
Informing for consent: The challenges across language, culture and gender

Sue Saunders and Allyson Davys

*Sue Saunders comes from an education background. She was a Senior Lecturer in Human Relations at the Wellington College of Education for some years. Also a counsellor Sue has, most recently, been working at Fertility Associates in Hamilton. She has contributed to a number of books and in 1998 had *Infertility, a Guide for New Zealanders* published by Penguin Books. Sue has a particular interest in information sharing, whether it is with couples using donor gametes or ensuring people have the best information available to them for treatment.*

Allyson Davys has 30 years' experience of working in social work and allied social services. This work has had a focus on counselling, training and education, and supervision, and involves work in government and non government agencies. For the last 15 years she has primarily been involved in the development of supervision practice and delivered supervision training to practitioners from a range of professions. She is currently employed half time as a senior lecturer at Auckland University and the other half is spent in private practice as a trainer and supervisor.

Abstract

Requirements to obtain informed consent prior to any significant medical intervention are covered by legislation and, for New Zealand social workers and counsellors, by their codes of ethics. The essential elements of informed consent are effective communication, full information and that it is voluntary and free from coercion.

The complexity of obtaining informed consent, when working with language barriers and between cultures is the focus of this paper. An immigrant, Muslim couple was referred to a fertility clinic for treatment. The woman was non-English speaking whilst her husband spoke enough English to get in a tangle. They were insistent that they use the husband's brother as an interpreter, an accepted and preferred practice within their culture but one which fell short of the requirements for interpretation of medical, clinical and ethical information. Combined with cultural limitations about what a man can discuss with his sister-in-law, the brother's interpreting was not only inadequate but incorrect and the process silenced the woman's voice.

The paper follows this complex case. It highlights the challenges to obtaining informed consent and identifies the steps taken to provide clear boundaries within which the communication could proceed between all parties and to thus ensure consent was well informed.

Informed consent history

In Aotearoa New Zealand it is a clear requirement of both the Code of Health and Disability Services Consumers Rights (a Regulation under the Health and Disability Commissioner Act 1994) and the Human Assisted Reproductive Technology Act 2004 that informed consent be

obtained prior to any significant medical intervention. It is also a requirement of the codes of ethics of both social workers and counsellors in Aotearoa New Zealand that clients give informed consent to any intervention.

'Informed consent', despite its current prominence, is not a new concept. In ancient days Egyptian, Greek and Roman documents record the need for patients' approval in some form, prior to a doctor's intervention (Mallardi, 2005). In more recent times a landmark judicial decision in 1914 determined that 'a person's right to self-determination would justify imposing an obligation on the health care provider to obtain consent' (Feld, 2004). Later in the 20th century the doctrine of informed consent was central to the Nuremberg Code, drawn up following the Nazi atrocities of the Second World War, and in 1964 was incorporated into the Declaration of Helsinki (Dyckman, 1999; Tymchuk, 1997).

The modern doctrine of informed consent is concerned with the protection of individual patient autonomy and self determination (Feld, 2004; Tymchuk, 1997). Initially this was focused on the need for practitioners (or researchers) to provide information, regarding procedures and outcomes, which they believed relevant for the patient to know. An increasingly aware and litigious public, however, has shifted this focus to a 'patient based' standard which 'mandates that a treating physician discloses as much information as a reasonable patient should wish to know' (Feld, 2004: 977).

The provision of information which a 'reasonable' patient should wish to know, however, is not necessarily straightforward and raises dilemmas. 'Informing for consent' as described by Tymchuk (1997) is a complex psychological entity and process. It not only includes how the information is presented and perceived but also how it is assimilated and made sense of by the patient. The patient's ability to recognise, understand and utilise information will be affected by a number of factors which include culture and environment.

The concepts of autonomy and self determination which underpin 'informed consent', are themselves lodged in western cultural values and do not always translate easily into multicultural contexts (Dyckman, 1999; Insoo, 2002; Marshall, 2006; Oguz, 2003). This poses challenges when formal statutory or professional requirements 'to obtain informed consent' conflict with family or community-based decision-making processes. In an international context some researchers have labelled this 'export of the Westernised doctrine of informed consent to developing countries as 'ethical imperialism' (Dyckman, 1999).

