (Doyle, 2011) are evidence of the failure of universal approaches in mental health. Fourth World peoples in countries such as Canada, Australia, and Aotearoa New Zealand illustrate that disparities continue, decades on, across a range of health, social, economic, and cultural factors (Doyle, 2011; Durie, 1994; Health and Disability Commissioner, 1999; McDonald & Milne, 2000; Sheridan et al., 2011; Sporle & Koea, 2004).

However, from failure comes opportunity; the idea of “culture as cure” grew from the failure of Western models to treat culturally different people and the proposal that providing culturally relevant treatment is likely to have better outcomes (Atdjian & Vega, 2005; Glover, 2001; Houkamau, 2010; Santiago-Irizarry, 1996; Walker, 1990).

In Aotearoa New Zealand, the indigenous Māori community is in a unique position because indigenous rights are documented in Te Tiriti o Waitangi (The Treaty of Waitangi), and its legislative equivalent the Treaty of Waitangi Act, 1975 (Hayward & Wheen, 2004).

Braun, Skene and Merry (2010) refer to the Treaty as the country's founding charter, stating that “*this does not diminish the rights of others, but makes explicit the special situation of the Indigenous people*” (p. 819). They further propose that “New Zealand doctors may be obliged to accommodate the expectation of the extended family to be present for much of the time a Māori patient is in hospital, and for the extended family to participate in decision making” (p. 820). Clearly, a whānau-inclusive model (Hudson, Milne, Reynolds, Russell, & Smith, 2010) is reflected in the case-study above. Williams (2010) describes “whānaungatanga”; the idea and

ideal of kinship/relationship as a key principle in traditional Māori society; that is, the relationship with the environment, relationships between humans, between humans and the non-human.

While Te Tiriti o Waitangi has been criticised by some for “not having any teeth” and “lacking legislative power”, Palmer (2008) stated that the Treaty of Waitangi or aboriginal title acquires political and symbolic meaning and, sometimes, legal power (Palmer, 2008). The power of the Treaty of Waitangi is the fact that it has “moral credibility”. As people become fully informed of the injustices that occurred during colonisation around the world, and in particular in Aotearoa New Zealand, their moral compass kicks in and their sense of justice and fairness prevails, highlighting the need for all people to enjoy equal health opportunities and outcomes.

The principles of partnership, participation, and protection underpin the relationship between the government and Māori under the Treaty of Waitangi. The Ministry of Health (2010), has articulated that:

- Partnership involves working together with iwi, hapū, whānau, and Māori communities to develop strategies for Māori health gain and appropriate health and disability services.
- Participation requires Māori to be involved at all levels of the health and disability sector, including in decision-making, planning, development, and delivery of health and disability services.
- Protection involves the government working to ensure Māori have at least the same level of health as non-Māori, and safeguarding Māori cultural concepts, values and practices.

In 1999, Robyn Stent, the New Zealand Health and Disabilities Commissioner, stated that the “Code of Rights . . . sits alongside Te Tiriti as a means of achieving ora through the empowerment of Māori consumers. The Code of Ethics does not seek to replace Te Tiriti but rather to enhance the wellbeing of Māori through encompassing its principles (Health-Disability-Commissioner, 1999).

When applying the Treaty of Waitangi principles to the process of informed consent:

- Partnership involves a collaborative formal relationship between psychologist and whānau, where the whānau feels empowered.
- Participation is a culturally safe process of discussions and exchanging ideas.
- Protection enables access to services where the duty to provide safety is the responsibility of the psychologist.

The Code of Ethics makes a clear declaration: “In giving effect to the Principles and Values of this Code of Ethics there shall be due regard for New Zealand’s cultural diversity and in particular for the provisions of, and the spirit and intent of, the Treaty of Waitangi” (2002, p. 1).

Unfortunately, the Guidelines on Informed Consent do not mention any cultural issues, issues for Māori, or the Treaty of Waitangi. Durie (2011) reminds us that since the 1980s there has been a moving away from a monocultural approach towards an indigenising of mental health services in New Zealand (Durie, 2011) with a by Māori for Māori approach to service development (Cram, 2009; Durie, 1994; Pihama, Smith, Taki, & Lee, 2004; Smith, 2006). While these services have been shown to increase Māori engagement and retention in both mental and general health services (Cram, 1997, 2001, 2009; Lawton et al., 2013; Pihama et al., 2004), most Māori are still seen within mainstream services. As such, we cannot simply see this as a Māori-only problem and leave it for Māori to find solutions.

Durie (2011) defined three broad pre-conditions for innovation in health care, which have been learned from what has occurred for Māori in New Zealand.

