

Advance Directives for Mental Health Treatment

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Advance directives are designed to establish a person's preferences for treatment if the person becomes incompetent in the future or unable to communicate those preferences to treatment providers. Mental health advance directives are similar to the more commonly used directives for end-of-life medical decisions. A patient must be competent to execute a mental health advance directive, and the directive must clearly express the patient's wishes. Once directives are executed, steps must be taken to ensure compliance, including adequate dissemination to providers, and to ensure that proxy decisions are consistent with the patient's treatment preferences. Potential effects of mental health advance directives include enhanced consumer empowerment; improved functioning; improved communication between consumers, family members, and providers; increased tolerance for consumer autonomy at the organizational level in community mental health agencies; and reduced use of hospital services and judicial proceedings. Issues to be clarified in future research and practice include strategies for increasing awareness of advance directives in mental health, barriers to execution of legally and clinically effective directives, practitioners' concerns, providers' compliance with directives, effects of directives on consumers and providers, effects of managed care on implementation of directives, and stakeholders' perceptions of the value of directives. (*Psychiatric Services* 50:919-925, 1999)

Advance directives are designed to establish a person's preferences for treatment should the person, in the future, become incompetent or unable to communicate those preferences to treatment providers (1). Mental health advance directives specify treatment preferences for times when a consumer of mental health services has a mental health crisis and is unable to communicate those preferences.

Advance directives have been most commonly used in medical care for end-of-life treatment decisions (2). The *Cruzan* (3) decision of 1990 un-

derscored a competent individual's constitutional right to control his or her medical care. The decision extended this right to incompetent individuals provided that they had indicated their treatment choices in advance when they were competent (3,4).

For many years commentators have suggested that advanced directives should be used for mental health treatment decisions (5). According to Appelbaum (6), advance directives are considered particularly appropriate in the care of persons with mental illness, which is frequently characterized by alternating periods of competence and

incompetence, because the directives afford these individuals an opportunity to state their treatment preferences when they are competent.

In fact, every state has enacted some form of statute authorizing advance health care directives that also authorizes mental health advance directives. Ten states also have specific laws addressing advance directives for mental health care (7). However, in a recent study, only about half of directors of community support programs were aware that their states had statutes that authorize mental health advance directives (8). Further, only recently has the mental health services literature included discussion of how mental health advance directives could actually be used and whether they would have a beneficial impact (9).

Mental health advance directives are similar in many ways to medical care advance directives. Both types of directives raise similar legal issues. Patients must be competent to execute them. The directives must clearly express patients' wishes. Once a directive is executed, steps must be taken to ensure compliance with it, including adequate dissemination and arrangements to ensure that proxy decisions are consistent with the directive.

This paper describes the types of mental health advance directives currently in use and reviews the current state of theory and research involving these directives. Special emphasis is given to issues of their execution and compliance and the potential impacts of the directives on consumers and providers. When relevant, we refer to the research on medical care advance directives. We also discuss gaps in our knowledge that can be addressed through future research and practice.

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Types of mental health advance directives

The two general forms of mental health advance directives are the instructional directive and the proxy directive (1).

Instructional directives

The instructional directive, based on the medical care "living will," contains instructions detailed by the patient in advance that tell treatment providers what to do in a mental health crisis should the patient become incompetent and unable to communicate his or her wishes (4). Instructional directives for mental health care can include instructions about consumers' treatment preferences and the reasons for those preferences (10) in the following areas (8; Gallagher E, unpublished manuscript, 1996):

- ♦ Use of medications, including types of medications to be used, dosages, administration methods, and timing of administration
- ♦ Use of specific treatment approaches such as electroconvulsive therapy (ECT) or group therapy
- ♦ Methods for handling emergencies, such as use of restraint, seclusion, or sedation
- ♦ Preferences for particular hospitals
- ♦ Identification of persons who should be notified about hospitalization and allowed to visit
- ♦ Consent to contact care providers and obtain treatment records
- ♦ Preferences regarding community-based alternatives to hospitalization
- ♦ Identification of persons to be responsible for child care, home and pet care, and financial matters
- ♦ Willingness to be approached about participation in experimental treatments or research studies
- ♦ Medical care issues.

