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A Critical Variable in the Self-Determination of Health and Mental Health Clients

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The Ethics of Informed Consent: A Critical Variable in the Self-Determination of Health and Mental Health Clients

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SUMMARY. Informed consent is a critical variable in the self-determination of consumers receiving health and mental health services. Consent has become a more stringent requirement in recent years. However, providers emphasize legal requirements rather than the true participation of consumers—the “spirit” of informed consent. This article discusses the elements of informed consent, the issues that reflect the “spirit” of consent, and recommendations for actions that foster self-determination in practice. [*Article copies available for a fee from The Haworth Document Delivery Service: 1-800-342-9678. E-mail address: getinfo@haworth.com*]

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INTRODUCTION

Self-determination—the right of every citizen to decide or determine the course of his/her life—is a presumption of American common law and a critical value of nursing and social work practice (Annas and Densberger, 1984; Freedberg, 1989). Self-determination in the context of health care means that every competent adult has the “liberty” to consent to or refuse a medical treatment (*ibid.*). In a landmark judicial decision, the Massachusetts Supreme Court ruled that,

The constitutional right to privacy, as we conceive it, is an expression of the sanctity of individual free choice and self-determination as fundamental constituents of life. The value of life as so perceived is lessened not by the decision to refuse treatment, but by the failure to allow a competent human being the right of choice.

The self-determination of health care consumers is intrinsically connected to the informed consent policies, procedures, and practices of health care providers.

Informed consent is the ethical doctrine and legal procedure that embodies the values of self-determination and provides the action necessary to bring those values to life. Informed consent has become a more stringent requirement in the provision of health care services in recent years. The ethical dimensions of informed consent—issues such as autonomy and beneficence—have been debated for centuries by the world’s greatest thinkers. The legal dimensions are more contemporary. The Nuremberg Code in 1949 emphasized the importance of voluntariness of choice following the Nazi medical atrocities in World War II on unwilling and uninformed patients. Landmark judicial decisions shaping informed consent and refusal in America developed primarily in the 1960s and 1970s.

The recent emphasis on legal requirements has resulted in detailed debates and conclusions about the “form” of informed consent. “What” must be included, “how” and “when” the information must be presented, and how legal consent is obtained is well-documented. The literature is filled with detailed decisions that translate into instructions to practitioners, regulations for institutions, and pamphlets for consumers about the requirements of informed consent.

However, with all of the legal and ethical emphasis, with all of the right intentions, the use of informed consent to enhance and respect the self-determination of clients is not working. The form has been developed, but the substance of informed consent is inconsistent. The substance is the commitment to practice a consent process that is based on the underlying

values of self-determination. This "spirit" of informed consent is often absent.

The purpose of this paper is to define and discuss the elements of informed consent, identify issues that can reflect the "spirit," and recommend actions that foster self-determination in practice.

INFORMED CONSENT: DEFINITION AND CHARACTERISTICS

George Annas (1989, p. 83) states that informed consent is "the most important legal doctrine in . . . treatment in health care facilities. He argues that "information is power," and the sharing of information results in the sharing of decisions. Therefore, informed consent has "transformed" the provider-patient relationship.

Definition and Derivation of Consent

There are many definitions of informed consent, but put simply, a provider cannot "touch or treat a patient" until that person has been given some basic information about what is proposed, and the person has agreed to it (ibid.). Kyler-Hutchison (1988, p. 285) extends this definition to include shared decision making, "The patient and provider collaborate in a continuing process intended to advance the patient's interest both in his or her health and his or her right to self-determination."

Informed consent is derived from the ethical principle of autonomy, which means that, ". . . a person chooses and acts freely and rationally out of her/his own life plan, however ill-defined" (Childress, 1982, p. 60). Acting freely is to act outside of the control of others—to be independent in one's actions. To deliberate rationally, one must be able to "rehearse imaginatively" different courses of action. Dworkin (from Childress, 1982) also includes the element of "authenticity" as part of autonomy. Authenticity is the ownership people experience about the reasons for their behavior—a congruence between the action and the person's beliefs, values, and life plans. Childress (1982, p. 64) notes that authenticity, "captures our sense that selves develop over time with persistent and enduring patterns; they are not simply collections of choices and acts." These elements of autonomy help us to think about the requirements of informed consent that have evolved through ethical debate and legal decisions, and the spirit of those requirements.

