Chapter 16

INFORMED CONSENT AND INFORMED REFUSAL

Ethical clinical services show respect for each patient's freedom, autonomy, and dignity. Informed consent—perhaps the most extensively recognized of the ethical safeguards in clinical work (Amer, 2013)—reflects that respect. In general, informed consent is the process of describing to patients the purpose, risks, and benefits of the services they will receive. Clinicians provide informed consent in order to ensure that clients know, understand, and are able to make an informed decision on whether they want to participate in the services we offer or refuse. Ethics codes highlight consent as a key value. The APA (2017a) ethics code sets forth five specific standards for informed consent (Sections 3.10, 10.01, 10.02, 10.03, and 10.04). The CPA (2017a) code emphasizes the many ethical aspects of consent, setting forth 11 specific standards (I-16–I-26) under the heading "Informed Consent;" an additional four standards (I.27–I.30) under the heading "Freedom of Consent;" and mentioning the term "consent" 58 times throughout the code. Section III-13 of the Canadian Code highlights the care we need to take to make sure clients have all the information they need regarding "integrity of relationships." In addition, to be fully informed, valid, and meaningful, consent needs to be:

> Clear and straightforward about all information needed to establish informed consent or any other valid written or unwritten agreement (e.g., fees, including any limitations imposed by third-party payers; relevant conflicts of interest; relevant business policies and practices; contact information of accountability bodies; mutual concerns; mutual responsibilities; ethical responsibilities of psychologists; likely experiences; possible conflicts; possible outcomes; and expectations for processing, using, and sharing any information generated.

The emphasis on consent in the codes may fail to make it into our trainings and if our training fails us, we may not be well prepared to provide informed consent to those who come to us for help (For the potential disconnect between codes, training, and conduct, please see the section "Ethics Codes in Context" in Chapter 27). To illustrate, in their study of how trainees learn about informed consent in therapy, Blease et al. (2020) found that among the problems was *ethics training by osmosis* and the role of the hidden *curriculum*, in which "unintended lessons communicated to trainees are likely to have reinforced omissions, oversights, and a general laxity about securing ethical informed consent" (para. 43). They call on organizations like APA to provide greater clarity to educators on this topic.

FRIGHTENING FORMS, EMPTY FORMALITIES, AND NEEDLESS BURDENS

Sharpening our ethical awareness in the area of informed consent helps us avoid common pitfalls. For example, nothing blocks a patient's access to help with such cruel efficiency as a bungled attempt at informed consent. We spend time and resources to make our offices warm and inviting, welcoming, and accessible to all. However, it is equally important to also help patients navigate and understand the dense forms (which clerks may shove at them when they first come through our door), our set speeches full of noninformative information, and our nervous attempts to meet externally imposed legalistic requirements such as the United States (US) Health Insurance Portability and Accountability Act (HIPAA) or the Canadian Personal Information Protection and Electronic Documents Act (PIPEDA). Indeed, even the hardiest patients will encounter some obstacles to fully grasp all of the legalistic content.

One trap we can fall into is resenting consent as a formality to be gotten out of the way instead of considering it an essential part of the patient's rights and our clinical work. Daniel Sokol (2009) wrote:

> [W]hat is the most redoubtable obstacle to valid consent? It is the still prevalent attitude that obtaining consent is a necessary chore, a ... hurdle to jump over. Too often "consenting" a patient is reduced to the mechanistic imparting of information from clinician to patient or, worse still, the mere signing of a consent form, rather than the two-way, meaningful conversation between clinician and patient it should be. If we can change this mindset [*sic*] and view obtaining consent as an ethical duty first and foremost, one that is central to respecting the autonomy and dignity of patients, then we will have taken a major step towards first class consent and uninterrupted lunches (p. 3224).

Viewing consent as an obligation and burden makes it hard to meet the needs of patients. Discussing their questionnaire study of patients' perceptions of written consent, Andrea Akkad and her colleagues (2006) wrote:

> Our findings add to evidence showing that even when the consent process satisfies administrative and legal requirements, patients' needs may not be met.... Though patients did identify several important advantages of the consent process, there was substantial uncertainty about the implications of signing or not signing the consent form.... Many patients did not see written consent as functioning primarily in their interests nor as a way of making their wishes known.... Although there is no straightforward relation between knowledge of rights and ability to exercise those rights, a lack of awareness of the limits and scope of consent is clearly undesirable, potentially causing patients to feel disempowered and lacking in control (p. 529).

Thus, a first step in remedying the situation is to recognize that informed consent is not a static ritual but a useful process.

PROCESS OF INFORMED CONSENT

The CPA (2017a) Ethics Code notes that psychologists "recognize that obtaining informed consent is a process that involves taking time to establish an appropriate trusting relationship and to reach an agreement to work collaboratively, and may need to be obtained more than once" (p. 14). The process of informed consent provides both the patient and us with an opportunity to make sure that we adequately understand our shared venture. It is a process of communication and clarification. Do we understand why the patient is seeking our help? Do we know what the patient expects, hopes, or fears from therapy? Does the patient understand the approach we will be using to assess and address the problem? Does the patient know the common effects of using such an approach and alternative approaches to their problem?

