Psychiatric Advance Directives:
A Compelling Idea in Search of Implementation

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You've joined Marvin Swartz's session (PADS). When you're done, reply LEAVE.

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Case Example

Ms. Allen is a 30 year old woman whose family reports to have a history of schizophrenia and several hospitalizations. When ill she often suffers from auditory hallucinations and delusions and often can not make or communicate healthcare decisions.

She is seen wandering and is brought by the police to the ED and later joined by her family who indicates she has stopped eating, appears to be hallucinating and is speaking incoherently.

The ED has no available records on Ms. A. since she has been hospitalized elsewhere in the past. The examining psychiatrist can not take a meaningful history.

The psychiatrist begins to prepare for involuntary commitment and, possibly, forced medication.
Case Example (continued)

The family asks to speak with the physician who is reluctant to speak with the family.

The sister indicates she is Ms. A’s Health Care Agent (HCA) and is prepared to make whatever decisions needed on Ms. A’s behalf. She indicates Ms. A has executed a Mental Health Advance Directive and a Health Care Power of Attorney (HCPA) (that appointed the sister as HCA).

She produces a copy of each and indicates they are also online at the NC Secretary of State’s Advanced Health Care Directory Registry.

In reviewing the documents, Ms. A has consented to hospital admission when needed, a regimen of medications, consent to speak to her doctors, other providers and family.

She also appoints her sister as HCA with authority to make whatever decisions are consistent with Ms. A’s previously expressed wishes.
Having never encountered such a situation the psychiatrist consults with the hospital attorney who recommends he proceed with admission and treatment under the authority of the advance instructions and health care power of attorney if he feels the patient is ‘incapable’ and will document it in the record.

The physician documents that the patient is ‘incapable’ and reviews the history and treatment responses with the Health Care Agent and outpatient psychiatrist.

The physician admits the patient based on the consent of the Health Care Agent who also consents to the treatment plan suggested after consultation with the local psychiatrist.

After several days of hospital treatment the patient is coherent and cooperative and the physician documents that she is now ‘capable’ and can make her own treatment decisions.
How Did the PAD Help?
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Getting PADs into the Mainstream: An Implementation Science Approach

• Implementation science
  – is the study of methods that influence the integration of evidence-based interventions into practice settings.
  – seeks to understand the barriers and facilitators that influence successful implementation of effective interventions.

• Question: What approaches can we use to get PADs into mainstream use?
What are Psychiatric Advance Directives (PADs)?

- Legal documents that allow persons when of “sound mind.”
- To refuse or give consent to future psychiatric treatment.
  - Advance Instructions
- May authorize another person to make future decisions about mental health care on behalf of the mentally ill person, if he/she becomes incapacitated.
  - Health Care Power of Attorney
Goals of an Advance Directive

• To ensure patients are treated according to their wishes
  – even when they can not speak for themselves.
• Even when incapacitated, provides a mechanism for:
  – exchange of clinical information,
  – consent or refusal of treatment.
• Appoints a proxy decision maker when a patient is incapacitated
Where did ADs come from?
Legal origins

• Medical, end-of-life directives:

  • Supreme Court decision (1990) Cruzan v. Director, Missouri Department of Health

  • Required “clear and convincing evidence” of a patient’s wishes in order to withdraw life-sustaining medical treatment

  • Defined need for written documentation as evidence of incapacitated patients’ treatment preferences
Where did ADs come from?
Legal origins

- Patient Self-Determination Act of 1991
  - Helped to implement medical advance directives and end-of-life “living wills”
  - Required hospitals receiving federal funds to
    - ask patients if they had an advance directive on admission
    - document advance directives and follow them
    - have a written policy for implementing advance directives
Origins and premises of PADs

• Notion of a “psychiatric will” proposed by Thomas Szasz as a way to avoid unwanted mental health treatment.

• Concept of end-of-life directives adapted as a way for mental health consumers to maintain control over their treatment choices during periods of incapacity.

• Sometimes viewed as “self-commitment” due to irrevocable provision.
Advance directives and the Greek myth of Ulysses

On his 10-year voyage back to Ithaca from the Trojan War, Ulysses was warned by Circe to take precautions if he wanted to hear the Sirens' transfixing song, or there would be "no sailing home for him, no wife rising to meet him, /no happy children beaming up at their father's face."