1. Innovation arises in response to a need for change – indicated when current approaches fail.
2. Innovation is more likely to occur when the right catalysts are present – including alliances between medical science and indigenous knowledge, and across other sectors such as health and education.
3. Innovation requires an enthusiasm for change – between sectors, communities, all people, and government.

Although it is clear that Māori live in diverse cultural worlds, where a singular shared reality no longer constitutes what it means to be Māori (Durie, 1998), Houkamau and Sibley (2010) have ventured so far as to suggest that there are now several differing profiles of Māori identity. This changing landscape presents even more challenges because of differences within whānau who identify as Māori. Putangitangi reflects the fluidity

and perhaps circumstance of the individual, leaving Māori to ask themselves “how safe is it to identify as Māori within this context?” This may be the position that Aroha finds herself in, reflecting on how safe it is to be Māori in a non-Māori context.



Guidelines

1. The Code of Ethics clearly states that the “spirit and intent of the Treaty of Waitangi” must be upheld. Thus, Aroha has the right to participation, partnership, and protection when she seeks professional services from any registered psychologist in New Zealand.
2. This may also mean that her whānau who attend with her also have rights and may take a consensual role in supporting Aroha to make a decision about what is in her and her baby’s best interests.

As you lead Tiana and the other whānau members back into the room, the processes of whakawhanaungatanga and whakawatea take place. Once introductions and karakia are completed, there is now time to discuss with Aroha and whānau the initial processes required in informed consent. The issues of partnership, participation, and protection are fully discussed. The whānau are also informed about the clinical limitations to informed consent across all parties who are involved with Aroha. As you begin the discussion, Tiana states that she does not “trust” the Pākehā process of psychology. She reports a previous experience she had, when a “court ordered” psychologist wrote a report on her as a mother and recommended that Aroha be taken from her. She says she knows of other whānau who have had similar experiences and is worried that a similar process will occur and she may “lose the right to see her mokopuna”.

Trust and Informed Consent

Eyal (2014) argues for a “trust-promotion” model of informed consent where “social trust” is necessary for society so that people will “seek medical advice, comply with it and participate in medical research” (p. 438). As a bioethicist Eyal (2014) delves into medical ethics and explores the importance of “trust” in societies, particularly as it relates to the population health literature, believing that mistrust has far-reaching consequences into population health. For example, African-Americans have a history littered with injustices related to forced medical research and procedures that disregarded ethical standards (Eyal, 2014) (see also Corbie-Smith, Thomas, & St. George, 2002; Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999).

New Zealand has its own public health trust issues: for example, the “Unfortunate Experiment” (Crampton & Parkin, 2007). Dr Herbert Green’s unethical study of women with cervical cancer led to the Cartwright Inquiry and culminated in the Cartwright Report and numerous recommendations for improvement; including patient advocates, nationwide cervical screening programmes, establishment of ethical review boards, and improved informed consent ethics and practices.



Guidelines

1. Sit and hear the concerns from the whānau. Discuss their right to complain and how this might occur.
2. Support their suspicion, encourage it, given it appears justified based on their previous experiences with the healthcare system.
3. Nevertheless, it is also important to return to the session today, establishing clear limits and boundaries for the session.

Electronic Records and Information Sharing

District health boards and many other agencies have adopted electronic health records (EHRs), but how

these electronic records are protected for patient privacy is not well understood. If electronic alerts or warnings are added to client files, are clients informed and do they give consent? When the patient is an infant or child, how are the notes a reflection of their parent or guardian's consent to be involved? This question is even more pertinent with regard to the changes introduced by the Vulnerable Children's Act (2014) which allows more sharing of information between agencies to improve the care and protection of children. Parents and whānau of children should be asked for permission to share information designed to identify children at risk more easily. While still in development at the time of writing, it is likely that whānau will have the right to ask for information not to be shared, and to withdraw consent if they change their mind about sharing information.

Aroha asks what records will be kept from today and who has access to them? She also wonders how long the records will stay around, what impact they may have on her baby, and how baby will be documented and discussed.



Guidelines

1. Be clear with Aroha about what records will be kept and for how long, and who has access to them, including her own rights to access to information held about her and her unborn child.
2. The discussion should include who could have access to electronic records and any security constraints.
3. Explain to Aroha that the safety of her baby is paramount and there may be limits to confidentiality of records if there were any safety concerns, but she and her whānau would be fully informed and involved in discussions.

Informed Consent and Research

As the whānau complete the initial process of gaining informed consent and are leaving the service, they sit in the waiting room again. It is then that Aroha sees a pamphlet for recruiting teen mothers into a research project being conducted by a local university. She picks up a pamphlet and asks about how she can be included in the research.