The UK Supreme Court (2015) described the process that creates an agreement to work together. It includes

> dialogue, the aim of which is to ensure that the patient understands the seriousness of her condition, and the anticipated benefits and risks of the proposed treatment and any reasonable alternatives, so that she is then in a position to make an informed decision. This role will only be performed effectively if the information provided is comprehensible. The doctor's duty is not therefore fulfilled by bombarding the patient with technical information which she cannot reasonably be expected to grasp, let alone by routinely demanding her signature on a consent form (Montgomery v. Lanarkshire Health Board, 2015).

Culture affects this process of communication and clarification. For example, the therapist might be from the dominant culture while the patient might be a recent immigrant who is currently in the process of adapting to the majority culture. Chong Wang (2009) points out that level of acculturation can influence how the client understands and makes sense of the process. For instance, level of acculturation can influence the desire for independent decision-making, ways of relating within cultural contexts, ways in which psychological disorders, authority, and so on are perceived and described, and what they think can help them to feel better (for more, see also Kleinman et al., 1978).

Wang suggests 11 helpful steps to assess level of acculturation:

1. In general, what language(s) do you read and speak?
2. What was the language(s) you used as a child?
3. What language(s) do you usually speak at home?
4. In which language(s) do you usually think or dream?
5. What language(s) do you usually speak with your friends?
6. In what language(s) are your preferred TV/radio programs?
7. In general, what language(s) are the movies, TV, and radio programs you prefer to watch and listen to?
8. Your close friends are ...?
9. You prefer going to social gatherings/parties at which people are ...?
10. The persons you visit or who visit you are ...?
11. If you could choose your children's friends, you would want them to be ...?

In addition to these questions, level of acculturation can be observed by noting the degree to which individuals follow the traditions, values, and beliefs of their traditional culture, the host culture (or dominant culture) or both cultures. Culture may also influence whether a form signed by the client is necessary and appropriate. The CPA (2017a) code states:

> If signed consent forms are required by law or desired by the psychologist, the individuals or groups giving consent, or the organization for whom the psychologist works, establish and use signed consent forms that specify the dimensions of informed consent or that acknowledge that such dimensions have been explained and are understood.

But the following section notes that psychologists "accept and document non-written consent (e.g., oral, a verbal agreement, a handshake, or other culturally normative exchange) in situations in which signed consent forms are not acceptable culturally or in which there are other good reasons for accepting non-written consent" (p. 14).

Informed consent also involves making decisions. The patient must decide whether to undertake this course of assessment or treatment, whether to start now or later, and whether to try a different approach or a different therapist.

We therapists must decide whether the patient is competent to exercise informed consent. For example, young children, adults who have been declared legally incompetent, and those who have significant cognitive impairment (e.g., neurodegenerative disease, impaired intellectual abilities) may not be capable of providing fully informed consent.

The presence of a severe psychological disorder requiring hospitalization does not by itself mean that the patient lacks the ability to give or refuse meaningful consent to therapy. Debra Pinals (2009) wrote:

> Adult patients with psychotic disorders are not automatically or always incompetent. Research has shown that most inpatients with mental illness have capacities to make treatment decisions similar to persons with medical illness. Patients with schizophrenia, however, have deficits relevant to capacity to make treatment decisions more often than patients with medical illnesses and depressive disorders. Patients with depressive disorders also are more likely to have some decision-making impairment compared with persons with medical illnesses (p. 35).

If informed consent is not possible, we therapists must decide whether the situation justifies an intervention in the absence of fully informed consent. We must also consider whether a fully competent patient has the information necessary to: (a) make an informed decision; (b) adequately understand that information; and (c) provide consent voluntarily.

Patrick O'Neill, a former president of the CPA, suggests that the process of informed consent take the form of negotiation:

> While most therapists recognize that negotiation can clear up clients' misconceptions, fewer recognize that negotiation is also a vehicle for clearing up the *therapist's* misconceptions. An open dialogue can make the therapist aware of features of the case that depart from both the therapist's model and his or her previous experience, and thus it serves as a corrective to the representativeness and availability biases (1998, p. 176).

Finally, informed consent is a continuing process. Williams (2008) wrote: "Obtaining consent is not a discrete event; rather, it is a process that should occur throughout the relationship between clinician and patient" (p. 11). The patient may consent to an initial psychological, neuropsychological, and medical assessment as well as to a course of individual or group therapy based on an initial, very provisional treatment plan. However, later the assessment results, the patient's response to treatment, and changing circumstances may

lead to a radical revision in the treatment plan. In such cases, the patient needs to understand the revisions made and agree to them.