A significant drawback of this type of mental health advance directive is the difficulty of anticipating future events with enough specificity to provide adequate instructions (6).

Proxy directives

The proxy directive, or health care power-of-attorney, allows an individual to designate someone else—a health care proxy—to make medical decisions on his or her behalf should

the individual become incompetent (4). In such situations the health care proxy is given legal authority to make medical decisions on behalf of the person who executed the advance directive. Depending on the terms of the directive, the proxy will make these decisions using a "substituted-judgment" standard (what the patient would want if the patient were competent to make decisions) or using a "best-interest" standard (what the proxy thinks is in the best interest of the patient). Most states use a best-interest standard (7).

Proxy-type directives are used more frequently than instructional directives (8) and can be used more broadly (11) because the proxy is able to take into account the actual circumstances of the patient's situation. It should be noted, however, that the terms of a directive or a statute may limit the power of the proxy to make treatment decisions (12; Gallagher E, unpublished manuscript, 1996). For example, in the absence of a concurring instructional directive, proxies cannot consent to invasive procedures such as psychosurgery, ECT, and restraint (7). Also, whether a proxy can make a hospital admission decision for an incompetent consumer is an unresolved legal question.

Instructional directives and proxy directives each have particular strengths and limitations. Winick (12) suggested that a combination of the two forms may be the most enforceable in court. The proxy directive confers broad decision-making authority on the proxy, who could then use the instructional directive to provide a court with strong evidence of the individual's intention. Thus the instructional directive could support particular decisions made by the proxy.

Execution of mental health advance directives

A recent study noted that only a few directors of community support programs in state mental health departments reported both awareness of relevant statutes and systematic attempts to promote execution (or creation) of mental health advance directives (8). However, even in those few states, estimated rates of execution of advance directives for mental health

care were less than 2 percent of the consumers served. Low rates of execution of mental health advance directives are consistent with low rates of execution for medical care advance directives (1).

Research that is relevant to methods for optimizing execution of mental health advance directives is summarized below.

Educational interventions and legal aid. Most interventions to increase rates of executing medical care advance directives have focused on educating patients and physicians (13). Educational interventions alone have had modest success (14,15), raising the rate of completion of advance directives by as much as 15 percent. Educational materials combined with free legal assistance and counseling have generated a completion rate of 50 percent for elderly individuals (16). This rate is significantly greater than the rate achieved through either education or counseling alone, and it also represents a 100 percent increase over the rate of execution when no advance directive training is provided.

Based on these studies of medical care advance directives, it would appear that the combination of education and legal counseling would be important to optimize rates of execution of mental health advance directives. However, one of these key components—free legal assistance—is often difficult to obtain for adults with severe and persistent mental illness who may be interested in creating advance directives (8,9).

Clear, concise training materials. Mental health advance directives need to be clear and relatively free of cumbersome jargon. Fleischner (7) reported that although many protection and advocacy agencies have developed informative training materials, the resulting mental health advance directives are generally lengthy and complicated. Semistructured advance directive documents, in contrast to open-ended documents, may be one promising method to surmount this problem.

Patient competency. Consumers must be competent to execute a mental health advance directive (4,17). Ensuring competency for consumers who have ongoing, fluctuating mental dis-

orders that can affect their abilities to recognize symptoms and incapacity is a complex matter. Furthermore, because mental health advance directives may be executed outside of a clinical context, it may be challenging to corroborate a consumer's competence at the time the directive is executed.

For medical care advance directives, some researchers suggest special competency tests, while others think that a thorough informed consent process is an adequate test (18). For mental health advance directives, it is likely that specialized competency assessment will be needed both to clearly document an understanding of concepts that are relevant to advance directives and to establish that the consumer was competent at the time of execution.

Involvement of service providers. Efforts to increase the execution of medical care advance directives have targeted physician-patient communication (13). In fact, some observers have noted that an important function of advance directives in general is to stimulate meaningful communication and treatment consensus between providers, consumers, and family members (17,19).