Four elements have been identified as evidence that a person has capacity to consent to being involved in research: understanding, appreciation, reasoning, and expressing a choice (Grisso & Appelbaum, 1998; Marson, Cody, Ingram & Harrell, 1995; Palmer & Jeste, 2006; Saks, Jeste, & Petrila, 2006; Zayas, Cabassa, Perez, 2005; Berg, Appelbaum & Grisso, 1996).

Understanding is “the ability to comprehend the disclosed information about the nature and purpose of the study, the procedures involved, and the risks and benefits of participating versus not participating” (Resnick et al., 2007, p.70). Appreciation refers to the ability to appreciate personal consequences of participating in research (Palmer & Jeste, 2006). Reasoning is defined as the ability to demonstrate that an individual weighs the risks and benefits of participating in the suggested research versus the alternatives to participation in order to arrive at a final decision (Grisso & Appelbaum, 1995; Misra & Ganzini, 2004). The fourth element expressing a choice, refers to a person's ability to voluntarily choose whether or not to participate in the proposed research without fear or sense of coercion (Roberts, 2002; Zayas et al., 2005). Although not mandatory, it is best practice to document the consent process. However, if a treatment is being offered that is experimental, it is necessary to document the rationale for offering such a treatment over standard conventional options.

Lee (2010) developed a brief (4-item assessment instrument) on the capacity of older adults to consent to research participation. The Older Adults' Capacity to Consent to Research (OACCR) scale includes:

1. What is the purpose of the study?
2. Tell me some of things that you will be asked to do in the study.
3. What are the risks or discomfort that you might face from participation in the study?
4. If you don't want to, do you have to be in this study?

Perhaps such questions could be slightly altered and used with all age groups to help psychologists facilitate an effective informed consent process:

1. What is the purpose of us meeting today?
2. Tell me some of things that will happen today.
3. If something makes you feel uncomfortable today, what can you do?
4. If you don't want to, do you have to stay in this meeting today?

Although there is an array of guidelines available on how and what to include when obtaining informed consent, doing this in actuality can be extremely challenging from cultural perspectives (Adams et al., 2007; Marshall et al., 2014; Quinn et al., 2012). When working cross-culturally a balance must be struck between Western concepts of ethics, local conditions, and cultural competence to facilitate a truly “informed” consent process. It is noted that consent documents can be too wordy, hard to understand, and be filled with medical terms and jargon that may be foreign to the participants (Quinn et al., 2012).

Researchers who wish to act ethically must ensure that they strive to be culturally competent (Adams et al., 2007). They must be capable of self-reflection and be aware of the potential impact that hidden, unconscious biases may have on shaping their interaction with participants who are minorities so that they have confidence in the researchers and thus the research itself (Thomas, Quinn, Butler, Fryer, & Garza 2011). Quinn and colleagues (2012) suggest that “*researchers should attend an educational programme to learn new strategies for strengthening communication with participants from whom they may differ by race, ethnicity, or class*” (Quinn et al., 2012, p. 11).

In Aotearoa New Zealand, research that involves Māori can be informed by guidelines developed by Hudson et al. (2010), which sets out how to ensure that Māori “best interests” are served. Additionally, the Code of Ethics has the expectation that psychologists will consider cultural needs during the consent process.

The challenge of gaining informed consent from Māori participants in research was identified in the genome project undertaken by Port and colleagues (Port, Arnold, Kerr, Gravish, & Winship, 2008). They stated that in offering genome testing to Māori families, they came face to face with how the rights of the individual sat alongside the rights of the collective. In other words, individual rights may be relinquished in the maintenance of tribal structure and certainly, in the Māori view, that includes inherent rights of the collective. This apparent over-riding of the individual may appear to undermine the fundamental principles of informed consent, but is supported by the inherent trust in the judgment of elders, loved ones, and fellow stakeholders.



Guidelines

1. Aroha may be assisted in making a decision about whether or not to participate in the research by encouraging her to find out more about it, to think about the pros and cons of participating, and by clarifying that she has a choice.
2. Particularly, as she is Māori, suggest she talks to whānau about their view.

Conclusion

Informed consent is a fluid process that may well be established at the beginning of the assessment or treatment, but which may change depending on the circumstances present and the client's experience as the process unfolds. A number of key principles, if followed, should assist the psychologist; respect each person as an individual and give enough information to enable them to participate in decision making while thinking of their needs within the context of their culture and family. Effective and clear communication is a key component to good practice as is documenting that communication and the outcomes. Importantly, be familiar with and be guided by clear policies and codes in order to proceed with a client (Rucklidge & Williams, 2007). Ultimately, be guided by what is in the best interests of the client.

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