THE FOUNDATION OF INFORMED CONSENT

Informed consent is one way we try to make sure that the patient's trust is justified, demonstrate that we are not trying to abuse our power, and make sure we express our caring in ways that the patient understands and agrees to. Sadly, for many decades, healthcare ethics paid little attention to this important process. How did informed consent move from invisibility to center stage? Several key court cases gave strong shoves to the healthcare professions, insisting that they recognize patients' fundamental right to informed consent. These decisions often involved medical practice, but much of the reasoning applies to assessment and psychotherapy.

Traditionally, the healthcare professions took an arrogant, authoritarian approach, the physician alone deciding what treatment the patient received. The Hippocratic Oath lacked the principle of informed consent. During the centuries leading up to the modern era, physicians tended to share the belief that "the experts'" decisions should not be questioned, especially by patients who lacked the training, knowledge, and objectivity to know what was good or what was best for them. This approach violated "the value of respect for persons' autonomy and their right to define their own goals and make choices designed to achieve those goals" (Grady, 2015, p. 855; see also Campbell et al., 2010; Robeson & King, 2014).

A legal case involving a hospital in New York marked a landmark shift away from this authoritarian approach. In 1914, Judge Benjamin Cardozo, who later became a justice of the US Supreme Court, wrote that "every human being of adult years and sound mind has a right to determine what shall be done with his own body" (*Schloendorf* v. *Society of New York Hospital*, 1914, p. 93).

It was not so much that this case changed the customary procedures by which physicians went about their work; it was more that Judge Cardozo articulated clearly the idea that it was the patient, rather than the physician, who had the right to decide whether or not to undertake a specific treatment approach. Unfortunately, the implications of this principle slept unnoticed for decades.

The Nuremberg trials and subsequent Nuremberg Code on Medical Intervention and Experimentation focused attention on the importance of informed consent. The trials revealed the horrific and inhumane practices of many healthcare professionals during World War II under the guise of "treatment" and "research" (Adam, 2007; Beauchamp, 2014; Cocks, 1985; Gallagher, 1990; Geuter, 1992; Koenig, 2000; Lifton, 1986; Lopez-Munoz et al., 2007; Muller-Hill, 1988; Pope, 1991; Proctor, 1988; Spitz, 2005; Thieren & Mauron, 2007). The Nuremberg trials and code emphasized the individual's fundamental right to informed consent or informed refusal of participation in treatment or research. O'Neill (1998) wrote:

> The two main ways of protecting the public from the healer are oversight and consent. Throughout most of the history of healing, the emphasis was on oversight: monitoring of professional activity by professional associations, regulatory bodies, or the courts. The Nuremberg Declaration gave a new, privileged c cc position to consent, putting control into the hands of the client (pp. 13–14).

Shuster (1998) noted how easy it could be, when the right to consent or refusal is ignored, to allow purportedly good ends to justify inflicting terrible—sometimes fatal—"treatments" on human beings without their knowledge or consent:

> This was the case of ionising radiation research motivated by the cold war and sponsored by the US government for national security. Patients in hospital, children, mentally ill and impaired persons, pregnant women, workers, soldiers, and others were used as experimental subjects often without their knowledge, or that of their families; many believed they were being treated for their medical conditions (p. 976; see also Advisory Committee on Human Radiation Experiments, 1995).

The landmark 1960 Kansas case of *Natanson* v. *Kline* focused on community standards for making real the patient's right to informed consent. The court reaffirmed the Cardozo principle: "Anglo-American law starts with the premise of thorough-going self-determination. It follows that each man is considered to be master of his own body" (p. 1104). The court stated that to make this determination, the patient obviously needed the relevant information. But what information was relevant was left entirely to the community of doctors to decide:

> The duty ... to disclose .... is limited to those disclosures which a reasonable .... practitioner would make under the same or similar circumstances .... So long as the disclosure is sufficient to assure an informed consent, the physician's choice of plausible courses should not be called into question if it appears, all circumstances considered, that the physician was motivated only by the patient's best therapeutic interests and he proceeded as competent medical men would have done in a similar situation (p. 1106).

This case exemplifies the *community standard rule*: Informed consent procedures must adhere only to what the general community of doctors customarily

do. It also reflects the strong value of autonomy and self-determination that underlies Western law, policy, and ethical decision-making.

In 1972, with decisions handed down by the Federal District Court in Washington, D.C., and the California Supreme Court, the full implications of Judge Cardozo's principle were realized. The reasoning began with the reaffirmation of *Schloendorf* v. *Society of New York Hospital* and an emphasis that the patient must have relevant information that only the doctor can provide:

> The root premise is the concept, fundamental in American jurisprudence, that "every human being of adult years and sound mind has a right to determine what shall be done with his own body...." True consent to what happens to one's self is the informed exercise of a choice, and that entails an opportunity to evaluate knowledgeably the options available and the risks attendant upon each. The average patient has little or no understanding of the medical arts, and ordinarily has only his physician to whom he can look for enlightenment with which to reach an intelligent decision. From these almost axiomatic considerations springs the need, and in turn the requirement, of a reasonable divulgence by physician to patient to make such a decision possible (*Canterbury* v. *Spence*, 1972, p. 780).