Elements of consent. There are four agreed-upon elements of informed consent according to experts in the field—disclosure of information, com-

prehension or understanding of the information, voluntariness of consent, and competence to consent (Annas, 1989). Disclosure of information includes presenting to the client a description of the proposed procedures, any possible alternatives, risks and benefits of both, the probability of success, and the implications of no treatment. In addition, issues like the opportunity to withdraw from treatment, confidentiality, and other information that would be provided by other providers in a particular situation should be included. Disclosure is based on the "reasonable person" standard—what an ordinary, reasonable person would need and want to know about a particular procedure in order to make a decision.

The disclosure should be presented in language that the client can understand, and the client must comprehend or realize the meaning of the information in regard to the impact on his/her well-being. This understanding of relevant information enhances both self-determination and rational decision-making (Annas and Densberger, 1984).

The consent must be voluntary. That is, the person chooses freely, without overt or covert pressures from others, or from the setting, affecting the autonomy of the individual. Excessive rewards, irrationally persuasive techniques, threats, and manipulations would be examples of coercion, which interfere with voluntary choice (Kyler-Hutchison, 1988). In addition, there are elements of coercion in "closed" environments such as prisons, mental institutions, and hospitals. These settings embody "subtle pressures" on clients to conform to particular kinds of treatment (Arbole-da-Florez, 1987; Reamer, 1987).

Finally, the client must be competent to decide. Annas and Densberger state that "competence and liberty are inextricably interwoven." If you are competent, you are at liberty to make your own decisions. Therefore, the determination of competence is the critical issue in relation to freedom of choice. Competence is a "capacity to understand and appreciate the nature and consequences of one's actions" (Annas and Densberger, 1984, p. 149). If the person understands the information necessary to provide consent, then the person had the capacity to understand it.

Assessment of competency. The functional approach to assess competency assesses the person's actual functioning in decision-making situations (President's Commission, 1982). The functional approach is congruent with self-determination in that it does not automatically deny choice because of a person's condition or a difference of values and beliefs from the larger community. This approach also helps the person self-determine through more clarity about the effects of the decision on his/her well-being.

Evaluating competency from the functional approach includes four tests (Annas and Densberger, 1984, p. 152): demonstrating a choice, dem-

onstrating an understanding of the relevant issues, an ability to rationally manipulate the relevant information, and demonstrating an appreciation of the nature of the situation. Appreciation is different from understanding the facts, in that the person must be able to show the "relevance" of the facts to his/her own unique situation. Assessing the dimensions of each of these informed consent requirements with every individual is necessary to evaluate whether true informed consent has taken place.

Exceptions to consent. The exceptions to informed consent include decisions in an emergency situation, the incompetency of the client to decide, a waiver of consent, and therapeutic privilege (Lidz et al., 1984). A waiver of consent means that the client intentionally and voluntarily relinquishes the right to give consent. For example, the "don't tell me what I don't want to 'know'" person, who wants the provider to carry the burden of worry, and to ultimately make the necessary decisions about care. The client must still be informed of the right to know and to decide.

Therapeutic privilege is the basis of the paternalistic argument, or parentalism. The provider withholds information because, in his/her judgment, the information would be harmful. It would violate the "primary duty" to do what is good or beneficial for the client. The legal and ethical debate about parentalism has resulted in agreement that disclosure can be withheld *only* when to disclose would be so traumatic to the client that he/she would be unable to engage in rational decision-making (Lidz et al., 1984).

When there is an exception to the informed consent process, then the decision is made by proxy—usually a family member, friend, partner, or sometimes the physician or provider. Even when the decision is made by proxy, the decision should reflect the client's values, beliefs, and life plan as much as possible.