Service providers' involvement in development of mental health advance directives is also thought to be important (20). However, too much involvement by providers may generate conflicts of interest. In addition, consumer-provider relationships may become strained, and consumers may feel coerced into signing advance directives that include treatment choices made primarily by service providers (6). Also, service providers often report that they do not have the time necessary to help consumers execute mental health advance directives (20,21). Given these issues, it is important to develop methods for execution of mental health advance directives that reduce the burden on treatment providers while still involving providers to increase the collaboration in treatment between consumers and providers.

Designating a proxy. Some consumers may have difficulty finding someone who will act as a proxy, thereby making it difficult for the consumer to create a proxy type of mental

health advance directive (9). Laws typically prevent treatment providers from serving as proxies, and often consumers have no other individual with whom they feel comfortable making their treatment decisions. However, a recent study suggested that 82 percent of individuals completing a mental health advance directive were able to name an appropriate proxy (22).

Compliance with mental health advance directives

Compliance with mental health advance directives refers to whether treatment providers follow the guidance provided by a directive during a mental health crisis. Very little is known about compliance with mental health advance directives (23). However, research about compliance with medical care advance directives has suggested some ways to increase compliance with mental health advance directives.

Compliance with medical care advance directives has been far from perfect; treatment consistent with directives has been reported to occur 20 to 50 percent of the time (18,24). This modest rate of compliance is surprising because many state laws exempt physicians from liability for complying with advance directives (1,12,23) while exposing them to liability if they do not comply (25). Some observers have suggested that mental health advance directives may have somewhat higher compliance rates (4). One pilot study, based on a very small sample, noted that all mental health advance directives used in times of crisis had been honored (9).

Dissemination. Lack of staff and physician awareness of medical care advance directives (18) and lack of documentation of the directives are commonly noted reasons for noncompliance (25,26). One study showed that medical care advance directives are transferred with a patient to a new facility in only one of every three cases (18). Heightening awareness of mental health advance directives and disseminating the directives among various treatment providers, such as outpatient, inpatient, emergency room, and crisis services providers, could present even more of a challenge than the dis-

semination of medical care advance directives.

Vague directives. For medical care advance directives, noncompliance is thought to be partly due to the use of vaguely written directives that do not adequately specify what providers should do in particular situations (1,27). On the other hand, directives that are overly restrictive may not be followed because they do not authorize care that providers believe to be appropriate (18).

Mental health advance directives have the potential to be more clearly and specifically written than medical care end-of-life advance directives because consumers of mental health care probably have already experienced the relevant events, such as being hospitalized and medicated (28). For example, consumers may describe treatments that have been helpful to them during previous mental health crises. They can also tailor the circumstances under which their advance directive should be activated—that is, when they should be considered incompetent. These circumstances may include signs of symptom exacerbation, such as when someone with periodic manic episodes incurs a high credit card debt (Gallagher E, unpublished manuscript, 1996). This type of specification could lead to earlier treatment than the consumer otherwise would receive.

Proxy decisions. Proxy decisions about treatment have been shown to correlate poorly with patients' stipulated treatment preferences in medical care advance directives, thus undermining compliance (29–33). Specific discussion between patient and proxy about medical care advance directives has been shown to increase agreement rates (1,34). However, researchers in one study cautioned that even intensive intervention to increase communication about medical care advance directives does not significantly increase compliance (35). For mental health advance directives, proxy or service provider involvement in presenting and explaining a directive during times of crisis is viewed as critical for compliance to occur (20,28).

Limitations of service systems. Shortages of specific services, such as hospital alternatives, that may be re-

quested in mental health advance directives may be a barrier to compliance (20,28). Further, service system and managed care constraints on hospital lengths of stay may also pose conflicts with directives that request longer stays rather than more intensive medical intervention.

Treatment refusal versus treatment requests. The legal foundations for refusing treatment using mental health advance directives include common-law rights to autonomy and self-determination and privacy and liberty rights (23). Thus a relatively strong legal foundation exists for concluding that mental health advance directives preserve a consumer's preference for not having certain treatments that the consumer knows to have been either unsuccessful or psychologically or physically harmful (6,12).

Under current laws, executing a mental health advance directive cannot prevent an individual from being involuntarily committed (4,12). However, mental health advance directives may prevent some inpatient commitments by suggesting less restrictive alternatives tailored to the individual's needs (8) that may not otherwise have been known or recommended by treatment providers. Further, mental health advance directives can affect treatment decisions during hospitalization (8,23).