To this end, it is the patient, and not the doctor, who must make the final decision. For this decision to be meaningful, it must be based on an adequate range of information provided by the doctor:

> It is the prerogative of the patient, not the physician, to determine for himself the direction in which he believes his interests lie. To enable the patient to chart his course knowledgeably, reasonable familiarity with the therapeutic alternatives and their hazards becomes essential (*Cobbs* v. *Grant*, 1972, p. 514).

This line of reasoning emphasized the exceptional trust and dependence inherent in healthcare, differentiating them from the milder versions of trust and dependence, often dealt with using a *caveat emptor* principle, characteristic of less intense, less intimate transactions in the marketplace:

> A reasonable revelation in these aspects is not only a necessity but, as we see it, is as much a matter of the physician's duty. It is a duty to warn of the dangers lurking in the proposed treatment, and that is surely a facet of due care. It is, too, a duty to impart information which the patient has every right to expect. The patient's reliance upon the physician is a trust of the kind which traditionally has exacted obligations beyond those associated with arms-length transactions. His dependence upon the physician for information affecting his well-being, in terms of contemplated treatment, is well-nigh abject (*Canterbury* v. *Spence*, 1972, p. 782).

This landmark case law specifically rejected the idea that doctors, through their community standards, could determine what degree of information the patient should or should not have. It was not up to doctors, individually or collectively, to decide what rights a patient should have with regard to informed consent or to determine those rights indirectly by establishing customary standards regarding what information was and was not to be provided. Patients were held to have a right to make an informed decision, and the courts were to guarantee that they had the relevant information for making the decision. The court observed in *Canterbury* v. *Spence*:

> We do not agree that the patient's cause of action is dependent upon the existence and nonperformance of a relevant professional tradition .... Respect for the patient's right of self-determination on particular therapy demands a standard set by law for physicians rather than one which physicians may or may not impose upon themselves (1972, pp. 783–784).

The case law clearly states the need for doctors to provide adequate relevant information regardless of whether the patient actively asked the "right" questions in each area. As a result, doctors were prevented from withholding or neglecting to provide relevant information because a patient did not ask. The doctors were seen as having an affirmative duty to make an adequately full disclosure:

> We discard the thought that the patient should ask for information before the physician is required to disclose. *Caveat emptor* is not the norm for the consumer of medical services. Duty to disclose is more than a call to speak merely on the patient's request, or merely to answer the patient's questions: it is a duty to volunteer, if necessary, the information the patient needs for intelligent decision. The patient may be ignorant, confused, overawed by the physician or frightened by the hospital, or even ashamed to inquire .... Perhaps relatively few patients could in any event identify the relevant questions in the absence of prior explanation by the physician. Physicians and hospitals have patients of widely divergent socio-economic backgrounds, and a rule which presumes a degree of sophistication which many members of society lack is likely to breed gross inequalities (*Canterbury* v. *Spence*, 1972, p. 783; see also (Montgomery v. Lanarkshire Health Board, 2015, which emphasized this principle).

Realizing that some patients would certainly choose not to undertake specific assessment or treatment procedures, the courts emphasized that understanding what might happen as a result of not getting adequate assessment or treatment was as relevant to making an informed decision as understanding the assessment and treatment procedures themselves. Thus, the California Supreme Court in 1980 not only reaffirmed the principles previously set forth in *Canterbury* v. *Spence* and *Cobbs* v. *Grant* but also affirmed that patients

have a right to informed refusal of treatment as well as a right to informed consent to treatment:

> The rule applies whether the procedure involves treatment or a diagnostic test.... If a patient indicates that he or she is going to *decline* a risk-free test or treatment, then the doctor has the additional duty of advising of all the material risks of which a reasonable person would want to be informed before deciding not to undergo the procedure. On the other hand, if the recommended test or treatment is itself risky, then the physician should always explain the potential consequences of declining to follow the recommended course of action (*Truman* v. *Thomas*, 1980, p. 312).

Recognizing that some doctors might be intimidated by the daunting thought of presenting to patients essentially all they had learned during their training and that patients might be ill-suited recipients of jargon-filled lectures, the court emphasized that the patient needed only the relevant information to make an informed decision but needed it in clear, straightforward language: "The patient's interest in information does not extend to a lengthy polysyllabic discourse on all possible complications. A mini-course in medical science is not required" (*Cobbs* v. *Grant*, 1972, p. 515).

In summary, in 1970, the courts gave to patients the right to make decisions to accept or reject treatment and gave to doctors the responsibility for making sure that patients had adequate information for making that decision. The California Supreme Court attempted to articulate the basis of this concept of informed consent:

> We employ several postulates. The first is that patients are generally persons unlearned in the medical sciences and therefore, except in rare cases, courts may safely assume the knowledge of patient and physician are not in parity. The second is that a person of adult years and in sound mind has the right, in the exercise of control over his own body, to determine whether or not to submit to lawful medical treatment. The third is that the patient's consent to treatment, to be effective, must be an informed consent. And the fourth is that the patient, being unlearned in medical sciences, has an abject dependence upon and trust in his physician for the information upon which he relies during the decisional process, thus raising an obligation in the physician that transcends arm-length transactions. From the foregoing axiomatic ingredients emerges a necessity, and a resultant requirement, for divulgence by the physician to his patient of all information relevant to a meaningful decisional process (*Cobbs* v. *Grant*, 1972, p. 513).