There is agreement about the elements of consent. However, the application of ethical and legal principles becomes more difficult when we are working in real life situations with complex and unique human beings.

ISSUES OF "SPIRIT" IN INFORMED CONSENT

The spirit of informed consent is embedded in issues of awareness, understanding, relationship, and attitudes. These dynamic properties affect whether, and how, the doctrine is applied in day-to-day practice with health care consumers. The following issues reflect an interplay of these properties and help to exemplify the complexity of informed consent as it applies to self-determination.

Consent as a Process

Consent is a dynamic process that happens within the "context" of the provider/client relationship (Childress and Fletcher, 1994). It is a "systematic disclosure of information to the client over time" (Reamer, 1987, p. 428) Giving consent is a personal process—to a particular person(s) for a particular treatment at a particular point in time (Arboleda-Florez, 1987). Past consent for the same procedure is not valid, and consent cannot be transferred to another provider.

Legal and moral dimensions. There is a tendency to become focused on the practical end result—the legal rationale of obtaining a signed consent form to prevent a lawsuit—rather than realizing the moral good, consumer participation, that occurs in the course of the consent process. The "good" is the self-determination that occurs as a result of the consumer participating in the shared decision-making—an example of the higher moral commitment (Lantos, 1993).

A metaphor for consent is a conversation over time, where provider and client together initiate, continue, and revisit various aspects of the client's understanding throughout the treatment process. Haas (1991) recommends starting with more general and universal aspects of the proposed treatment, moving toward specific descriptions of procedures, implications, etc., as needed.

Timing and usefulness of information. Consent as a process is respectful of how human beings integrate and synthesize information. During an emotionally traumatic experience, it is difficult to capture and retain what has been said, let alone the meaning of what has been said. The opportunity to reflect, and ask more questions that stimulate the need for more specific information, leads to a more "informed" consent over time.

The timing of informed consent discussions makes a difference in the usefulness of the information. For example, in the United States, the Patient Self-determination Act has reinforced the Public's awareness of self-determination and their right to provide advance directives (such as living wills and CPR directives) to providers about their wishes. Institutions are required to provide written information on admission that educates clients about treatment decisions. However, as Hassmiller (1991, p. 30) notes,

. . . linking the question of self-determination to the emotionally draining events of hospital admission is a severe problem in tact—let alone patient education.

How, and at what point in a client's life, this information is presented makes a difference in the usefulness of the information. A thoughtful

conversation at a time when a person is not in an acute situation can be more useful. Social workers and nurses are in critical roles with consumers to provide this education as a part of their daily work in relationship to others—living out the spirit of informed consent in their work.

Assessment over time. The complex issue of assessing the competency of the individual is also related to process. Competency is relative to the physical and mental state of the person at the time the treatment is presented (Arboleda-Florez, 1987). Conditions such as temporary psychosis, organic brain states, depression, etc., that cause some confusion may affect the ability of a usually competent person to consent or refuse treatment. A severely depressed person may give a “passive consent” that is more reflective of the depression than a reasoned decision. In turn, individuals may pass through stages of denial, despair, and depression and reject medical treatment they may later be willing to accept.

Autonomy in the decision process for persons with chronic illness is different from assessing decisions with the acutely ill, or in an emergency (Cassell, 1977). Chronicity of condition allows time for the client to gain further knowledge, and to test personal beliefs against the reactions of others. There is time for the provider to know the client; to establish that motives and decisions are congruent with other characteristics and history of that person. In emergency situations these factors are not assessable.

In treatment refusal situations, it is important to assess the reversibility of a condition; to think about the effects of symptoms that impact decision-making. For example, the client who is under extreme duress from the discomfort of difficult breathing, sleep deprivation, and effects of medication, fever, and pain may refuse to consent to a ventilator. Refusal of such life support could be followed by death. Many times these symptoms are a result of reversible states, and the reversal over time may change the perspective of the person about treatments. In the interim, a policy of “do no harm”—work to support life and encourage thoughtful decision-making—may be the best course. The touchstone of assessing competency is to look for a “thoughtful” decision making process, taking into account reversible versus irreversible conditions, and the level of preparedness for the decision versus impulsiveness that affects the quality of the decision.