Ulysses accordingly ordered his men to stop their ears with beeswax and bind him firmly to the mast and instructed them that if he gestured to be set free, they should stick to the original agreement and bind him tighter still.
Increasing interest in PADs in the US: new laws in 26 states since 1991
Do Patients want to complete PADs?
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PAD prevalence... and latent demand

Would you want to complete a PAD if someone showed you how and helped you do it?

66% – 77% said yes.

2004 MacArthur Network Survey of 1,011 psychiatric outpatients:
Have you completed a mental health advance instruction or appointed a health care agent for future MH treatment?

4% – 13% said yes.
Two parts to Psychiatric Advance Directives

• Advance Instructions for Mental Health Treatment (NC GS §122C-77):
  – Similar to a living will.
  – Documents wishes, consent or refusal of future care.

• Health Care Power of Attorney (NC GS §32A-25):
  – Appoints another person to make decisions during crises.
  – May be designed with limited or broad powers.

• Not required to have either, in some states can have either or both.
Instructional Directives

• Usually permits individual to plan for, consent to, or refuse:
  – Hospital admission
  – Medications
  – Electroconvulsive treatment
  – Other treatments for mental illness.

• Takes effect in the event individual loses ability to make decisions (is “incapable”).
Making an Instructional Directive

• Any adult “of sound mind” can make.
• Signed in presence of two witnesses:
  – Not a relative.
  – Not person’s doctor, mental health provider or other staff.
  – Not staff of a health care facility in which the client is a patient.
• Must be notarized.
• Present to doctor and other mental health treatment providers.
What should the doctors or staff do with the Instructional Directive?

• Must make a part of medical record.
• Must act in accordance with instructional directive when patient is determined to be “incapable”.
• May notify all other providers to follow instructional directive.
What does “Incapable” Mean?

“...in the opinion of a physician or eligible psychologist the person currently lacks sufficient understanding or capacity to make and communicate mental health treatment decisions.”
Must clinicians always honor the instructions?

• Clinicians may disregard instructions:
  – Not consistent with “generally accepted community practice standards.”
  – When treatments requests are not feasible or unavailable.
  – When treatment requests would interfere with treating an emergency.
  – Instructions may be over-ridden by involuntary inpatient commitment.
  – Conflicts with other law.
Health Care Power of Attorney (HCPA)

• Allows a person to appoint someone to make treatment decisions when consumer is “incapable” or “incompetent”.

• Can be combined with instructional directive,
  – but may be two different forms.

• Any capable adult may execute.
Who can serve as the health care power of attorney?

- Any competent adult 18 or older.
- Person usually cannot be providing health care to consumer.
- Consumer can often name several people to serve if one unavailable.
When does health care power of attorney take effect?

- When patient is found to be “incapable” and continues during period of incapacity.
- Usually determined by physician or psychologist.
- Finding that patient is “incapable” must be in writing.
What powers does the health care power of attorney have?

- Can make whatever treatment decisions the consumer could usually make;
  - Unless the patient limits the authority of the health care power of attorney.
  - Patient can instruct health care power of attorney on decision about medications, ECT, hospital admission, other.
Why aren’t Psychiatric Advance Directives in the mainstream--yet?

• Many patients, clinicians and families have not been sold on their benefit

• About half of states have these specific laws.
  – States do allow psychiatric advance directives under medical advance directives.

• Advance directives may be difficult to complete for some patients.

• Help in completing advance directives may not always be available.

Implementation Question: How can we address these barriers?
Why don’t people complete PADs?
Patients’ perceived barriers to PADs (N=469 participants)

- Don’t understand enough about PADs.
- Hard to find someone or somewhere to get help to complete the PAD.
- Don’t know what to say or write in the PAD.
- Don’t have anyone I trust enough to make decisions for me.
- Don’t have a doctor I trust.
- Don’t like to sign legal documents (or you don’t trust legal documents.)

85% percent endorsed at least one barriers  
55% reported 3 or more of the barriers
Problems with implementing PADs in usual care: Clinicians’ perceived barriers to implementation

- Perceived operational barriers
  - lack of communication and coordination across clinical settings
  - lack of access to the document in a crisis
- Perceived clinical barriers
  - Fear of inappropriate treatment requests
  - consumers’ desire to change their mind about treatment during crises
  - concerns with consumers’ competency to complete document
- Legal defensiveness
  - Psychiatrist: “Would I rather be sued by a patient because I didn’t follow their advance directive, or by somebody else because I did?”