These principles began to pass from case law into legislation. Section F of Indiana's *House Enrolled Act of 1984*, for example, stated:

> All patients or clients are entitled to be informed of the nature of treatment or habilitation program proposed, the known effects of receiving and of not receiving such treatment or habilitation, and alternative treatment or habilitation programs, if any. An adult voluntary patient or client, if not adjudicated incompetent, is entitled to refuse to submit to treatment or to a habilitation program and is entitled to be informed of this right.

ADEQUATE INFORMATION

The information provided during the consent process will differ according to the professional service (e.g., assessment, therapy) and other factors. However, any consent process can be evaluated in terms of whether it adequately addresses the following set of questions. This list may be useful in planning new consent procedures or reviewing existing approaches to consent in any setting:

- Does the patient understand who is providing the service and the clinician's qualifications (e.g., license status)? If more than one person is involved (e.g., a therapist and clinical supervisor), does the patient understand the nature and implications of this arrangement?
- Does the patient understand the reason for the initial session? Although in many instances patients will have scheduled an initial appointment on their own initiative and for relatively clear reasons, in other instances they may have been referred by others (perhaps an internist or a court) and not clearly understand the reason for the session.
- Does the patient understand the nature, extent, and possible consequences of the services the clinician is offering? Does the patient understand the degree to which there may be alternatives to the services provided by the clinician?
- Does the patient understand actual or potential limitations to the services (e.g., an insurance policy's limitation of coverage to a specific dollar amount) or to the clinician (e.g., the therapist is an intern whose rotation will conclude in 3 months, after which they will no longer be available to the patient)? Does the patient understand the ways in which the services may be terminated?
- Does the patient understand fee policies and procedures, including information about missed or canceled appointments?
- Does the patient understand policies and procedures concerning access to the clinician, to those providing coverage for the clinician, or to emergency services? For example, under what conditions, if any, will a therapist (or someone else providing coverage) be available by telephone between sessions during business hours, at night, or on weekends? (Chapter 15 discusses these issues.)

- Does the client understand processes and procedures in the case of death or disability of the clinician (see Chapter 18, Creating a Professional Will)?
- Does the patient understand exceptions to confidentiality, privilege, or privacy? For example, does the patient understand the conditions, if any, under which the clinician might disclose information about the patient to an insurance company, the police, or the courts? Does the person understand under what conditions other people in the setting (such as clerical workers, clinical supervisors or consultants, administrative supervisors or other administrative staff, quality control personnel, utilization review committees, auditors, researchers) may learn about the patient and the services provided to them, whether through discussion (case conferences, supervision, consultation) or writings (clinical chart notes, treatment summaries, administrative records)? Chapter 21 provides a discussion of these issues and exceptions.

CONSIDERATIONS IN PROVIDING INFORMED CONSENT

No rigid method can do the work of fulfilling a patient's right to informed consent. No set method can relieve us of a thoughtful response to the unique individual patient.

Informed consent is an ongoing process, not a static set of pro forma gestures. It grows out of the relationship between clinician and patient. It must fit the situation and the setting. Consent must respond not only to the standards of the clinician's professional associations, such as the APA or the CPA, but also to the relevant state and federal laws. It must be sensitive to the client's ability to understand the relevant information (e.g., Is the client a young child, developmentally disabled, suffering from severe thought disorder?) and situation (e.g., Is the patient in the midst of a crisis, referred for mandatory treatment by the courts, being held against their will in a psychiatric hospital?). It must be congruent with the client's culture. We can never do away with human sensitivity, professional judgment, and ethical active ethical awareness.

The following considerations can help us create and nurture the process of informed consent.

Failing to Provide Informed Consent

As we think through the best way to provide informed consent for the individual patient, it may be helpful to keep in mind that this fundamental right is sometimes violated, perhaps often. We can take those instances to justify our own

decisions to shortchange a patient's right to give or withhold consent, or we can use those instances as an opportunity to strengthen our ethical awareness and consider the matter from the patient's perspective. How would we feel if we were the patient who had been kept in the dark and given no chance to make a decision on an informed basis?

An example of the withholding of informed consent involved the provision of free medical care to hundreds of US citizens (J. H. Jones, 1981; see also Rivers et al., 1953; U.S. Public Health Service, 1973). The program began in 1932 and continued to 1972. If all we were told was that the government, through what eventually became the *US Public Health Service*, was giving us comprehensive medical care, how would we likely feel? Grateful? Relieved that we would be spared financial burdens? Excited that we would have access to state-of-the-science medical interventions provided by the federal government? Would any of us turn down this rare but wonderful opportunity?

