

**Back****14 page(s) will be printed.**

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**Record: 1**

**Title:** INFORMED CONSENT MEETS MANAGED CARE.  
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**Source:** Health & Social Work; Feb98, Vol. 23 Issue 1, p25-33, 9p

**Document Type:** Article

**Subject Terms:** \*INFORMED consent (Medical law)  
\*MANAGED care plans (Medical care)  
\*MEDICAL care  
\*ALTERNATIVE approaches  
\*DECISION making  
\*MENTAL health

**Author-Supplied  
Keywords:** ethics  
HEALTH AND HUMAN RESOURCES  
health care  
Health Costs and Health Insurance  
informed consent  
managed care  
managed care.  
NAICS/Industry Codes621330 Offices of Mental Health Practitioners  
(except Physicians)

**Abstract:** The doctrine of informed consent requires that health care providers disclose to patients the nature of procedures to be performed and the attendant risks, benefits, and alternatives. Equipped with an understanding of their options, patients then have the right to consent to treatment or to refuse it. Obtaining informed consent can be an intricate process, in part because of variations in patients' capacity for understanding and the complexities of health conditions. Managed care further complicates the procedure because structural and economic factors may influence providers' options and patients' choices. This article reviews the features of informed consent as they apply under managed care and addresses ways to ensure that consent is appropriately delivered under managed care systems. [ABSTRACT FROM AUTHOR]

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**Full Text Word Count:** 6173

**ISSN:** 03607283

**Accession Number:** 310755

**Database:** Academic Search Premier

**Notes:** IN THE LIBRARY

## **INFORMED CONSENT MEETS MANAGED CARE**

The doctrine of informed consent requires that health care providers disclose to patients the nature of procedures to be performed and the attendant risks, benefits, and alternatives. Equipped with an understanding of their options, patients then have the right to consent to treatment or to refuse it. Obtaining informed consent can be an intricate process, in part because of variations in patients' capacity for understanding and the complexities of health conditions. Managed care further complicates the procedure because structural and economic factors may influence providers' options and patients' choices. This article reviews the features of informed consent as they apply under managed care and addresses ways to ensure that consent is appropriately delivered under managed care systems.

Key words ethics; health care; informed consent; managed care

Informed consent is considered an essential element of the helping process, carrying with it connotations of honesty, trust, and mutuality in the serious business of making health care decisions. Having been shaped by legal, clinical, and ethical doctrines, informed consent is based on the presumption of choice — that providers have the ability to inform patients about their options and that patients have the capacity to accept or decline various alternatives without coercion.

In contrast, managed care, the dominant form of health and mental health care delivery, bases its success on the constriction of choice — limiting the pool of providers through impaneling, using "best practices" to narrow clinical options, and using gatekeepers and other forms of utilization review to efficiently channel the flow of patients. Managed care not only presents new challenges for the proper execution of informed consent but also increases the amount of information about which consent must be given. This article examines three core elements of informed consent — understanding, voluntariness, and disclosure — as they are shaped by managed care and describes options for overcoming the barriers to genuine informed consent.

### **MANAGED CARE**

There are, it seems, as many definitions for managed care as there are manifestations of it. In essence, though, the term is what it says it is — the management (through a variety of functions) of care (including health, mental health, and social services). Such "care management" occurs through a variety of methods. It can be accomplished structurally, for example, through health maintenance organizations (HMOs), where the spectrum of care for a particular population is provided within a fixed prepaid budget. Care is also managed through policies that encourage providers to use services judiciously — by paying them on a capitation basis rather than by fee for service, by promising a flow of referrals for discounted rates, by rewarding efficient use of services through bonuses or by punishing overuse through salary "withholds" or deselection from panels. Policies are also structured to encourage service recipients to be more cautious in their service use by limiting reimbursement to certain classes or panels of providers, by funneling access to specialists through physician gatekeepers, by penalizing inappropriate use of "high end" care such as emergency rooms, and by limiting access to costlier medications or procedures. Through these and other methods, managed care controls access to care and in doing so controls costs.