Implementation Question: How do we address these barriers?
Research questions

• What are the barriers to PADs?
  • completion and use
  • different stakeholders, different perceived barriers
• Does structured PAD facilitation work for people with serious mental illness?
  • address, overcome barriers
  • result in completed, legally-valid PADs
• When patients do complete PADs, what do these documents contain?
  • structure
  • clarity, feasibility of instructions
  • concordance with clinical practice standards
Facilitated Psychiatric Advance Directives: A Randomized Trial of an Intervention to Foster Advance Treatment Planning Among Persons with Severe Mental Illness

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Objective: Studies show a high potential demand for psychiatric advance directives but low completion rates. The authors conducted a randomized study of a structured, manualized intervention to facilitate completion of psychiatric advance directives.

Method: A total of 469 patients with severe mental illness were randomly assigned to a facilitated psychiatric advance directive session or a control group that received written information about psychiatric advance directives and referral to resources in the public mental health system. Completion of an advance directive, its structure and content, and its short-term effects on working alliance and treatment satisfaction were recorded.

Results: Sixty-one percent of participants in the facilitated session completed an advance directive or authorized a proxy decision maker, compared with only 3% of control group participants. Psychiatrists rated the advance directives as highly consistent with standards of community practice. Most participants used the advance directive to refuse some medications and to express preferences for admission to specific hospitals and not others, although none used an advance directive to refuse all treatment. At 1-month follow-up, participants in the facilitated session had a greater working alliance with their clinicians and were more likely than those in the control group to report receiving the mental health services they believed they needed.

Conclusions: The facilitation session is an effective method of helping patients complete psychiatric advance directives and ensuring that the documents contain useful information about patients' treatment preferences. Achieving the promise of psychiatric advance directives may require system-level policies to embed facilitation of these instruments in usual-care care settings.

(Am J Psychiatry 2006; 163:1943–1951)
Key findings:
PAD document content

- Prescriptive vs. proscriptive function: Almost all PADs included treatment requests as well as refusals, but no participant used a PAD to refuse all treatment.

- Most PAD included specific, relevant information about relapse factors, crisis symptoms, medication and hospitalization preferences, ECT, contact information and other instructions.

- Concordance with standard care: PAD instructions were systematically rated by psychiatrists, and mostly found to be feasible and consistent with clinical practice standards.
Key findings: outpatient treatment engagement (cont.)

- At 6 months follow-up, PAD completers had
  - Significantly greater improvement on treatment satisfaction scale (Mental Health Support Program—MHSP—scale)
  - Adjusted OR=1.71 for top quartile
  - “As the result of services I received, I deal more effectively with daily problems…I am better able to control my life…I am getting along better with my family…I do better in school and/or work.”
Key findings: outpatient treatment engagement (cont.)

- At 6 months follow-up, PAD completers had
  - higher utilization of outpatient services
    - medication management visits (probability 41% vs. 33% per month)
    - outpatient crisis prevention visits (probability 19% vs. 10% per month)
- At 12 months, PAD completers had significantly increased concordance between requested and prescribed meds.
Key findings:
prevention of crises and coercion

- By 6 months follow-up, PAD completers had fewer crisis episodes (adjusted OR=0.46)
- At 24 months, PAD completers had reduced likelihood of coercive crisis interventions (adjusted OR=0.50)
Example
I do not consent to the administration of the following medications:

1. Haldol - causes my jaw to lock
2. Lithium or Tegretol - Reverses Fx tests & kidney dysfunction
3. Cloacin - hallucinations
4. Tegretol - locks my jaw
5. Depakote - acid reduces lining of stomach & intestines of colitis & spine weakness
6. Serzone - makes me high or manic
7. Prozac - makes me manic
8. Soma - makes my muscles feel like alcohol (believe)

Conditions or limitations:

- All Martinez is to be managed at home where my special foods are prepared by me or health care aide as no hospital can provide my expensive diet & cost effectiveness of medication which does not cost USP standard no generic meds. I need to be on Folic acid & psychotropic drugs & I can't be spared unnecessarily hospital stay. In the event of MI or CVA = Regional ICU where my team of doctors can treat me in hospital of choice - not St. Luke on UNC campus
- Church due to be notified ASAP if I am hospitalized. Do not notify or his family as they are hostile relatives
- No meds other than CPR drugs to be given's notification

I do not consent to being admitted to a health care facility for mental health treatment.
“I do not consent to the administration of the following medications . . . [lists 9 meds]”

“. . . Episodes are to be managed at home where my special foods are prepared by me or health care aide as no hospital can afford my expensive diet. . .”