What the participants were not told is that they were being used to study the effects of syphilis when it goes untreated. Treatment for syphilis was in fact withheld from all the individuals. Research procedures were presented as treatment, for example, painful spinal taps were described to the subjects as a special medical treatment.

Although Public Health Service officials denied that there were any racist aspects to this research, participation in the program was limited to African Americans. The 40-year Tuskegee syphilis experiment is one of the most infamous in US history. This horrific experiment led to the institution of federal Institutional Review Boards for protection of human subjects (US Center for Disease Control and Prevention, retrieved February 28, 2010).

Other examples are numerous. To illustrate, for one stretch of time, hospitals performed AIDS tests on virtually all patients without their knowledge or consent, sometimes in direct violation of state law (Pope & Morin, 1991). As another example, Stevens (1990) described a testing center that administered the Stanford-Binet Intelligence Scale so that students could be placed in the appropriate classes at school. The information schools received contradicted what was given to the child's parents. In one case, the report sent to the school "recommended that David be placed in a class for average students;" the report sent to the parents recommended that "David should be placed in a class for superior students" (p. 15). Here is how the testing center explained the policy, "The [report] we send to the school is accurate. The report for the parents is more soothing and positive" (p. 15).

How would we feel if we relied on the government and healthcare professions to provide us with free medical care when in fact they were observing and assessing the consequences of an untreated painful, virulent, usually fatal disease? How would we feel if we went to a hospital for help

and were given an AIDS test without our knowledge or permission? How would we feel if we were given completely false information about the results of an intelligence assessment because someone else thought it would be "more soothing"?

Benefits of Informed Consent

Approaching the issue of informed consent, we may, as clinicians, fear that providing adequate information to patients and explicitly obtaining their consent will somehow derail therapy and may in fact have detrimental consequences for our patients. However, research has not supported these fears. Trachsel and grosse Holtforth (2019) note that "beyond legal and moral duty, informed consent can benefit the psychotherapeutic process and outcome" (para. 11). A variety of studies have indicated that the use of informed consent procedures makes it more likely that patients will become less anxious, follow the treatment plan, recover more quickly, and be more alert to unintended negative consequences of the treatment Handler (1990). Moreover, Debra Pinals (2009) describe that "informed consent can enhance the therapeutic alliance and help improve treatment adherence" (p. 33).

Limits of Consent

Informed consent is not a strategy to insulate a clinician from responsibility when performing unethical or illegal acts:

> At least one case has suggested that there are limits to what a patient can validly consent to. In that case, several adults were treated with a form of therapy that involved physically beating them. The defendants argued they could not be sued because the plaintiffs had consented to the treatment; however, the Court of Appeals refused to accept the consents as a defense. This decision implies that a patient's consent will not be deemed valid if acts consented to would otherwise be illegal or contrary to public policy (such as a sexual relationship between therapist and patient). An earlier case held that whether touching is therapeutic or nontherapeutic goes to the essence of the act and may vitiate a consent (Caudill & Pope, 1995, pp. 553–554).

Consent for Families and Other Multiple Clients

When we provide therapy to couples, families, or groups, we have a special responsibility to provide adequate informed consent and informed refusal to each person. We also have the responsibility to address issues specific to therapies involving more than one patient. For example, consider the following questions:

- What are the limits of confidentiality and privilege for material disclosed by one of the patients involved in couples, family, or group services?
- Will the therapist hold confidentially from one family member material disclosed by another family member?
- If so, what effect would that have on the trust of the other family member if that other family member discovers that you have kept information from them?
- If one client receiving couple therapy waives privilege, does the privilege still apply to the other member of the couple?

APA Ethics Code (APA, 2017a) standards 10.02 (a) and (b), Therapy Involving Couples or Families, describes the importance of clarifying who the patient is and the relationship the psychologist will have with each person involved. The standard also provides guidance in addressing conflicting roles, should they arise.

Issues related to informed consent are best clarified at the outset of the treatment, and on a continuing basis to clarify conflicts or potential conflicts that might arise during the therapy process. The 2002 APA Ethics Code included a new standard 10.03, Group Therapy, that requires that "when psychologists provide services to several persons in a group setting, they describe at the outset the roles and responsibilities of all parties and the limits of confidentiality" (p. 1073). Thus, psychologists must describe at the outset of group therapy the unique roles and responsibilities of both therapist and patients in the group therapy, including the fact that while group members are advised to maintain confidentiality about other group members, they are not held to legal liability or ethical codes of conduct. It may be helpful, although not required, to have group members sign an informed consent document, including the group rules and guidelines.

Unequal Opportunity for Informed Consent

It is crucial that all our clients have equal access to informed consent. Unfortunately, research suggests that some clinicians may use factors such as race and income level to justify short-circuiting the informed consent process for some clients. For example, in an examination of informed consent practices, Benson (1984) found that a patient's race and socioeconomic status was systematically related to whether important information was disclosed to them.