The buyers of health care — employers, individuals, and state and federal governments — put a premium on cost containment and predictability following unprecedented growth in health care expenses through the 1980s. In part the escalating costs were attributed to a fee-for-service system that rewarded excess service use and the fact that consumer

behavior with regard to health care differs from that with other products and services. Because the users of health care and the purchasers of it are not necessarily the same and because of the way health services have been marketed, consumers had little incentive or ability to "comparison shop" on quality or price (Public Agenda Foundation, 1994). The insertion of managed care into the health care buyer-user equation was designed to alter that process. A third party that could negotiate rates, assess quality, and promote efficiency would save the system from cost increases that could not be sustained. By the measure of cost containment, managed care has been reasonably successful. In psychiatric care, both inpatient days and length of stay have been substantially reduced (Schreter, 1993), and in 1996 medical costs in the United States increased by only 2.5 percent compared with a 3.3 percent rise for consumer prices overall (Church, 1997).

Not surprisingly, though, managed care strategies have had troubling consequences as well. Financial penalties for using emergency care may lead to fatal delays in seeking help, for example, in the case of heart attacks (Anders, 1996; Church, 1997). Gatekeeping may delay access to specialists beyond crucial points in arresting a disease (Anders, 1996; Council on Ethical and Judicial Affairs, 1995). Stringent application of "medical necessity" criteria can eliminate care for serious but not life-threatening mental health conditions (Reamer, 1997; Substance Abuse and Mental Health Services Administration [SAMHSA], 1996). Reimbursement systems predicated on low utilization provide incentives to "cherry pick" populations for only the healthiest patients (Haas & Cummings, 1991; Hillman, 1990; Iglehart, 1992; Karon, 1995). And treatment decisions, for example, on the length of stay after childbirth or for doing mastectomies on an outpatient basis, may be financially expedient at the expense of health or psychosocial considerations.

### **INFORMED CONSENT**

In discussing the "complex lineage" of informed consent, Appelbaum, Lidz, and Meisel (1987) noted that it is "a theory based on ethical principles, given effect by legal rulings and implemented by clinicians" (p. 3). At its base is the principle of autonomy, which recognizes that the individual has "personal freedom of action or the right to do as one pleases within restrictions" (p. 22-23). From this follow two elements central to informed consent — that individuals should be able to act, free from coercion, and that they must be in possession of adequate facts to make rational decisions about their well-being. In this regard, informed consent is linked to the value of self-determination, wherein "the rights and needs of clients to be free to make their own choices" (Barker, 1995, p. 339) are acknowledged and fostered. Kutchins (1991) and Morreim (1988) have noted further that the right to informed consent is embedded in the nature of fiduciary relationships, wherein one party has differential power and thus that party has the inherent responsibility to share necessary information with the other. This stands in contrast with a contractual "let the buyer beware" model in which a party is obliged to disclose no more information than the other party demands. Clearly, in the case of health care where the provider "holds all the cards" with respect to the patient's condition and available options, patients must trust that this information will be shared thoroughly and freely with them without their having to seek it.

Over the past 150 years, court rulings have shaped the doctrine, moving from requiring simple consent to informed consent, delineating parental consent for procedures involving minors, and changing standards of disclosure from those based on medical judgment to those based on what the average lay person would need to know. Today, informed consent generally encompasses three standards or preconditions: ( 1 ) competence, ( 2 ) freedom from coercion (or "voluntariness"), and ( 3 ) understanding (Reamer, 1995) and several "elements of disclosure," or the areas of information to be shared. The NASW Code of Ethics (1997) addresses both the standards and elements of disclosure, stating in part, "Social workers should use clear and understandable language to inform clients of the purpose of the services, risks related to the services, limits to services because of the requirements of a third-party payer, relevant costs, reasonable

alternatives, clients' right to refuse or withdraw consent, and the time frame covered by the consent. Social workers should provide clients with an opportunity to ask questions" (pp. 7-8).

The code goes on to describe the provisions that should be made for ensuring informed consent from clients who are not literate, who may experience language barriers, whose capacity to give consent is impaired, or who are receiving services involuntarily. In all these instances workers are compelled to make alternative means of communication available, to build in client choice wherever possible, and to ensure that parties representing clients are informed and acting in the clients' best interests. Furthermore, the code requires that consent be obtained before taping or observation of services by a third party and that services delivered by media (such as TV, radio, or computers) be accompanied with information on the limits and risks attendant to those methods.