Process of a condition. Providers sometimes assess competency based on the diagnosis rather than the capacity of the person. People traditionally viewed as incompetent, such as persons with severe mental illness or developmental disabilities may be competent to decide at a particular point in time. For example, a woman who suffered with Schizophrenia was admitted to the hospital with breast cancer. The options for treatment

included mastectomy or lumpectomy with radiation for 6 weeks. The doctors felt she could not tolerate the radiation over time and decided on a mastectomy. When she joined the breast cancer support group, she learned of the other options available from the women in the group. She was quite distressed, as she had not been informed of the possible choices. In fact, she felt the mastectomy was more distressing to her than tolerating a series of radiation treatments. The providers' choice for her did not represent her authenticity, only their stereotypes.

The flexible use of time is possible for chronic conditions in the form of advance directives. Rosenson and Kasten (1991) discuss the "Ulysses" contract to promote self-determination for persons with mental illness in the event of a psychiatric crisis. The contract helps the individual plan for treatment in advance, when he/she is able to think and decide from a reasoned perspective. The contract then facilitates care at a time when the individual may not be deemed competent, according to the values and wishes of the consumer.

Cultural factors. The process of consent provides the opportunity to explore with individuals and families the cultural issues that are unique to their authenticity. The individualistic nature of legal doctrine in the U.S. does not always fit for people from other cultural backgrounds. For example, the Russian Jewish immigrants who are hospitalized in the U.S. have a very different sense of what information they want to know, than most Americans. They are used to medical personnel from their country making the decisions and informing them about what they should do. They often become very distressed when offered detailed information about their condition, and the expectation that they make a choice.

The spirit of informed consent is to be aware of personal stereotypes or societal stigma that may cloud our view before a determination of competency or decisions about disclosure are made. The provider must be sensitive to the cultural and ethnic differences among clients, and utilize those differences in the consent process. Finally, the provider must develop a keen awareness of his/her own values, in order to be responsible about the influence those values have in the self-determination of clients.

The timing of assessing competency. Determining competency before requesting the person's consent is a helpful rule. It is a common behavior of providers to question competency "only when a patient refuses to consent to a recommended treatment" (Annas and Densberger, 1984, p. 153). Further, it is easier to act on the side of a client's ambivalence that we agree with, rather than supporting autonomy by resolving the ambivalence through a clarification of the issues (Jackson and Younger, 1979). The latter requires a communication process—the spirit of informed consent.

The Nature of the Relationship

When a consumer walks in the door he/she "enters into a relationship with the provider(s)" (Cassell, 1977). The nature of this relationship is complex. What is certain is that the provider acquires a responsibility for the consumer that is not "morally relieved" because the person consents or refuses to consent to treatment. How providers think about informed consent in relation to self-determination is the essence of the "spirit" issue. Katz (1981) distinguishes between the "doctrine" of informed consent and the "idea" of consent. The doctrine is legalistic—documenting the communication process that is necessary to demonstrate consent took place. The "idea" of consent rests with spirit—supporting the rights of health consumers to participate in their medical decision making process. In our litigious society there is sometimes more of an emphasis on consent as a legal contract rather than the collaboration of partners in "full, mutual participation" (Arboleda-Florez, 1987). Ladd (1978) articulates the latter as the "ethics of responsibility"; provider and client develop a personal relationship that seeks to attend to the client's needs rather than focus on the legal requirements.

The attitudes of providers about the nature of the relationship with clients shape the consent process, and ultimately, the degree of self-determination of the client. The implementation of the process of consent varies from provider to provider according to their attitudes about two issues—the distribution of power in the relationship, and what constitutes proper disclosure (Haas, 1991).