In experiments when the FDA declared an exception to informed consent requirements on people who were unresponsive when given a life-threatening event considered so urgent that surrogate consent was allowed, those selecting the "virtual guinea pigs" in these experiments showed a significant preference for using Black people. This selection among this vulnerable population is an

echo of the Tuskegee study's preference for experimenting on Black people. Black people were chosen so far out of proportion to the general population that they ended up constituting almost a third of the research sample (29.3%) in contrast to their representation in the general population (13.4%) at the time (Feldman et al., 2018; see also Serchen et al., 2020).

Cognitive Processes

Clinicians must maintain up-to-date knowledge of the evolving research and theory regarding the cognitive processes people use to make decisions (see Arbuthnott et al., 2006; de Bruin et al., 2015; Douglas & Bigby, 2020; Hess, Lipner et al., 2015; Hess, Strough et al., 2015; Kahneman, 2011; Kleespies, 2014; Taleb, 2010; Zsambok & Klein, 2014). This body of research and theory can help us understand the factors that influence clients who are choosing whether to participate in assessment or treatment procedures.

At a Harvard University hospital, McNeil, Pauker, Sox, and Tversky (1982) presented individuals with two options based on actuarial data concerning patients suffering from lung cancer. The data indicated whether patients had chosen a surgical or a radiological treatment for their cancer and what the outcome had been. Of those who chose surgery, 10% died during the operation itself, an additional 22% died within the first year after the surgery, and another 34% died within five years. Of those who chose radiation therapy, none died during the radiation treatments, 23% died within the first year, and an additional 55% died by the end of five years.

If you were given those actuarial data, which intervention would you choose? When these data were presented, 42% of the participants in the study indicated that they would choose radiation. Note that the data were presented in terms of mortality—the percentages of patients who died. When the same actuarial information was presented in terms of percentages of patients who survived at each stage—for radiation, 100% survived the treatment, 73% survived the first year, and 22% survived five years—only 25% chose radiation. The change from a mortality to a survivability presentation caused a change in the way individuals cognitively processed the information and arrived at a decision.

Because our interventions may have profound effects for our patients and the decisions they may make regarding whether to begin therapy and what sort of therapeutic approaches to try are significant, we have an important ethical responsibility to attend carefully to the form in which we present information relevant to those decisions.

Problems with Forms

Many of us may be so eager to start doing therapy that we try to avoid talking with our clients about consent issues. We try to push all the responsibility off onto a set

form and let the form do the work. Those of us who work in clinics or hospitals may not even handle such forms. When the client shows up for an initial appointment they may be handed an imposing-looking form by the receptionist, asked to read it, sign it, and return it before seeing the therapist. The form itself may have been crafted by the clinic's or hospital's attorney and may not even have been reviewed by a clinician. The wording may be in intimidating legalese and bureaucratic jargon. Such forms may be intended more to protect the organization against successful lawsuits than to help the client understand the options and make reasonable decisions. Bernister and Dobson warn against putting all our trust in forms; they posit, "The extent to which these consent forms are true indicators of consent is debatable" (2011, p. 303, see also Pope, 2015a).

Providing information in written form can be vital in ensuring that clients have the information they need. But the form cannot serve as a substitute for an adequate process of informed consent. At a minimum, the clinician must discuss the information with the client, allow them to ask any questions they may have, and based on their professional judgment determine whether or not the client has adequate understanding of the relevant information.

Clinicians using consent forms must ensure that their clients have the requisite reading skills. Illiteracy is a major problem in the US; clinicians cannot simply assume that all of their clients can read. Moreover, some clients may not be well versed in English, perhaps having only rudimentary skills in spoken English as a second or third language.

Not only must the client be able to read, but the form itself must be readable. Grundner (1980) noted that great effort has been made to ensure that "consent forms have valid content, but little effort has been made to ensure that the average person can read and understand them" (p. 900). He analyzed five forms with two standardized readability tests and found that "the readability of all five was approximately equivalent to that of material intended for upper division undergraduates or graduate students. Four of the five forms were written at the level of a scientific journal, and the fifth at the level of a specialized academic magazine" (p. 900).

Reading a form does not ensure that the client understands the material or can remember it, even a short time later. Robinson and Merav (1976) reinterviewed 20 patients four to six months after they had read and signed a form for informed consent and had undergone treatment. They found that all patients showed poor recall regarding all aspects of the information covered by the form, including the diagnosis, potential complications, and alternate methods of management. Cassileth et al. (1980) found that only one day after reading and signing a form for informed consent, only 60% of the patients understood the purpose and nature of the procedures. A perfunctory indication from clients that they understand can be unreliable (Irwin et al., 1985). The clinician bears the responsibility for ensuring that the client understands the information

It would be comforting to believe that the identification of problems in these early studies led to effective solutions. Unfortunately, the problems have continued to emerge. For example, research by Akkad et al. (2006; see also Armstrong et al., 2012; Commons et al., 2006; Dixon-Woods et al., 2006; Wallace et al., 2008) found that:

> As suggested in previous work .... many thought the primary function of the form was to protect the hospital .... These findings are disconcerting for healthcare professionals and patients alike and raise questions about how far current consent processes genuinely fulfil their aim of safeguarding autonomy and protecting patients' rights (p. 529).