Mental health advance directives can be used to request preferred treatment. Rosenson and Kasten (36) noted that often consumers who ask for specific treatments, medications, or even hospitalization without advance directives are turned down because they are considered not to need the treatment. Mental health advance directives may help support treatment preferences for these individuals. At least one case partly supports these assumptions. In *Angliss v. Western State Hospital* (37) a patient was awarded \$600,000 when he had requested clozapine in his mental health advance directive but received other, less-well-tolerated neuroleptic drugs. However, the case was later dismissed on appeal.

Consumers who have executed a mental health advance directive may also be able to voluntarily receive in-

patient treatment they might not otherwise obtain (37). For example, Oregon's law allows mental health advance directives to specify advance consent to a 17-day hold, except in the case of emergency hold or commitment (9). By describing the circumstances under which a consumer wants to be admitted to a hospital and the preferred treatment, a consumer may actually expedite hospital admission and treatment provision.

Revocation of advance directives. Consumers may want to design an irrevocable mental health advance directive so that they cannot override treatment preferences expressed while competent during times when they are not competent and may refuse the treatments (4). This type of advance directive can, in some ways, be considered a "Ulysses contract" (23,38,39). The term "Ulysses contract" is derived from the mythical Ulysses in Homer's *Odyssey*, who asked his shipmates to bind him to the ship's mast and keep him there regardless of any requests he might subsequently make to be taken down. By entering into a contract with his men that he could not later revoke, Ulysses severely limited his future freedom to act. Though sorely tempted, he could not order his men to follow the voices of the sirens to their collective destruction.

One case report supports the enforceability of Ulysses contracts within a mental health context. Epstein and colleagues (40) described the case of a woman who repeatedly refused to have surgery due to overwhelming anxiety. She devised an advance directive to have anxiolytics administered even if she later refused to have the surgery. In addition, she appointed her husband as a proxy to carry out her wishes as she expressed them in the advance directive. Nonetheless, courts have generally been reluctant to uphold such irrevocable Ulysses contracts when challenged (23,38,39).

As noted, the Ulysses contract implies that the consumer cannot revoke the mental health advance directive when incompetent. In states that have adopted specific statutes about mental health advance directives, all note the irrevocability of the directive after loss of capacity. In states without such

statutes, the necessity of competency for revocation of mental health advance directives is less clear (7). One example of this issue is the case of *Rosa M.*, in which the court upheld a New York woman's revocation of her prior consent to be given ECT (4). The court determined that she was indeed competent to revoke her consent.

However, even if a mental health advance directive is revoked, service providers or a court may need to make a treatment decision for a patient based on a substituted judgment standard (41). In such a case, it is likely that the court would review the mental health advance directive to help it make the decision that the patient would have made if competent.

Other legal and ethical constraints. Mental health advance directives are unlikely to be upheld if they specify "unreasonable" treatments. For example, a provider may not comply with the advance directive if he or she does not ethically or professionally agree with the proposed treatment (10), if the specified treatment involves illegal or unapproved drugs, or if the treatment is beyond the consumer's financial resources (11).

Some consider the fact that mental health advance directives may be legally overridden under certain circumstances to be so detrimental to consumers that it outweighs the potentially positive effects of the directives (8). Despite this problem, some consumer advocates suggest that if mental health advance directives are ignored, consumers are no worse off than they would have been had they not executed an advance directive (9).

Potential effects of mental health advance directives

Given the dearth of research about execution of mental health advance directives and about compliance with them, it is not surprising that very little is known about their effects. However, a number of authors have surmised possible effects, which are briefly described below within a four-level model of intrapersonal, interpersonal, organizational, and service system effects (42).

Intrapersonal level. By affirming consumers' legal right to make treatment decisions (5,10), execution of

and compliance with mental health advance directives may enhance consumer empowerment, respect, autonomy, self-determination, and perceived choice of treatment (8,9,36; Gallagher E, unpublished manuscript, 1996). Consumer functioning and symptom reduction may also be enhanced by compliance with mental health advance directives that results in treatment consistent with consumer motivation and choice (12,43, 44; Ridgway P, unpublished manuscript, 1988). In general, research suggests that having choice and control over important life decisions, such as the selection of treatment or housing, is critical to physical and psychological well-being. For example, housing choices have been linked to improved health status of elderly individuals (45,46) and improved residential stability and life satisfaction for people with serious and persistent mental illness (47).