Clearly, informed consent is neither a solitary act nor a simple matter of having a client "sign off" on services. It is a process "intended to guarantee the client's freedom, privacy and safety" (Houston-Vega, Nuehring, & Daguio, 1997, p. 52), which demands the utmost knowledge, skill, and sensitivity on the part of the worker. Kutchins (1991) referred to informed consent as "a time bomb ticking away for social workers" (p. 111) given the adverse nature of some of the information they are compelled to share (for example, on treatment effectiveness). Perhaps the greater time bomb lies in the suspicion that many workers routinely avoid meeting both the spirit and the letter of the law when it comes to informed consent (Appelbaum et al., 1987). If it is questionable, as a baseline, how often and how thoroughly workers secure informed consent, what then of the additional burdens posed by the advent of managed care?

#### **COMPONENTS OF INFORMED CONSENT UNDER MANAGED CARE Understanding**

The principle of understanding in informed consent means generally that the patient comprehends the information supplied and the meaning the information has for him or her. Informed consent requires workers not only to disclose information but also to make sure that the recipient understands it. Generally, discussion about the concept of understanding focuses on the issue of competence and the individual's capacity to supply consent (Reamer, 1990). Less attention is paid to the external preconditions that shape the principle of understanding; that is, what fundamental knowledge is required for the individual to comprehend and evaluate the information he or she is given? Whatever definition of "understanding" is applied, there is clear agreement that permission rendered without it is not valid consent to treatment (Appelbaum et al., 1987).

How then does this relate to managed care? Understanding forms the foundation by which other information or "elements of disclosure" are received and weighed. If patients select a health plan on the basis of cost, without an appreciation for the limits on care that might accompany a discount plan, can they be said to have had sufficient understanding on which to base their decision? If they do not understand the systemic pressures to limit care, should they trust in the fiduciary relationship to help them make a rational, informed decision about the direction of their care? Mechanic (1994) raised this issue in reporting on a study in which he found among a group of "well-educated and sophisticated consumers ... The vast majority of new HMO enrollees believed that 'in this plan the doctor is only concerned about my health and not limiting the plan's cost,' a perception clearly in error" (p. 220).

Another case in point involves prescription medications. "Formularies" are manuals that guide doctors' decisions about which medications to prescribe, giving information about cost, effectiveness, and side effects. Through the structure of formularies and health plan policies, physicians may be steered to cheaper alternatives within a class of drugs (Anders, 1996). Although patients may be told about the medication being prescribed and the relevant side effects, they may not be informed about the range of alternatives or the degree to which cost is being used as a criteria for medication selection. On the other hand, with understanding and complete information, the spirit of informed consent

can be met. Given the choice between medications of different costs and effects, the patient can elect the tradeoffs (for example, paying the difference if they feel other factors, such as the diminution of side effects, are a prevailing concern) rather than having the decision made for him or her from behind a veil of secrecy.

Sabin (1995) implicitly took the element of understanding to another level in discussing rationing. He noted that people affiliate with health plans that take responsibility for managing the care of a given population from a fixed pool of money, but the participants are not apprised of the criteria by which allocation decisions are being made. He suggested that some of the suspicion and criticism directed to managed care treatment limits may be because publicly understood and sanctioned limits on care are missing. Hall (1993) and Appelbaum (1993) also examined informed consent relative to rationing, describing the complexities and possible avenues for achieving "economic disclosure." Although they disagreed about the means to do so, both authors acknowledged that to the extent that financial factors affect coverage and services, potential recipients must be informed.

As with the examples related to individual care, understanding the context and ramifications of a decision is a necessary precondition for providing genuine consent. Clearly it is unreasonable to include a thorough review of U.S. health policy with every patient contact. No doubt, under the unregulated fee-for-service system, patients lacked a similar depth of understanding about the ways structural factors affected their care and thus, at times, may have received unnecessary tests and procedures because it was financially rewarding to do so. Although there are dangers inherent in over-service, the current pressures and incentives to limit care make informed consent all the more important. At the very least we must recognize that patients' lack of understanding limits informed consent and that there is a general role for social workers in educating the public about managed care's effects on the delivery of social services.

### **Voluntariness**

The concept of voluntariness indicates that consent must be freely given, without coercion, and that consent rendered under duress is not valid. Coercion can take many forms, including making receipt of some services contingent on acceptance of others (Reamer, 1987) or threatening to end the treatment relationship if a patient will not agree to certain services (Appelbaum et al., 1987). The resulting question under managed care is the extent to which patients' choices are made independent of undue pressures.

