Forensic Issues: Health Care Proxy, Advance Directives, and Guardianship

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Topic

A. ***Overview***

Forensic issues are common in medical rehabilitation settings. A "forensic issue" is one that intersects with the legal system. The issues that might arise at the intersection of medical rehabilitation and law include *health care proxies*, *advance directives*, and *guardianship*. Clinicians in rehabilitation settings often need to determine *what* are the patient's preferences for care and *with whom* they can legally discuss health care decisions when a patient is unable to make decisions for him/herself. There are certain legally defined roles and documents that can assist a health care provider under such circumstances. The following is intended to provide guidance for professionals in medical rehabilitation settings. However, legal requirements may differ depending on the state in which one resides; therefore, it is recommended that treatment teams consult state and local guidelines. A list of state and local bar associations is provided by the American Bar Association [1].

B. ***Terminology***

1. **Advance Directives**

Instructions that indicate an individual's preferences for health care if the individual loses the ability to make or communicate decisions for him/herself. The types of decisions typically specified in an advance directive include health care proxy (HCP), a living will, organ and tissue donation, or power of attorney (POA).

a. ***Health Care Proxy*** **(*HCP*)**, or health care power of attorney, is a legal document whereby the *Principal* (an individual) appoints an *Agent* (usually a family member or close friend) to make health care decisions if the individual loses the ability to make or communicate decisions for him/herself. The role of an Agent is variable, depending on whether the Principal has given the Agent the authority to make all health care decisions, or whether certain limitations have been placed on the Agent's authority.

b. ***Living Will*** documents preferences about life-prolonging measures, organ and tissue donation, and psychiatric advance directives. Preference for

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organ and tissue donation may be listed on an individual's driver's license if it is not listed in a living will.

c. ***Power of Attorney (POA)*** is a written authorization to act/make decisions on someone else's behalf. There are many different types of POAs (i.e., durable POA, general vs. limited POA, financial POA, and medical POA), though the most relevant in medical rehabilitation settings is the Medical or Health Care POA, which is also known as Health Care Proxy (HCP), Health Care Surrogate, or Health Care Representative.

2. ***Guardianship***
The legal process whereby the Court appoints a guardian for a mentally or physically incapacitated person who is unable to make or communicate safe or sound decisions for him/herself. The incapacitated person is an individual who is unable to care for his/her basic needs, to the extent that his/her health or safety is in jeopardy. Guardianship may be appointed on an emergency (temporary) or permanent basis. Guardianship can be limited to specific areas of need, or unlimited. The decision-making powers of a guardian may not only include health care decisions, but also other aspects of personal well-being (i.e., housing and placement decisions and arranging caregivers), and financial decisions (i.e., designation as Social Security Representative Payee). There may be one guardian, or there may be more than one person, working together as coguardians.

Importance

A. ***Ethical responsibility to the patient***
The physical and cognitive impairments and disabilities that are experienced by patients in rehabilitation settings can render a patient unable to make or communicate his/her preferences for health care, and in some conditions, unable to make decisions about finances or basic well-being, such that health and safety may be in jeopardy. Unfortunately, many individuals may not have an HCP or Advance Directives to make their preferences known. The need for an HCP or Advance Directives may first come to the attention of the family when faced with a debilitating condition of a family member. The professionals who are part of treatment teams have legal and ethical standards that require them to look out for the best interests of their patients [2–4]. The ethical responsibility to an incapacitated patient is enhanced by clinicians' awareness of forensic issues that are most relevant to their clinical setting. Furthermore, the clinician's attentiveness to forensic issues can facilitate the process and ensure that the patient's desires for health care are met.

B. ***An informed treatment team***
Treatment teams play an important role by (1) facilitating a discussion about benefits of Health Care Proxy, Advanced Directives, or Guardianship, or (2) in providing documentation or information to guide decisions that will need to be made by an Agent or the court.