Interpersonal level. The communication of consumers' preferences through a mental health advance directive may potentially improve family relationships because it may prevent quarrelling about treatment decisions (9,12). In addition, the treatment alliance between consumers and providers and the involvement of consumers in treatment decisions should be enhanced by the communication and problem solving between consumers and their treatment providers that is involved in execution of mental health advance directives (9).

Organizational level. Having consumers execute mental health advance directives at a community mental health agency could affect the agency's values or "social climate" (48). Because execution of mental health advance directives enhances consumer choice and control, routine execution of the directives in a community mental health center may increase the agency's tolerance of consumer autonomy and independence in making decisions about treatment (8,9).

Service system level. Compliance with mental health advance directives that specify interventions warranted for early warning signs of symptom exacerbation may prevent further decompensation and hospitalizations (8, 9,36). Use of mental health advance

directives may also reduce court time and costs (8,12), especially if they reduce the need to designate court-appointed guardians or to determine competence in a judicial proceeding (9,12).

Because mental health advance directives allow specific treatments to be refused or requested in advance, some observers have hypothesized that they lead to more expeditious care, thus reducing lengths of hospital stay (6,8,9,23). On the other hand, if a consumer uses an advance directive to request less intensive intervention or to refuse treatments that could facilitate early discharge, the directive may serve to increase lengths of stay. This scenario highlights the conflict between the rights of individuals to choice and autonomy versus the social and economic costs to society generated by consumers who cannot be discharged because they refuse treatments that would likely permit discharge.

Future directions for clinical practice and research

Because considerably more is unknown than known about mental health advance directives, they constitute an area that is ripe for developing and implementing new practice methods as well as for conducting research. Below we discuss the most prominent gaps in our knowledge and how they may be addressed.

Clinical practice issues

How can awareness of mental health advance directives be increased? Consumers, providers, and service administrators currently know very little about mental health advance directives. Clearly, basic education about them would be an important first step. Ideally, education would be provided on a state-by-state basis because laws regulating advance directives vary among states. Involvement of protection and advocacy organizations, legal aid organizations, and consumer and parent groups is critical to the success of educational interventions. In addition, providers from all sectors of the mental health system, including inpatient, outpatient, and crisis services, must be involved in the educational process.

How can mental health advance directives be executed successfully? No standardized methods that are appropriate for widespread use in facilitating execution of mental health advance directives currently exist. To increase execution of these directives, several problems must be overcome. Training in preparing clearly written advance directives must be developed, and the options of instructional and proxy directives and combinations of these types must be covered. Methods for clarifying and establishing legally adequate competence to execute a mental health advance directive must be determined. Consumer-provider collaboration in execution of mental health advance directives must be facilitated. Sufficient counseling and legal assistance must be provided, and ways to find appropriate proxies must be specified.

One recent development that addresses some of these issues is the CD-ROM program AD-Maker (22). The program provides information about mental health advance directives, requires consumers to complete a brief assessment of competency to execute an advance directive, and then guides them through the process of creating an instructional or proxy directive. AD-Maker "interviews" the consumer about key topic areas such as medications, specific treatments, and methods of handling emergencies. Answers to the interview questions drive branching logic, enabling selective presentation of material that reduces the complexity and amount of information that consumers must process. Warning prompts appear if the consumer does not choose any of the options or otherwise responds in a way that is highly unlikely to lead to providers' compliance. This type of guided development reduces the risk that directives will be written in a way that makes them likely to be nonenforceable.

Will mental health advance directives be able to describe all potential clinical circumstances? Although mental health advance directives may not be able to describe all possible circumstances, this limitation does not eliminate their utility. Mental health advance directives will most likely be helpful in guiding treatment

for situations similar to those the consumer has experienced in the past. When new situations arise, an instructional directive may be helpful in deciding some issues, such as the person's tolerance of specific medications, but not others, such as the circumstances in which the consumer should be hospitalized. Adding provisions for a proxy who could give insight about treatment interventions that are probably acceptable to the consumer might be helpful in addressing unanticipated situations. These new experiences can also provide the consumer with information that may later be incorporated into a revised advance directive.