This paper discusses this western ideology of 'informing for consent' as it applies to an immigrant Muslim family who have limited English language. The couple have been referred for fertility treatment which requires an understanding of sophisticated and complex medical procedures and a navigation of the intricate, challenging ethical arena of donated gametes.

The case study

First meeting

A couple were referred to the fertility clinic by their obstetric and gynaecology specialist. The referral letter commented on the woman's high FSHs. (FSH is a hormone which indicates the level of ovarian reserve (eggs). A high FSH is a primary indicator of low ovarian reserves.

For this woman the very high FSH was thus an indicator of early menopause.) The referral letter stated that the couple were Muslim and noted the need for a female doctor. An appointment was accordingly made with an appropriate doctor. The husband later changed the appointment. Unfortunately a female doctor was not available at this new time but the husband asserted that this was not a problem and they were happy to see a male doctor. The husband had limited English and his wife had none, however, he said they would not need an interpreter as they would bring a family member.

On arrival at the clinic the couple were accompanied by the husband's brother who was to act as the interpreter. During the consultation with the clinic doctor several things became apparent. Firstly the woman had had previous lower abdominal surgery but did not know what for. Significantly the couple did not know, or maybe understand, about the FSH prior to the appointment. They believed that they were there to initiate an IVF (in vitro fertilisation) cycle. The husband was shocked and very emotional when he understood the implications of his wife's high levels of FSH. Further, despite the assurances that a male doctor was acceptable, the doctor was clearly unable to perform the examinations required for this type of treatment. Finally the husband was not prepared to do a semen analysis as he had previously fathered a child.

Due to the couple's distress the doctor made an urgent referral for counselling and they were seen immediately. At counselling further things became apparent. The brother-in-law could not talk directly to his sister-in-law on this topic. Communication with her was thus always through her husband. Her responses through the two men made little sense and gave no indication that she comprehended the issues. She was effectively silenced. All of the family present appeared to have a very limited knowledge of reproduction and they held some erroneous ideas of fertility treatment regarding donated gametes. For instance they believed that an egg donated from another woman would still produce a child with the characteristics of the wife since it grew in her body.

At the end of the session, however, they expressed a wish to be put on the donor egg waiting list, but became very perturbed when told that they would first have to have more counselling and with an independent female interpreter so that the counsellor could talk with the woman.

Between counselling

The next contact was initiated by the husband who wanted appointments for more counselling, but was not prepared to accept an independent interpreter. He was very angry (and possibly felt quite powerless) and tried to make the clinic comply with his wishes by coming into the clinic and yelling or phoning and yelling at whoever he spoke to.

The clinic was conscious of comments by the Health and Disability Commissioner on the Code of Health and Disability Services Consumer's rights:

..it is important to remember that an effective service cannot be delivered, and right 4 [right to services of an appropriate standard] of the code cannot be met, if a provider is unaware of the full nature of the symptoms and the consumer fails to understand the requirements of ongoing treatment. Accordingly, if not having an interpreter means that a provider's obligation to provide services with reasonable care and skill cannot be met, then it is my view that no services should be provided (Health and Disability Commissioner).

A clinic meeting resolved to deal with the impasse by writing to the couple and explaining the requirement for engaging an independent interpreter, before proceeding with treatment, and why this was necessary. The legislation which governs fertility treatment was cited and explained. The acts quoted were:

- Privacy Act 1993 – to reassure them of the confidentiality of an interpreter.
- Human Assisted Reproductive Technology Act 2004 – to inform them of the importance of informed consent, (Part 1, 3b) and the right to autonomy (part 1, 3e). Also noted was the Act's requirements for donor offspring with regards to registration and information sharing.
- Code of Health and Disability Consumers' Rights 1996 – the provider agrees to have a support person present but can exclude support people if it is in the interests of the patient. In this instance the brother-in-law cannot be seen as a support person for the wife.