1. **Facilitate discussion**
Certain medical conditions allow for the opportunity to consider forensic issues before the patient becomes incapacitated. For example, in neurodegenerative disorders, prior to significant cognitive decline, the patient has time to set up Advance Directives and to have discussions with the individuals who he/she will entrust with making decisions when he/she is no longer able. Other medical conditions do not allow for the opportunity to discuss forensic issues beforehand, yet the treatment team can highlight key issues for individuals who are tasked with managing the affairs of such individuals. For example, a patient with a traumatic brain injury (TBI) may need assistance with certain activities of daily living (e.g., medication management, driving, financial management, and cooking) but not with other activities, depending on the location and severity of

injury. Certain overlearned sequences are retained even with memory impairment from a neurological insult. Therefore, the individual with TBI may still maintain some independence for tasks that they have done for years or decades (e.g., familiar routines or hobbies). In most cases, the least restrictive environment is preferred to allow the patient to maintain independence as long as possible.

2. **Guide decisions**
   What decisions will the POA or guardian need to make? The team has a unique understanding of the medical treatment plan including areas of deficit and areas of preserved cognition and physical function. Based on this understanding of the patient, the treatment team can help the POA or guardian make informed decisions about the level of care needed for the incapacitated person's mental and physical health. Discussion of the patient's known values (what the patient values if he/she could speak for themselves) can help Agents make informed decisions on the patient's behalf. For this reason, documentation about both strengths and weaknesses are important (see documentation section below). Using residential placement as an example, the treatment team can guide decisions based on the medical, cognitive, and mental characteristics of the incapacitated person's condition to help the Agent determine the most suitable discharge disposition for the patient, such as discharge to home with support from family caregivers or home health care, or to a more structured long-term care setting if appropriate.

Practical Applications

A. ***Advance Directives***

An advance directive typically includes Power of Attorney, Health Care Proxy, Living will, Organ and tissue donation, and Psychiatric advance directives. Although an advance directive may include all elements defined below, each element may be specified in separate legal documents. For example, someone may have organ and tissue donation noted on his/her driver's license, and a separate document for HCP, whereas another person many have all elements specified in the Advance Directive (i.e., HCP, Living Will, and POA). The "Five Wishes" publication contains the legal documents for HCP and a living will, in addition to other questions that allow an individual to state their personal, spiritual, or emotional wishes [5]. An individual can *make and change* decisions in an Advance directive as long as he/she is still able/competent to do so.

1. **Power of attorney *(POA)***
   a. ***General* vs. *limited POA***
      1. A **general POA** allows an Agent to manage all of the Principal's affairs.
      2. A **limited POA** is restricted to specific types of transactions or decisions. The different types of limited POA commonly include financial POA, and medical POA, or more specific situations, such as management of a specific estate, trust, or investment portfolio, or to sign a contract. Most relevant to medical rehabilitation settings is a Health care POA, also known as Health Care Proxy (HCP). Although HCP is an especially important issue for rehabilitation providers, other types of POA may also be a discussion point for patients and their families, depending how an injury or illness affects their ability to make specific types of decisions.
   b. ***Durable* vs. *Springing POA***
      1. **Durable POA** is effective immediately as soon as the Principal (the individual who appoints an agent) signs the document and can take effect whether or not an individual has been determined to be incapacitated. If the treatment team is aware that a durable POA is in effect, once documentation is received by the Agent, the treatment team can consult

with the Agent to assist in making decisions, according to the provisions of the POA.

2. **Springing POA** is effective should the Principal become incapacitated. The criteria for determining whether or not an individual is incapacitated may be stated in the POA. The criteria often require a clinician's certification that the individual is incapacitated. If a clinician is called upon for a competency evaluation in the context of springing POA, it may carry a sense of urgency in order for the Agent to be able to make decisions in a crisis or an emergency.

c. ***Appoint/Revoke***. An individual can *appoint* a POA and he/she can also *revoke* a POA at any time, as long as he/she remains mentally competent to do so, with a written document that is signed by the Principal and witnessed (generally by a notary).

d. ***Oversight***. Unlike guardianship, there is no oversight of the POA by a court or other authority. If there is abuse of power, it is usually only dealt with in a court of law after suspicious activity has been identified.

e. ***If no financial POA*** is in place, family members, close friends, or other community agencies can apply to be the representative payee for an incapacitated person who receives Social Security Income.