Similarly, Özhan et al. (2014) found that over half the patients surveyed in the study reported that they had not even read the form, citing a variety of reasons such as they found the form hard to understand, they did not have enough time, or they didn't have their glasses with them. In another study, Weckbach et al. (2016) gave patients a 10-item multiple-choice test to see if they understood the necessary information for the consent they had previously given. They found that less than a third were answered correctly, and concluded that the "patients' informed consent is barely based on knowledge" (p. 3). Finally, a more recent study by Lustgarten and colleagues (2017) found that the readability of informed consent documents at university counseling centers are challenging for college students to comprehend—reflecting similar results from earlier studies on the readability of informed consent forms (see also Ogloff & Otto, 1991).

Engaging effectively in the process of informed consent requires us to have sufficient knowledge regarding our ethical responsibilities as well as a deep respect for the rights and dignity of the patients we serve. The next section provides some scenarios that can help us think a little more about the complexities of the informed consent process.

SCENARIOS FOR DISCUSSION

You work full time for a health maintenance organization (HMO) that requires the clinician to obtain written informed consent from all patients before providing therapy. One of the HMO physicians refers a patient to you for therapy. When the patient shows up for the initial session, you discover that the patient has recently been permanently blinded by an explosion and wants help in making the transition to living without reliance on this particular sense.

- How do you feel?
- What are the initial consent issues that you consider?
- In what ways, if at all, should the consent process explicitly address therapeutic approaches specifically developed for those without sight?
- If you were not fluent in Braille, the HMO provided no consent forms in Braille, and no HMO employee could write in Braille, how would you approach the HMO's requirement that written consent be obtained before clinical services were provided?
- If the patient asked if any of the interventions you planned to use had been validated as effective for those without sight, how would you respond?
- If the patient asked if your graduate training and supervised experience included adequate work with sightless patients so that you were competent to provide services to this population, how would you respond?

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You work for a clinic that allows no more than eight sessions of outpatient therapy in any given year. A new client tells you during the first session that surprising and intrusive memories have started to occur about experiences of incest as a child. The client thinks that the parent who perpetrated the incest may now be sexually abusing several grandchildren.

- How do you feel?
- What are the informed consent and informed refusal issues, if any, that you consider during this initial session regarding a formal assessment of this client?
- What are the informed consent and informed refusal issues, if any, that you consider during this initial session regarding potential clinical interventions for this person?

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You have just begun working as a counselor at a university counseling center. At your first meeting with the counseling center director, you ask if the center has consent forms. The director replies, "I'm so glad you brought that up. We've been leaving that up to individual counselors, but we need one that

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everyone can use. I've been looking at your curriculum vitae, and I think you're the perfect person to design the form. Please have it on my desk by next Thursday."

- How do you feel?
- Assuming that there is no way you can get out of this task, what process would you use for designing the form?
- What issues or elements are you sure the informed consent form should address?

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You have agreed to provide therapy to an adolescent who had gotten in trouble for drinking. The parents have agreed to allow the sessions to be confidential, given your ethical responsibilities. However, they now request to see the records because they have reason to believe that their adolescent is smoking pot.

- How do you feel?
- What are the legal and ethical factors you consider?
- What do you think you might say to the parents?
- What do you think you might say to your client?
- To what extent does your form for informed consent adequately address the issues that this scenario raises?

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You work for a large healthcare company. Utilization reviews are required before additional sessions are provided. You realize, during the review, that although you believe sexual orientation is a critical issue and focus for your gay client, you did not inform your client that the information would be revealed to the reviewer.

- How do you feel?
- What consent issues does this situation involve?
- What possible approaches do you consider in deciding how to handle this situation?
- What information concerning utilization review, peer review, and similar review processes should an adequate form for informed consent and informed refusal contain?

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You are engaging in the process of informed consent with a client who has been very quiet. She is looking at you attentively as you describe the process of therapy. She then states, "I really don't want to be here, but they told me that you are the only one who can save me. Please, you are my only hope. I cannot take this anymore, tomorrow is my birthday, and I will have a party at the office where I live. Would you please cut my hair, it is so long, I cannot breath with it."

- What are you thiking?
- How are you feeling in the moment?
- How would you proceed?
- What are your responsibilities in this case?

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You work at an immigration detention center with unaccompanied minors. You know that all of the information that you write down about your clients can be used to determine the result of their petition for asylum. However, you also know that if you share this information with your clients during the informed consent process they will be afraid to share information that can be crucial to the development and delivery of an effectivey treatment plan. One of your clients, an 11 year-old boy of Guatemalan descent, whom according to his file has refused to eat or talk for several days, says to you "Dr. please help me, I really want to tell you about what is happening to me in this place, but you must promise me that you will not tell anyone."

- How do you feel?
- What do you think?
- What are some of the consent challenges that working in this setting presents?
- How would you respond to your client?
- What would you do?