Enough anecdotal evidence exists to raise concerns. Managed care's efficiencies are obtained by streamlining care, for example, through the use of standardized treatment protocols or "clinical path models." The question of voluntariness comes into play when a patient rejects the recommended treatment — for example, refusing psychotropic medication for depression because of negative experiences with past medications. To what degree do the patient and provider have access to alternative interventions? If there are penalties for not using the expected model, will resulting pressures (on either the patient directly or through pressures on the clinician) diminish the ability to voluntarily give consent?

Voluntariness also emerges as an issue if recipients lack any choice about their health plan enrollment, or if coercion, threats, or misinformation are used to force them into managed care or into certain plans. For example, "[a]s of October 1994, 38 states and the District of Columbia had 71 freedom-of-choice waivers whereby Medicaid beneficiaries are 'locked in' to managed care plans and must receive all services through these plans" (Kaiser Foundation, 1995, p. 8). Still others have choice but may be subjected to unethical or illegal tactics in the enrollment process (Davis, 1995; Perloff, 1987; SAMHSA, 1996). The issue of choice in joining plans becomes particularly crucial when authors such as Hall (1993) suggest that subscribers signing on with HMOs are giving global consent to future treatment limitations. Countering Hall, and acknowledging

the importance of voluntariness, Appelbaum (1993) noted that subscribers increasingly are presented with only a single choice of plan and that information on treatment limitations at the time of enrollment may have little meaning to people unaware of their future health risks.

### **Elements of Disclosure**

**Elements of disclosure** are the areas of information that should be provided as part of informed consent. In a recently promulgated "Bill of Rights" groups such as the American Psychiatric Association, the American Nurses Association, NASW, and the Society for Social Work Administrators in Health Care addressed individuals' rights to information when receiving mental health or substance abuse services ("Treatment Bill of Rights Issued," 1997). The groups asserted that patients should be informed about the nature and extent of benefits, the expertise and credentials of their providers, the right to file appeals and grievances, and the right to information on contractual limitations. From within the insurance industry, the American Association of Health Plans has instructed its member organizations to "provide, on request, clear information about how participating physicians are paid, how treatment decisions are reviewed, the basis for specific treatment decisions, whether a specific drug is covered and how plans determine whether a treatment is designated as 'experimental'" (Gleick, 1997, p. 39).

There is consensus that to the extent that people have a choice in enrolling in managed care or the ability to select among plans, they need information on the array of choices to anticipate how their selection will fit with their particular constellation of needs. Plans vary in the breadth and depth of coverage, in the location and accessibility of services, in the number and qualifications of the providers used, and in the degree to which patients bear certain costs (for example, co-payments) or penalties (for example, for seeing an "out-of-net-work" physician). The materials describing such options can be difficult to digest, even under the best of circumstances, as Anders (1996) noted in describing his annual effort to determine the "best" option during his employer's open-enrollment period. Similarly, related to the application of managed care to Medicaid recipients, Perloff (1996) suggested a vital role for social workers in preparing recipients to effectively select and use such plans.

Many authors have noted, however, that promotional materials designed to enroll beneficiaries do not tell the whole story about the extent and processes for coverage (Brett, 1992; Levinson, 1987; Mechanic, 1986). Although plans may indicate that enrollees are eligible for 20 sessions of outpatient mental health care per year, would-be recipients may find themselves hard pressed to get that, when resources are predicated on physician referral, medical necessity, and gatekeeper review. Situations such as these reinforce the call for deeper understanding on the part of health care consumers and the need for information about appeals procedures in the event of difficulties, questions, or complaints.

Appeals and grievance processes have always been part of health care delivery. Under fee-for-service structures, patients were urged to seek second opinions to be sure that a recommended procedure was truly necessary. With the threat of underservice accompanying managed care, other appeal mechanisms are springing up in both health systems and regulatory agencies. As a standard part of informed consent, patients should be apprised of these options. This and other seemingly straightforward actions can be complicated, however, by "gag clauses," which implicitly or explicitly constrain the provider from sharing information that the patient may use "against" the payer. Also referred to as "nondisclosure clauses," such covenants typically require that workers "refrain from making disparaging statements that interfere with the contractual relationships between parties and existing or prospective participants ... during the term of or following the termination of" a provider's contract (Winegar, 1992, p. 214).