The distribution of power. The sharing of power is a relatively new idea for providers. Haas (1991, p. 175) states that providers and consumers are "raised on the notion" of "doctor knows best." The traditional medical and psychiatric provider/client relationships have reflected this skewed distribution of power. However, the trust and confidence in "the Doctor" was based on a personal relationship. Further, the "tools of medicine" were so poor that according to Cassell (1977) medical care functioned totally "at the agency of the patient." With the advent of new technology, the advances in mass communication, and the "product orientation" of managed health care, has come a deterioration in confidence and a change in client's roles. The client now expects more information and involvement and is no longer the "passive recipient" (Arboleda-Florez, 1987).

These changes necessitate new roles for providers as well. The spirit of informed consent calls for a partnership between provider and client. Partnerships are based on egalitarian relationships that respect and appreciate the different strengths each bring to the decision process. The provider brings medical and technical information and the client brings

“personal, affective, and subjective” information to the decision process (Lidz, Meisel, Zerubavel, Carter, Sestak, and Roth, 1984). The representation of each is necessary to meet the requirements of independence and authenticity that are the foundations of autonomy. The medical and technical information allows for a reasoned, independent decision. But only the client has access to the values, beliefs, and cultural norms that are a part of self-definition. It is this personal expression, according to Cassell (1977, p. 18) that “restores authenticity by preserving the person as he/she defines himself/herself.”

Sharing of power. The sharing of power is difficult and providers resist for many reasons. First, sharing information increases the possibility of being challenged about what is being offered (Haas, 1991). The provider must be informed and willing to consider other options that may be suggested by the client. In addition, the provider must be comfortable with the proposed treatment, in order to explain it fully. While some providers would see a challenge as resistance, Haas (1991, p. 186) notes that it is “hard to imagine losing therapeutic ground by treating consumers as if they were potential collaborators . . .”

Second, providers typically are committed to a particular mode or form of treatment. In a landmark study on informed consent in psychiatric institutions, Lidz et al. (1984) found that the staff were “deeply committed” to the outcome of their decisions. They felt there was a “right” decision and presented information in a way that the client would be convinced of that perspective—emphasizing the benefits of the staff choice, and the negative consequences of the client’s failure to agree to the choice. Sharing power means letting go of emotional investment in method.

Third, there is a contradiction between intellectual support of the rights of clients and demonstrating that support in actual practice. Wilk, in a study on social worker attitudes about the rights of people with mental illness, found that there was more support for rights conceptually than for rights in actual practice. Similarly, a study of the ethical dilemmas of medical social workers (Proctor, Morrow-Howell, and Lott, 1993) found the workers quick to assume that elderly clients were too confused to communicate or to participate in disposition planning. The “most troublesome situations” were those where confusion was intermittent and supporting self-determination was more time consuming. Sharing power through information and decision-making takes time and effort. When rights interfere in the usual mode of practice, the support decreases.

Disclosure of Information

Since understanding is the critical connection to competency and choice, disclosure becomes important. Information can be shared verbally and in writing. The research about disclosure presents some disturbing findings. For the most part, the level of understanding of the information disclosed is not very high, and the disclosure plays a small part in the overall understanding (Lidz et al., 1984). There are a few common reasons that stand out.

Language and form. Consent forms notoriously use language that is too complex for the typical reader to use the information for decision purposes. In one study, only 15% of the forms were in language as simple as Time magazine (National Commission for Protection of Human Subjects of Biomedical and Behavioral Research, 1978). Most of the forms are written at an advanced undergraduate or graduate level (Grunder, 1980; Handelsman, Martinez, Geisendorfer, Jordan, Wagner, Daniel, and Davis, 1995). Additionally, the length of the consent forms and the lack of time to assimilate the information (Epstein and Lasagna, 1969; Morrow, Gootnik, and Schmale, 1978) render the spirit of the form meaningless.

Legal emphasis. Increased pressure from legislation and regulations (e.g., mandatory disclosure) results in clinicians fulfilling legal requirements without thinking about disclosure as the opportunity to communicate with clients about self-determination (Handelsman et al., 1995).