The next contact with the couple was two months after the letter from the clinic had been sent. The husband wanted to make an appointment to bring in a 16-year-old relative of his wife with a view to her donating an egg. He stated that they were prepared to do some more counselling and confirmed they would accept an independent interpreter. This contact prompted another letter from the clinic, this time asking for the relative's birth certificate to confirm her age. It was explained that, if they wanted to use her as an egg donor, a separate application would need to be made to ECART (Ethics Committee on Reproductive Technology) on their behalf, as all donors under the age of 20 are required to have specific ethical approval.

Second meeting

The second visit included the couple and two of the wife's female relatives, the 16-year-old potential egg donor and her older sister who had come to support the younger sibling. Also present was an independent female interpreter who was engaged by the clinic. The two sisters and interpreter first saw the female doctor and then came to counselling.

In counselling it became apparent that the 16-year-old was too shy to speak so it was suggested that the counsellor talk with the older sister and 16-year-old could listen. The sisters then could talk to each other.

The session began with an outline of the process of IVF. The younger sister's reaction at the mention of a vaginal scan was one of shock. When asked, the older sister confirmed that the younger sister had been prepared for marriage. At this point it was recognised by the counsellor that none of this family really understood what IVF involved. The counsellor talked at length about the IVF process with the older sister until she understood. All present agreed then that IVF was highly inappropriate for this 16-year-old girl.

The couple were then invited to come into counselling and the sisters left. Through the interpreter the counsellor explained IVF to the couple. This revealed many gaps in their knowledge. The wife found her voice and, through the interpreter, asked a lot of questions. The couple also realised that IVF was not appropriate for the wife's young relative. It was agreed that if another donor became available the couple would need to start the process again with a female doctor and an independent interpreter.

Informed consent

The Guidelines on the New Zealand Bill of Rights Act 1990 state that informed consent is a process, rather than a one-off event. The essential elements of informed consent include communication, full information and freedom from coercion.

- Effective communication: in a form, language and manner that enables the consumer to understand the information provided to them. In an environment that enables both the consumer and provider to communicate openly, honestly and effectively; and where necessary and reasonably practicable, including the right to an interpreter.
- Full information: to give all relevant information to the consumer including, for example, honest and accurate answers to questions about services and the receipt of, on request, a written summary of the information provided.
- Informed consent should be voluntary and free from coercion.

(The Guidelines on the New Zealand Bill of Rights Act, 1990: 20).

Informed consent and the current situation: The problems

Effective communication

The Code of Health and Disability Services Consumer's Rights, Right 5, gives every consumer the right to effective communication.

Communication in this situation was not effective. The information was not presented in a manner which enabled the consumer(s) to understand. Cultural practices, added to a language barrier, compromised the ability of the couple, particularly the wife, to understand complex information.

According to their own culture the husband's brother was an appropriate person to act as an interpreter. But he lacked the ability to deal with the technical complexity of the information and had insufficient knowledge of the human (particularly female) anatomy. In addition, the information being relayed had serious implications for the future of this couple's fertility. This was a scenario which was bound to elicit strong emotions from the key participants and, even without a language barrier, was information which was hard to hear accurately. The situation was compounded by the possibility of loss of face for the brother-in-law if he acknowledged the difficulty of interpretation. The prohibition of the brother-in-law to speak directly to the woman in this context further complicated the communication and effectively silenced her.

It became clear that before any progress could be made, effective communication had to be established. Whilst the essentials of the need to pursue an alternative form of treatment appeared (at this point) to have been grasped by the couple, the need for an independent interpreter was not immediately accepted. This was evident in the series of distressing exchanges between the husband and the clinic, the former wishing to continue treatment but resisting an independent interpreter.

The clinic's response, which was to identify the legislation within which it operated and to locate its authority to request an independent interpreter within this legislation, proved effective. The written material was provided and after a period of time the couple reappeared to continue to consider their treatment options. By providing information and a rationale

for the requirements of treatment, the clinic assisted the couple to begin to understand and so navigate a system which had previously been incomprehensible and alien.

Full information

'Consent is not valid unless it is given with complete understanding of what is being consented to' (Code of Health and Disability Services Consumer's Rights, Right 6).