2. **Health Care Proxy (HCP)**

a. An HCP has the ***authority to make any health care decision***, including access to medical records, the ability to admit the incapacitated person to health care facilities, the power to withhold or withdraw life-sustaining treatment or artificial nutrition and hydration, and organ donation. The HCP can access medical records to assist him/her in making informed decisions and to provide documentation for admission to health care facilities or to apply for medical benefits.

b. ***Advance Directive supercedes*** if HCP in Advance Directive is different from another HCP document.

c. Advance directive can indicate who an individual does NOT want as HCP.

d. ***No HCP***. If there is no designated HCP, medical personnel must identify a health care surrogate. State laws provide guidance for whom to select as a health care surrogate in the absence of an HCP. In order of priority, the health care surrogate should be the incapacitated person's: (1) guardian, (2) spouse, (3) adult child, (4) parent, (5) sibling, and (6) other relative or friend who is in regular contact and familiar with the incapacitated person's religious or moral beliefs. Without a clear guide for an individual's health care preferences, there may be a higher chance of misunderstandings or disagreement among family members during a medical crisis.

e. Check local laws as HCPs may or may not be mandatory in your jurisdiction.

3. **Living Will**

Declares an individual's preferences for life-prolonging measures. The requirements vary somewhat by state, but in general a living will goes into effect if an attending physician certifies that an individual (1) has an incurable injury, disease, or illness with no reasonable expectation of recovery, and (2) the use of life-prolonging procedures will not prevent the dying process and serves only to prolong the dying process. A living will typically includes preferences for:

a. ***Artificial nutrition and hydration.*** many living wills only indicate preference for or against artificial nutrition and hydration.

b. ***Cardiopulmonary resuscitation (CPR)***. If the preference is for no CPR, many states require an additional Do Not Resuscitate (DNR) form.

c. ***Mechanical respiration***

d. ***Pain relief***

e. ***Other*** procedures, such as major surgery, blood transfusion, dialysis, or antibiotics

4. **Organ and tissue donation**
   Whether or not an individual wishes to participate in organ and tissue donation upon his/her death.
5. **Psychiatric Advance Directives (PAD)**
   Psychiatric Advanced Directives (PAD) are similar to general Advanced Directives discussed elsewhere in this chapter. However, Psychiatric Advanced Directives specify instructions and preferences of an individual, if at some point in the future he/she is no longer able to make decisions for him/herself due to psychiatric illness. For example, a PAD may specify treatment, such as which type of medications or treatment facilities they prefer, or a PAD may designate an HCP for mental health care, or preferences for a guardian if they are deemed incapacitated due to a psychiatric illness.

B. ***Guardianship***

Many of the conditions discussed in this book can result in an individual being incapacitated either temporarily or can lead to long-term or permanent physical, cognitive, and/or functional impairment. When the severity of impairment jeopardizes an individual's health or safety, the court may appoint a guardian. The following highlights issues relevant to medical rehabilitation settings. More detailed information is provided by the National Guardianship Association, Standards of Practice [6].

1. **Difference between guardianship and HCP/POA**
   a. In the case of HCP or POA, the Principal is mentally competent to make and communicate decisions at the time the HCP/POA is created. In contrast, guardianship is appointed only *after* an individual has become incapacitated.
   b. For HCP or POA, the Principal retains the right to elect an Agent, or conversely, the Principal can revoke HCP or POA. For guardianship, the court appoints a guardian. Anyone can petition the court to remove a guardian if there is concern that the guardian is not acting in the best interests of the protected person.
   c. There is more oversight from the court for guardianship. Guardians must file a report with the court on a yearly basis and notify the court if there are any major changes (e.g., a change in living arrangement).
   d. Guardianship is a more involved legal process than HCP and can therefore take more time and incur more legal fees compared to HCP or POA.
2. **Who is appointed as guardian**?
   The court may appoint a family member, a friend, or a local agency as the guardian. The decision as to who will be the guardian depends on who is available and most suitable to act in the best interests of the incapacitated person. More than one person can be appointed as guardian, in which case the guardians act as coguardians and both are responsible for managing the affairs of the incapacitated person.