Gag clauses have been prohibited in recent months because of consumer and government backlash against them, yet the philosophy that bred them may be harder to

eradicate. In either case, they point to a larger issue of the conflicts of interest embedded in many managed reimbursement systems. As the managed care "Bill of Rights" states, in part, "Individuals have the right to be informed by the treating professional of any arrangements, restrictions and/or covenants established between third-party payer and the treating professional that could interfere with or influence treatment recommendations" ("Treatment Bill of Rights Issued," 1997, p. 8). Numerous authors have described the potential effects of such arrangements and have called for disclosure when the professional's status or financial well-being may be at odds with the patient's. They cite conflicts arising when a portion of the provider's base pay is "withheld" pending the achievement of certain efficiency standards, when there are financial penalties for overuse of inpatient care or referrals to specialists, or conversely, when bonuses are offered for limiting use of such resources (Council on Ethical and Judicial Affairs, 1995; Gottlieb, 1992; Hillman, 1990; Newman & Bricklin, 1991). All conflicts are not financial, however. Providers who fear adverse "report cards" on their performance or fear being dropped from panels may also find their treatment decisions constricted accordingly (Castro, 1994; Higuchi & Newman, 1994; Terry, 1994). Even though the disclosure of such conflicts is consistent with the principles of informed consent, some have questioned the feasibility of such discussions or disagree about whether physicians or health plans should bear the responsibility for such discussions (La Puma & Schiedermayer, 1994; McCormack, 1996).

Finally, managed care brings new requirements for a traditional area of disclosure — the limits of patient-provider confidentiality. Patients routinely sign forms to allow the sharing of information necessary to secure reimbursement from their insurer. At the same time they function under the premise that the information shared with their physician, nurse, psychologist, or social worker is protected. Yet with managed care an increased amount of clinical information is necessary for utilization review and reimbursement, which commonly involves the electronic collection and storage of that information such that privacy can no longer be assured with any certainty (Davidson & Davidson, 1996; Gostin et al., 1993; Kolata, 1995; Schick, 1996; Schultz, 1994). Patients should be informed about both conditions and be allowed to guard their information or change their reimbursement accordingly. Particularly in the area of mental health, anecdotal accounts indicate that armed with full information on the vagaries of information privacy, clients may elect to pay out of pocket rather than run the risk that information may be shared with their employers or future service providers (Karon, 1995; Strom, 1994).

### **OVERCOMING THE CHALLENGES TO INFORMED CONSENT**

As the foregoing suggests, practitioners may find it difficult to fulfill the demands of informed consent. Particular challenges may arise as a result of limited knowledge about managed care and constraints on time and relationships with patients. This section will suggest options for addressing these potential obstacles.

As noted earlier, managed care is a diverse and rapidly evolving entity. How can workers remain aware of managed care's developments and understand them with the depth necessary to inform and protect clients? The convergence of understanding about the needs and vulnerabilities of one's primary client population or setting and an understanding of managed care will help to narrow and deepen the knowledge base necessary for providing thorough information.

Fundamental knowledge about managed care can be obtained through a variety of texts, chapters, or articles (see, for example, Corcoran & Vandiver, 1996; Jackson, 1995; Paulson, 1996). With a basic understanding of the terminology and mechanisms of managed care, it becomes easier to stay abreast of its developments. Professional or organizational newsletters, trade journals, and even daily newspapers are avenues for updating knowledge about managed care. Conferences, staff discussions, and written materials specific to certain fields of practice (child welfare, developmental disabilities, mental health) can acquaint workers with trends and implications of concern to their particular group of clients.

Even with knowledge to share, the structure of service delivery — with limits on the number of sessions or length of service — may conspire against workers ensuring that clients are fully informed. Ideally, informed consent should follow a "process model" wherein the patient receives "information over time, in a fashion that allows it to be contemplated, shared and assimilated" (Appelbaum et al., 1987, p. 157). Patients should not be bombarded at the outset of treatment with information they are not ready to hear and cannot adequately digest. Balancing the demands of informed consent with the realities of service delivery requires conscious use of the time available, attention to the worker's tone and attitude, and use of a variety of means to convey information. These elements combine for effective use of informed consent processes.