“. . . DO NOT NOTIFY my son ________ or his family, as they are hostile relatives.”

“I do not consent to being admitted to. . .[lists 4 hospitals] where “abusive treatment” has occurred . . . I would want a legal aid attorney to see me ASAP.”
Facilitated PAD medication instructions:

A. I agree to administration of the following medication(s):

I agree to Zyprexa because it treats my manic-depression, brings me back to reality, clears illusions, helps me think clearly.

B. I do not agree to administration of the following medication(s):

I do not want Lithium or Tegretol because it could compromise my kidney functioning and two function tests were once affected. Depakote
Welcome to the North Carolina Advance Health Care Directive Registry! We are pleased to offer this service of registering your Advance Health Care Directives online for easy accessibility.

Internet: www.sosnc.com
Getting PADs into real-world practice: Facilitation of PADs by peers and clinicians on ACT teams

New research study funded by a grant to Duke University from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR 90IF0027) (J. Swanson, PI, 2016)

• Research study implemented FPAD intervention in usual-care settings as delivered by two kinds of staff on Assertive Community Treatment (ACT) teams: certified peer support specialists and non-peer clinicians

• ACT consumers (N=145) were randomly assigned within teams, to FPAD from either a peer (n=71) or a clinician (n=74)

• The rate of PAD completion and quality was measured and compared to the previous research standard and across facilitator type.
Key findings: Study of PAD facilitation on ACT teams

PAD completion rates

[Research facilitators in prior study] 61%
ACT peer specialists 42%
ACT clinicians 57%

Percentage of PADs rated as high quality across 4 measures
Peers 97-100%
Clinicians 76-90%

• Overall completion rate and quality of PADs facilitated by peers compared to clinicians was not statistically significantly different.

• Peers and clinicians could play a crucial role in increasing the supply of PADs, an important step toward improving their implementation so that providers implement them in mental health care.
Summary of key findings across studies

• Large latent demand but low completion of psychiatric advance directives among public mental health patients in the USA

• Structured facilitation (F-PAD) by clinicians and peer specialists and trained staff can overcome most barriers to PADs: Most patients who are offered facilitation complete legal PADs

• Completed facilitated PADs tend to contain useful information and are consistent with clinical practice standards
Summary of key findings (cont.)

- Even though PADs are designed legally to determine treatment during incapacitating crises, they can have an indirect benefit of improving engagement in outpatient treatment process.

- PADs can help prevent crises as well as reduce the use of coercion when crises occur.

- Need for system-wide implementation efforts. As yet, PADs remain a promising idea with little implementation in usual care.
Developing a Strategy to Effectively Implement PADs: A Proposal

1. **Barrier**: Low numbers of PADs on file.
   - **Solution**: In partnership with NAMI, the State, MCOs and providers: create community coalitions to train facilitators to facilitate PADs.

2. **Barrier**: Lack of access to documents.
   - **Solution**: Place them in electronic records, on USB drives & online ‘vaults’.

3. **Barrier**: Lack of ‘system’ awareness & resistance.
   - **Solution**: Community coalitions, education, clinician champions, quality improvement efforts in health systems

4. **Barrier**: Low rate of actual PAD use/activation.
   - **Solution**: Train HCAs to intervene as PAD activators/crisis advocates/crisis navigators
Addressing Consumer/Patient Barriers
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What would be important to know about the effective implementation of PADs?
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Welcome to the National Resource Center on Psychiatric Advance Directives

PATIENTS AND CONSUMERS
Find out what you need to know about preparing your own psychiatric advance directive in your state using this simple step-by-step guide.

More details....

Find out more...

HEALTH AND LEGAL PROFESSIONALS
Access practical, clinically focused information as well as comprehensive legal resources to help you make decisions when you encounter psychiatric advance directives in practice.

FAMILY MEMBERS AND FRIENDS
Help a family member with mental illness prepare for a psychiatric crisis using advance instructions or health care power of attorney documents.

More details...

Psychiatric advance directives are relatively new legal instruments that may be used to document a competent person’s specific instructions or preferences regarding future mental health treatment. Psychiatric advance directives can be used to plan for the possibility that someone may lose capacity to give or withhold informed consent to treatment during acute episodes of psychiatric illness.

State-by-State Information

NRC-PAD Web Blog

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