   Sometimes, the decision is straightforward as to who may be the best person to be appointed as guardian. In situations when family members or other individuals are in disagreement as to who will be the guardian, the clinician must be aware that his/her chart notes may be used in guardianship proceedings. Chart notes should stay objective, yet detailed enough to make the patient's wishes known.
3. **Temporary vs. Permanent Guardianship**
   a. ***Temporary Guardianship*** can be appointed in an emergency situation when there is not enough time to wait for appointment of a permanent guardian. For example, if there is an acute debilitating illness, such as a traumatic brain injury, an individual may need a guardian to quickly assist in making important medical decisions. Temporary guardianship may also be granted if the appointed guardian is suddenly unable to act as guardian (also known as substitute guardianship). Temporary guardianship will

terminate after a specified time (e.g., after 60 days), or after a specific task is accomplished (e.g., to assist in making a specific medical decision).

b. ***Permanent Guardianship*** is granted indefinitely (i.e., permanently) when an individual has a condition that is not expected to improve in the future. This type of guardianship could be revoked or modified by the court if the protected person regains capacity, or if the appointed guardian is no longer able to serve as the guardian.

4. **Limited vs. Unlimited Guardianship**

a. ***Limited guardianship*** is restricted to specific areas of need. This allows the protected person to maintain independence over certain areas of life, yet receive assistance in other aspects of life that he/she is not able to manage. For example, guardianship may be limited to health care decisions, residential placement decisions, or financial decisions (e.g., designation as Social Security Representative Payee).

b. ***Unlimited or full guardianship*** allows the guardian to manage all aspects of the protected person's affairs.

5. **Guardianship vs. conservatorship**

A guardian may or may not also be a conservator. Both guardianship and conservatorship are legal proceedings that appoint someone else to manage the protected person's affairs. However, a conservator manages the protected person's **assets**, whereas a guardian has responsibility for an individual's **health and welfare**. A conservator in some jurisdictions is also referred to as a guardian of estate, property guardian, or financial guardian.

6. **Clinical Example**

Mrs. Smith is a 68-year-old female. She was in a motor vehicle accident, resulting in a severe traumatic brain injury. One year postinjury she remains unable to manage her basic activities of daily living, she has persisting language deficits that limit her ability to understand or communicate, and her treating providers do not believe she will have much more improvement. She has been at a rehabilitation hospital for the past several months and is now ready for discharge. Her daughter, Mary, had POA when the accident happened, so was able to manage her affairs in that capacity. However, Mrs. Smith insists on being discharged back home without assistance, to her house where she previously lived alone. Mary petitioned to become her mother's guardian so she can have more authority to manage her mother's residential placement decisions and to manage her other affairs. The judge granted Mary unlimited guardianship due to the severity, breadth, and chronicity of Mrs. Smith's deficits.

Tips

A. ***Role of Clinicians***

1. ***Informed Consent***. All medical treatments require informed consent by the patient or a surrogate if the patient cannot consent him/herself.

2. ***Assent***. Even if an individual is deemed incapacitated, he/she can still be involved in his/her treatment decisions by providing assent. For example, someone who is unable to make decisions for him/herself due to a medical or psychiatric illness may need a guardian to provide consent for treatment, yet the treatment team can engage the incapacitated person in his/her own health care by obtaining assent. By evaluating whether or not an individual is in agreement (i.e., assent) with certain health care decisions, the treatment team will go a long way toward recognizing the dignity of an incapacitated person, regardless of his/her inability to make or communicate decisions. Readers are encouraged to consult state and local guidelines or institutional review boards (IRBs) for a more complete definition of *assent* as it applies to specific populations and settings.