Appelbaum et al. (1987) suggested that at various phases of the working relationship (no matter how abbreviated) the worker inform the patient of the crucial issues at that juncture. Good timing also suggests that some information be provided before it is needed. For example, as populations receiving aging, mental health, or children's services convert to managed care, staff can help consumers make informed choices about plans, based on the options available and individual needs and preferences. For clients with an ongoing relationship with a social worker, attention to "open enrollment" periods and the conscious choice of health plans may avoid difficulties later on. Practicing informed consent in a preventive manner allows for the better use of time when the need for care arises.

Various information methods can also be used to optimize the use of time. For example, patients can be given written information on policies, their condition, or available treatments to review and discuss at a subsequent session (Levinson, 1987). They may be shown a video or be informed about fees by a clerical worker and go on to discuss the implications with the professional in charge of their case. Regardless of the method or sequence in which information is given, the worker's approach is of central importance. Harried, rushing workers or those who operate from an authoritarian stance may inhibit questions or persuade the client to express understanding and agreement, when in fact they feel neither. Authors such as Gutheil, Bursztajn, and Brodsky (1984) recommended that organizations and the professionals who work in them view informed consent not as "red tape" to be avoided or overcome but rather as a clinically effective way to share concerns and uncertainties, drawing the client in as an ally in decision making. The legal benefits of informed consent are thus linked to the therapeutic advantages. In fact, done well, informed consent may facilitate the therapeutic alliance and allow for more effective use of the time available for treatment.

### **APPLYING INFORMED CONSENT**

The following case examples demonstrate how social workers in various settings can practice informed consent and the ways that time, attitude, and methods of informing can be used to do so effectively.

Clients seeking services in a private practice setting meet with the office manager to review their health benefits. During the first session the clinician discusses the fit between their needs, as she sees them, and their health benefits, offering clients the choice to pay directly for services or to use their health benefits to pay for them. Confidentiality waivers include straightforward information about the types of information the clinician may be asked to share with the insurer.

When a man's Medicaid coverage is converted to managed care, he is sent a letter describing the time line for the conversion and answering some common questions about the choice of plans and the services covered. Later he meets with his caseworker, who further explains the letter's contents and helps him find a plan to fit his needs. His priority is to continue with the psychiatrist who has been treating him for several years. The caseworker points out other aspects of the plans that he should be concerned about, for example, how to gain access to services when the clinic is closed and what services would not be covered. She also explains how the plan would affect their work together

and that some of their meetings would now be by phone rather than in the office. To ensure that he understands, his caseworker asks him to summarize what he had decided about the plan, and she offers him a list of directions and numbers that he can use when he needs help or has questions.

A patient is in need of a surgical procedure and is informed that it will be done on an outpatient basis, as is the now-standard practice for such a procedure. The patient has few supports at home and is concerned about his ability to care for himself. The patient is assured that if his condition is such that he cannot go home, he will be admitted and that social services will be involved to assist him following the operation. The patient is informed about the options to appeal within the health care center and with his insurance company.

A woman receiving Medicare enrolls in managed care. During her first office visit, a nurse explains how her medication and payments will be covered under the new plan and gives her a brochure, including directions for making appointments in the future.

A teenager is referred for chemical dependency services. He and his family view a video about the nature of substance abuse, the philosophy of the program he is entering, and the steps the program will take in treating his problem. After the family views the video, a social worker answers their questions and makes sure that they understand that dropping out of the program may affect their ability to get future services covered by their insurance.

A psychiatrist learns that her patient's medication is considered to have "limited efficacy" and will not be covered by insurance. She contacts the patient, taking time to explain the situation and describing what other medications would be available and how they would differ from the one he had been taking. The patient is given written information about the new medications, the expected effects and possible side effects, and the steps to take if he experiences difficulties with them.

## **CONCLUSION**

Informed consent is a fundamental patient right and professional responsibility. To meet the standards of the doctrine, social workers and other health care providers must make sure that clients possess full information about their conditions and options, that they understand the information and are competent to respond, and that they are making their decisions free of coercion. The advent of managed care both extends the amount of information patients need and compromises their ability to fully deliver informed consent. Social workers have a crucial role in fostering patient consent, in helping patients and other professionals understand the dimensions of this right, and in ensuring that it is not distorted or eroded in the name of efficiency and cost savings.

Informed consent requires workers not only to disclose information but also to make sure that the recipient understands it.

Informed consent should follow a "process model" wherein the patient receives "information over time, in a fashion that allows it to be contemplated, shared and assimilated."

The author thanks Lyungai Mbilinyi for her assistance in preparing this article.

Accepted September 11, 1997

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