Informed consent does not only concern the information provided but must also consider the process, context, environment and the ability of the recipients to understand, assimilate and make sense of that information. This may include consideration of environment and culture (Tymchuk, 1997).

Several factors interfered with this couple's ability to understand and assimilate the information provided. Firstly they arrived at the clinic believing that they would begin IVF. In consultation with the clinic doctor they were told that the wife was in premature ovarian failure (premature menopause) and that if they wished to continue with treatment they would have to consider IVF using donated oocytes (eggs). The implications of the first piece of news distracted them from absorbing the information which was provided about IVF and the added complication of using donated eggs.

Secondly, an assumption was made (common to many clinical settings) that people have a basic understanding of the functioning of the human body and in particular of their own medical history. In this situation, although the couple knew the woman had had previous lower abdominal surgery, they did not know for what reason. Further, they were obviously confused by the process of donated gametes and the process of explanation of genetics was hindered by the complications of the brother-in-law's interpretation and his inability to directly communicate with the woman.

A juxtaposition of cultural values becomes evident when one places the western imperatives for 'informed consent' alongside a culture where decision making may be communal, vested in the family or with a particular family member. Gostin (1995) presents a view that in order to fully accommodate personal autonomy the medical community should consider 'allowing patients to stray from a western model of independent medical decision making and act in the manner that best accords with their own cultural values' (cited in Insoo 2000). The questions arises, 'who in this family needs to know?' Is it the woman, as it is her body which will be involved in the treatment? Is it the husband as the chief decision maker? Is it both? In the arrangement which was organised by her husband, an arrangement which was appropriate to their culture, the woman had no voice. In terms of current legislation and professional codes in Aotearoa New Zealand, this does not meet the requirements to ensure informed consent.

Voluntary consent

The third element of informed consent is that it is voluntary and free from coercion. In this situation voluntary consent is intricately bound with issues of privacy. The migrant population in Aotearoa New Zealand is small and individuals can be identified. Accessing fertility treatment is a private issue for most couples regardless of culture and circumstance. For this couple the ability to have children was directly related to personal and community status, thus the husband's standing with his peers and community was dependent on his wife's

willingness to undergo fertility treatment. The consequence of 'known' infertility was shame, privacy was of utmost importance. Given these imperatives can consent be freely given?

The ability to make an informed choice and give informed consent requires understanding. The presence, in this situation, of an interpreter who was a male family member with no medical understanding, prevented everyone from having 'reasonable' information to make an informed decision, regardless of the preferred form of decision making.

Informed consent in practice.

Informed consent is a process not a one-off event.

Consistent with the idea of informing for consent the fertility clinic acknowledges that the consent form is only evidence of consent, not the consent itself. The process of providing information, encouraging discussion and inviting questions is the means by which the person is informed and assisted to understand the procedure to which he or she is consenting. It is the person witnessing the consent who has the responsibility to ensure that this has occurred. (FA Consents Policy, 2006).

RTAC (Reproductive Technology Advisor Committee) comments that 'information should be comprehensible to individual patients. Special attention is required for patients for whom English is not a first language ... Interpreting services should be available. (Section 2.6 RTAC Guidelines, 2002).

The University of Florida Institutional Review Board (2004) has designed the following guidelines in this regard:

- That informed consent information must be presented in a language understandable to the potential subject and should embody all the necessary elements for legally effective informed consent.
- A competent interpreter, fluent in both English and the subject's native language, should present an oral translation of the written summary of the study or treatment in a language understandable to the subject.
- A witness fluent in both English and the subject's native language must be present for the informed consent discussion. The competent interpreter may serve as such a witness.

The Oregon Health and Science University (2005) adds to this by stating that the documents should be translated into a language the patient understands. They require that wherever possible the interpreter should be a trained healthcare interpreter. Significantly they acknowledge that some people are more comfortable using a family member but this, they state, should not be encouraged. Patients who insist on using family members should, in the opinion of the University, sign a waiver releasing the provider from responsibility or liability for adverse consequences.