3. ***Staying alert to a person's level of capacity at all times*** *to* comprehend, appreciate, and make or communicate decisions about his/her personal affairs, including health care, living arrangement, food, clothing, etc., is essential.
   - ***Decision-making capacity can flux***. A person's decision-making capacity can fluctuate (i.e., not be permanent and can change over time) and may be context dependent (e.g., only during a urinary infection). Clinicians may be the first to recognize that an individual's ability to make or communicate his/her own decisions has declined or become compromised. The treatment team has the responsibility to monitor and identify whether there is an elected HCP, or if not, to determine who is the appropriate health care surrogate. In either case, the clinician's role in documenting competency is an important step in the process of determining when HCP or POA goes into effect, or whether guardianship will be appointed by the court.
   - ***Decision-making capacity domains***. Different domains of capacity determination exist (e.g., medical decision-making capacity, financial capacity, driving capacity, testamentary capacity, or capacity to live independently). The attending physician should consider whether he/she can evaluate the patient's decision-making capacity, or whether another specialist needs to perform a capacity evaluation. For example, if a patient is suspected to have cognitive impairment and poor judgment, but performs well on brief cognitive screening, the attending physician may make a referral for a more comprehensive neuropsychological evaluation by a neuropsychologist trained in capacity evaluations for the particular domain.
   - Refer to the separate chapter in this book regarding details about determination of decision-making capacity and competency.
4. ***Expert Witness***. The clinician may be called upon by an attorney as an expert witness to give his/her clinical opinion regarding the patient's cognitive or functional impairment.
5. ***Consent for ordinary*** **vs**. ***extraordinary medical treatment***. Who can provide informed consent for medical procedures for an incapacitated person? An appointed guardian, health care proxy, or POA can provide consent for **ordinary medical treatment**. However, a guardian has limited authority to consent for extraordinary health treatment, such as admission to a nursing home facility, admission to a mental health facility, authorization for use of antipsychotic drugs, or other medical treatments that are considered extraordinary. The guardian must ask the Court for approval to manage **extraordinary medical treatment**.
6. ***Documentation*** in a clinical report or chart notes should assert the following:
   i. ***Cause/etiology of incapacity***. What is the known or suspected etiology of cognitive or functional impairment? For example, is there a medical condition that is known to be the cause of cognitive impairment, such as a recent history of a stroke? Upon clinical evaluation, are the clinical course, lab results, and cognitive testing consistent with a cortical neurodegenerative process, such as Alzheimer's disease?
   ii. ***Extent of incapacity***. Which domains of cognition or functional impairment are affected? Is the condition affecting multiple cognitive domains, or isolated to specific cognitive domains (memory, executive function, language, visuospatial, or sensorimotor)? Which aspects of daily living are impacted by the condition—cooking, cleaning, self-care, driving, financial management, health care and medication management, social function, communication, etc.?
   iii. ***Areas of preserved function***. It is important to document areas of preserved function. This can help an HCP

or guardian understand which tasks the incapacitated person can be expected to handle independently and enhance the person's overall well-being by giving him/her a sense of independence and agency in his/her life. For example, after summarizing areas of cognitive or functional deficit, be sure to include an assessment of the patient's strengths, including cognitive strengths, functional abilities that are preserved, or general personality features that will help them adapt to their environment.

iv. ***Likelihood they will regain capacity***. If the condition is reversible or partially reversible, when should the patient be re-evaluated to determine whether cognition or function has improved?

v. ***Concurring determination*** of incapacity, or a second opinion, is required in some cases. Please refer to local jurisdiction for details on whether this is required in the specific case, and who is able to make the concurring determination.

vi. ***Relevant forms***. Requirements for different forensic issues vary by state. Consult state and local guidelines for specific forms or criteria that may be needed from treating providers.

B. ***Other team members and local resources***

1. ***Social work*** may be familiar with family dynamics or other life situations that have a bearing on certain forensic issues. They may also be familiar with the procedures that are needed for handling certain forensic issues.
2. ***Neuropsychologists*** are skilled at assessing a patient's cognitive functioning. They can provide a comprehensive neuropsychological evaluation or help the treatment team understand how cognition affects a patient's decision-making capacity.
3. ***Forensic psychologists/neuropsychologists*** may be needed for complex legal issues. For example, if there is a dispute among family members, or if there is a criminal investigation that affects the incapacitated person, a forensic psychologist or neuropsychologist may be helpful.
4. ***Legal services***. A patient may need legal representation, depending on the forensic issue. Local attorneys or legal advisors for your local institution can help you determine local laws for your jurisdiction, or whether or not the patient would benefit from legal representation.
5. ***Local organizations*** can be a good resource for providers and their patients. For example, local support and guidance are often available for individuals with disorders such as dementia, stoke, TBI, multiple sclerosis, or cancer.

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