The use of written consent forms can enhance further verbal conversations—giving both permission and education. However, there is also a danger of the written form being viewed by worker and consumer as having covered the needed information. In this instance, complex issues such as confidentiality are presented in general and there is no further discussion. Consumers may assume everything is confidential, and the worker may not communicate the limits of confidentiality (Braaten, Otto, and Handelsman, 1993). For example, in managed care situations, the third party payors such as insurance companies may not protect the confidentiality of the consumer. In fact, data banks at this level may be accessed by other insurance companies and the information used against the consumer at some point in the future. The consumer may not be aware that he/she can ask questions about the information presented or bring up totally new areas to discuss (ibid.).

In summary, the “spirit” of disclosure is embedded in consent as a process, with both verbal and written information presented over time. The worker must enter into the disclosure from the perspective of a partner, who expects the other partner to be able to participate fully. Therefore, as Braaten et al. (1993, p. 568) states, “It’s clearly necessary . . . not only

to cover what clients want to know, but also what they need to know, even if it does not occur to them to ask."

THE "SPIRIT" THROUGH COMMUNITY

The changes in health care—for example, managed care, have made it difficult, if not impossible, for an individual provider to assure that the "spirit" of informed consent occurs. Multi-disciplinary teams face consumers with a variety of health care workers who do a variety of tasks. Each worker may assume that the consumer was informed by someone else. Increasing pressure to perform in "real world" constraints of time, funding and increased caseloads affect providers' abilities to individualize the informed consent process. As Tower (1994, p. 191) notes, "Self-determination is frequently the first right to be violated in the name of expediency, protection, or cost-containment." Perhaps the "spirit" of informed consent can best be achieved through relationship, consumerism, and community.

Relationship—with providers, with friends and family, with other consumers—is one of the most potent ways for the spirit of informed consent to develop. Cassell (1977, pp. 17-18) argues that "autonomy is exercised in relation to others; it is encouraged or defeated by the action of others as well as by the actor." It is the process of interacting with others that helps people get in touch with themselves and what is meaningful to them as individuals. Providers forget that information that helps in the decision process can come from many persons and places. Too often, what is disseminated from the provider is viewed as the only information necessary or available.

Individuals in this society, and particularly persons who are sick or disabled, are sometimes isolated from family and friends. Most importantly, they may be isolated from others who have experienced similar conditions who can help with self-determination through sharing their experience. Providers can assist by helping consumers with access to resources and information from as many sources as possible. Expanding social networks to include opportunities for conversation with "survivors" increases the potential for true informed consent from a variety of perspectives.

As examples, think of the variety of support and self-help groups available that focus on many health care related topics. The breast cancer support group at a hospital provides an opportunity to share experiences that are medical, familial, and emotional/psychological in nature. The nurse and social worker can give technical information about the effects of

chemotherapy, and what, theoretically, a person can expect. But, it is the other breast cancer survivors who can express the experience of losing their hair and their husbands, and still maintain their sense of humor. This sharing of experience gives permission to identify and receive support for each person's authenticity. This in turn provides information to use in the process of making further medical decisions. In addition, the group becomes a source of information for other resources, such as where to get the best wigs and the best second opinion. Information critical to informed consent decisions is disclosed by other consumers in a way that cannot be duplicated by providers.

The group experience helps individuals to re-define their role from patient or client to that of "consumer." Acting as a consumer "helps to elevate a sense of control over their lives" (Tower, 1994, p. 192). The role of consumer, according to Tower, respects the basic doctrine that, "... Individuals with direct life experience with a particular life condition are more knowledgeable about their own needs and interests than are their professional counterparts" (ibid.).

CONCLUSION

In conclusion, social workers and nurses can return to the original argument of the "spirit" of self-determination. Freedberg (1989, p. 34) reminds us that the locus of client self-determination has always, "... resided in a sense of common humanness between worker and client, not in policies and procedures, methods and protocols." The conversation of consent over time can include information from many sources. The consent process can also act as a catalyst to extend the consumers' social network of support and information. The "real work" of the health care worker is to act as a tool to help consumers self-actualize, consistent with their own biographies.

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