How do mental health advance directives differ from standard crisis plans? Mental health advance directives can be developed along a continuum of formality. An informal advance directive may simply be verbal instructions to treatment providers or supportive others about treatment preferences. Advance directives can also take the form of a listing of written treatment preferences that could be used in times of crisis. The most formal mental health advance directive is a document that is similar to advance directives for medical care and that includes language necessary to increase its likelihood of being upheld in court.

On the informal end of the continuum, a mental health advance directive may differ little from a well-articulated crisis plan. One question then is whether the goals of advance directives can be achieved by the development of thoughtful crisis plans or whether legally binding documents are necessary. In practice, it will be important to determine whether consumers and treatment providers experience the development of mental health advance directives as different from standard crisis planning and whether advance directives alter treatment in crisis situations for individuals who already have crisis plans.

What are key practitioner concerns? Practitioners have numerous questions about the implementation of mental health advance directives. One example is whether advance directives will bring about inequitable treatment of consumers with similar

clinical presentations and circumstances. Another is whether treatment providers in emergency room and crisis service settings will have the time to refer to and use a mental health advance directive. Providers may also have questions about how advance directives will be kept accessible to all relevant treatment providers and whether providers will be liable if they comply with an advance directive and harm befalls the consumer as a result. These questions can be addressed only through actual implementation of mental health advance directives within a service system.

Areas for research

What circumstances promote compliance with mental health advance directives? Very little is known about compliance with mental health advance directives, partly because the study of compliance is complex. Compliance is probably not an all-or-nothing proposition—some aspects of advance directives are likely to be complied with in some circumstances. Consequently, research must untangle which aspects are often complied with and what variables lead to this compliance. Initial research should examine the presenting problems of consumers and the circumstances in which mental health advance directives were consulted. Other issues for research include the dissemination of processes for using advance directives, the involvement of proxies, the identification of content of directives that led to compliance, and the circumstances for and results of judicial intervention.

How will mental health advance directives be affected by managed care? Lengths of stay for inpatient psychiatric treatment are often largely determined by the guidelines of managed care organizations. Mental health advance directives may indicate preferred practices that are incompatible with such guidelines. For example, an advance directive could specify a preference for a longer hospital stay instead of a more medically intensive shorter stay recommended by a managed care organization. Thus whether and under what circumstances preferences specified in mental health advance directives would be given prior-

ity over managed care guidelines is an important area of study.

What are the impacts of mental health advance directives? No empirical investigations of the effects of mental health advance directives on consumers, their treatment providers and family networks, or their services have been conducted. Clearly, study of these particular effects is an important and timely area for future research, especially given the increased interest in consumer-driven services.

How are mental health advance directives perceived by various stakeholder groups? Implementation of mental health advance directives will affect a number of stakeholder groups. For example, a set of empirical questions could focus on the role of proxies, including what do proxies do, what percentage of consumers name a proxy, whether proxies make decisions consistent with advance directives in times of crisis, whether proxies feel that mental health advance directives are helpful in the provision of services, and what the relationship is between proxies and service providers.

Treatment providers could be asked about whether they perceive mental health advance directives to be helpful and about how the process of developing and implementing directives has affected their relationship with consumers. Family members could be asked about whether an advance directive reduced their decision-making burden, helped clarify the consumer's wishes, or improved their relationship with the consumer. Legal and advocacy groups could be queried about characteristics of the service system and legal issues that may impede the execution of and compliance with mental health advance directives.

Conclusions

Although the beneficial potential of mental health advance directives has been discussed for many years, only recently has the confluence of the consumer self-help movement, the concept of consumer-driven services, and the legal precedents of medical care advance directives brought this important issue to the forefront. Combined with emerging technologies to facilitate execution of mental health

advance directives, such as the CD-ROM program AD-Maker, extensive implementation of advance directives in mental health care is becoming increasingly feasible. The promise of mental health advance directives to increase consumer empowerment, to improve crisis treatment planning, to improve consumer-provider-family relationships, and to reduce hospitalizations makes implementation of mental health advance directives and the study of their processes and effects important goals. ♦

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