Other authors have particularly commented on the use of family members as interpreters in Muslim families. The Health Care Providers' Handbook on Muslim Patients (The Islamic Council of Queensland) recommends a professional interpreter while stating that informed consent must be verbal and written in their own language. Denholm (2004) notes that while

a family member may be the interpreter of choice it may inhibit the woman's willingness to speak freely and may influence her decision making, particularly if the husband interprets for the wife. Denholm comments further on the importance of consulting with the family about any interpreter. Concerns about confidentiality as well as ethnic and gender differences may limit the couple's ability and confidence to speak freely.

Where to from here?

A number of assumptions were identified that affected the way in which this couple were handled by the clinic.

The assumptions

- That patients would arrive at the clinic aware of the purpose of the referral, i.e. that the referral doctors would have already informed the patients of their situation and possible options.
- That the interpreter chosen by the family would be the most suited to the task (in this case the brother-in-law) and that he or she would have adequate understanding and background to do this competently.
- That the woman was happy with the arrangement and would be able to cope with her reproduction being talked about by men.
- That these people would be able to cope within our system.
- That the woman would question until she understood.
- That lack of questions indicated that the couple understood what was being said.

These assumptions were clearly erroneous in relation to the situation described above. As a consequence a number of changes were identified for future practice in the event of a patient, or couple from a different cultural background and with limited understanding of English, being referred to the clinic:

- Slow the couple's progress through the clinic. This may mean that couples only see one professional on each visit and that there are specific time lags between visits in order to allow for information to be translated, digested and considered.
- Encourage families to bring chosen people for support (who may also give help with interpretation).
- At all times use an independent professional interpreter who is gender appropriate.
- Clinic professionals to discuss with the independent interpreter the best ways of communicating with each person and to identify any limitations to the interpreter's ability to discuss issues with the couple.
- Provide written material for the interpreter to read with the couple. Where possible provide information written in the couple's language.
- Require informed consent to be signed in front of the doctor, with the interpreter present, so questions can be asked to ascertain understanding.

Summary

Informing for consent across culture, language and gender is a major challenge for any health care provider. At the interface between accepted cultural practice and regulatory requirements for informed consent we acceded to a couple's wish for a family interpreter.

This effectively blocked the communication of the information necessary for the couple to understand the treatment being offered. Their subsequent recruitment of a highly inappropriate egg donor was evidence of the extent of their misunderstanding of the treatment process. The particular choice of interpreter also prevented the participation of one of the key parties to the treatment, the wife, as she was unable to directly communicate with him and thus with the clinic staff. Without confidence in the knowledge and independence of a professional interpreter it was very difficult, if not impossible, to check the level of understanding of the couple. Treatment could not proceed without this assurance. The couple's resistance to an independent interpreter was addressed by providing them with written information to explain the reasons for the clinic's insistence on this step and to reassure them about confidentiality. Subsequent meetings with an independent health care interpreter allowed the family to fully understand the treatment and to make their own decisions about proceeding further.

Conclusion

Working with this couple provoked a critical review of clinic practice and assumptions, and brought about good learning. We also recognised that, although exacerbated by language and cultural differences, many of the issues encountered were equally relevant to any of the people who enter the complex world of fertility treatment.

We learned to be wary of many of the basic assumptions which are made when patients arrive at a fertility clinic. It should not be taken for granted that patients are familiar with their medical history and diagnosis, and have a basic understanding of human anatomy. We were reminded again that in an area of medicine where bad news is common it is all too easy to leap onto the next step of treatment without allowing the patients to assimilate the reality of the news for them. Further, a person's emotional response to information can prevent them from appreciating other information given at the same time. We were also reminded that privacy is a central theme for many people who enter into fertility treatment. For some it stems from a sense of the intimacy and personal nature of human reproduction, for others it may come from a sense of personal failure and shame, for yet others there is the social and community status which may be harmed by the knowledge becoming 'known'.

We are grateful to all the patients, and in particular this couple, who have allowed us to ponder, review, renew old knowledge and develop new understanding.

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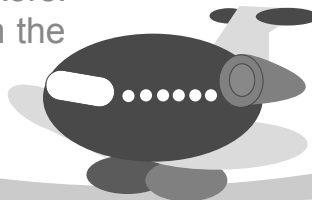
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