Integrating Psychiatric Advance Directives into Clinical Practice

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What are PADs?

- Psychiatric advance directives (PADs) allow people to declare preferences and instructions for future mental health treatment.
- 25 states have passed specific PAD statutes. All states provide health care power of attorney, which patients can use to plan for their psychiatric as well as medical treatment.
- JCAHO requires psychiatric hospitals to ask patients if they have PADs and to assist patients complete PADs.

Increasing interest in PADs – new laws in 25 states since 1991

Arizona	Hawaii	Idaho
Illinois	Indiana	Kentucky
Louisiana	Maine	Maryland
Michigan	Minnesota	Montana
New Jersey	New Mexico	North Carolina
Ohio	Oklahoma	Oregon
Pennsylvania	South Dakota	Tennessee
Texas	Utah	Washington
Wyoming		

Why use PADs?

- Enhances autonomy and self-directed mental health care, consistent with North Carolina Person Centered Plans.
- Provides ER and inpatient doctors with transportable documentation of a patient's treatment preferences and history
  - Medical disorders, emergency contact information, side effects of medication
- Improves therapeutic alliance and treatment adherence.

North Carolina DMH/DD/SAS State Strategic Plan 2007-2010

- Objective: Develop Comprehensive Crisis Services
- Consumer Outcomes
  - Increased % of consumers with crisis plans
  - Decreased # violent/suicidal acts
- Systems Outcomes
  - Increased continuity of care for consumers between crisis services and ongoing services.

From Policy to Research

- In 2002, Duke was awarded NIMH grant to develop and test an intervention to facilitate PADs among people with mental illness.
- In 2003, the Greenwall Foundation funded a North Carolina website on PADs.
- In 2005, the MacArthur Foundation provided support for the National Resource Center on Psychiatric Advance Directives, which has state-by-state info on PADs, educational webcasts, and the latest news and research on PADs.

NIMH Funded Study of the F-PAD Intervention

- *N*=469 adults with schizophrenia, schizoaffective disorder, bipolar disorder, or depression were interviewed at baseline and one-month, six-months, and one-year.
- After a baseline interview, participants were randomized to control or F-PAD intervention group where subjects met one-on-one with trained facilitator to create a PAD.

Facilitated PAD Intervention

- The Facilitated Psychiatric Advance Directive (FPAD) Intervention was designed as a structured but flexible session to provide orientation to PADs, as well as direct assistance to help people with mental illness to complete a PAD.
- The FPAD reviewed past treatment experiences and educated participants about writing an advance instruction and designating proxy decision makers.

Facilitated PAD Intervention

- If participants wished to prepare a PAD, the facilitator provided assistance in doing so by
  - (1) eliciting preferences and advance consent/refusal for psychotropic medications, hospital treatment, or ECT.
  - (2) gathering information about crisis symptoms, relapse and protective factors, and instructions for inpatient staff (e.g., effective strategies to avoid use of seclusion and restraints).

Facilitated PAD Intervention

- Assistance was also provided for notarizing PADs, filing them at local health care facilities, and storing them in the U.S. Living Will Registry and NC Online Registry.
- This process takes on average 2 hours.
- Fidelity is monitored at the start of training to assure a quality F-PAD process sensitive to clinical issues that arise.

PAD content: Crisis Symptoms

- 98% of subjects listed at least one crisis symptom they wanted to communicate to inpatient doctors (median=5).
- 21% listed aggression/anger as crisis symptom
- 24% listed self-harm or suicidal ideation as crisis symptom

Crisis Symptoms

- “I believe I need to hurt myself because the television is talking to me.”
- “I shake all over and have gotten seizures.”
- “I give things away and have difficulty sleeping and eating and have racing thoughts and become aggressive, especially in the ER.”

PAD content: Medications

- 94% gave advance consent to treatment with at least one psychotropic medication.
- 77% refused some medication.
  - 76% gave reasons
  - 72% listed side effects for refused meds
- No participant refused all medications and or treatment.

Medication Choice

- “I refuse Haldol because it makes me stiff, I get blurred vision, and feel like a zombie.”
- “I don’t want Depakote because one time I had it and I got Pancreatitis.”
- “They’ve given me Ativan before but I absolutely do not want any medications I could become addicted to.”

PAD content: Hospitals

- 88% gave advance consent to hospitalization in at least one specified facility
- “I want to go to X because it is closest to my parents and they treat me well there.”
- However, 62% also documented advance refusals of admission to particular hospitals
- 51% gave reasons, such as, “I do not wish to go back to Y, I was thrown in a dark room and am scared and was hurt by another patient last time.”

Emergency Contacts

- Includes family, friends, doctors and counselors that s/he would want to have contacted in the event of crisis.
- Facilitates communication between inpatient and outpatient treatment providers.
- In the study, consumers listed on average 3 emergency contacts.

PAD content: Relapse Factors

- All subjects listed at least one risk factor for relapse (median=3).
- 58% specified nonadherence with medication or other treatment as a relapse factor.
- “Not taking my medications after going home.”
- 20% described detailed behavioral patterns of decompensation.
- “Getting into a cycle where I work too much, get less sleep, become stressed and then manic which morphs into psychosis.”

Protective Factors

- Virtually all (98%) of consumers listed protective factors (median=4)
- “Being with interesting friends and co-workers and not isolating in my room.”
- “Getting up everyday and being around people I like.”
- “Working at the voc rehab keeps me busy and out of trouble.”

Staff Instructions

- 52% wrote instructions to staff on ways to reduce reliance on restraints and seclusions.
- 75% wrote wanting to be treated with respect
- “Be honest with me and supportive.”
- “Please treat me with respect and listen.”
- “Staff should know if I’m crying, I can’t ask anymore but need someone to talk with me; otherwise I’ll hurt myself.”

Staff Instructions

- “Please let me wear a coat if I’m cold on the unit.”
- “Staff needs to know if I’m hearing voices to run, then I’m not wanting to hurt myself or anyone else and I just want to be talked to.”
- “I need to have a cigarette during intake, I can’t calm down without a smoke.”
- “I want a shot if I get out of control.”
- “If staff is trying to restrain me, they should know I have a porto-cath.”

PAD content: Other Information

- 62% refused ECT under any circumstance.
- 72% of the sample listed a history of side effects to particular medications.
- 16% listed additional medical conditions they wanted providers to be aware of but which may have behavioral components (e.g., diabetes, hypothyroidism, hypertension).
- 28% of subjects also documented medication and/or food allergies.

PAD completion rates by study group

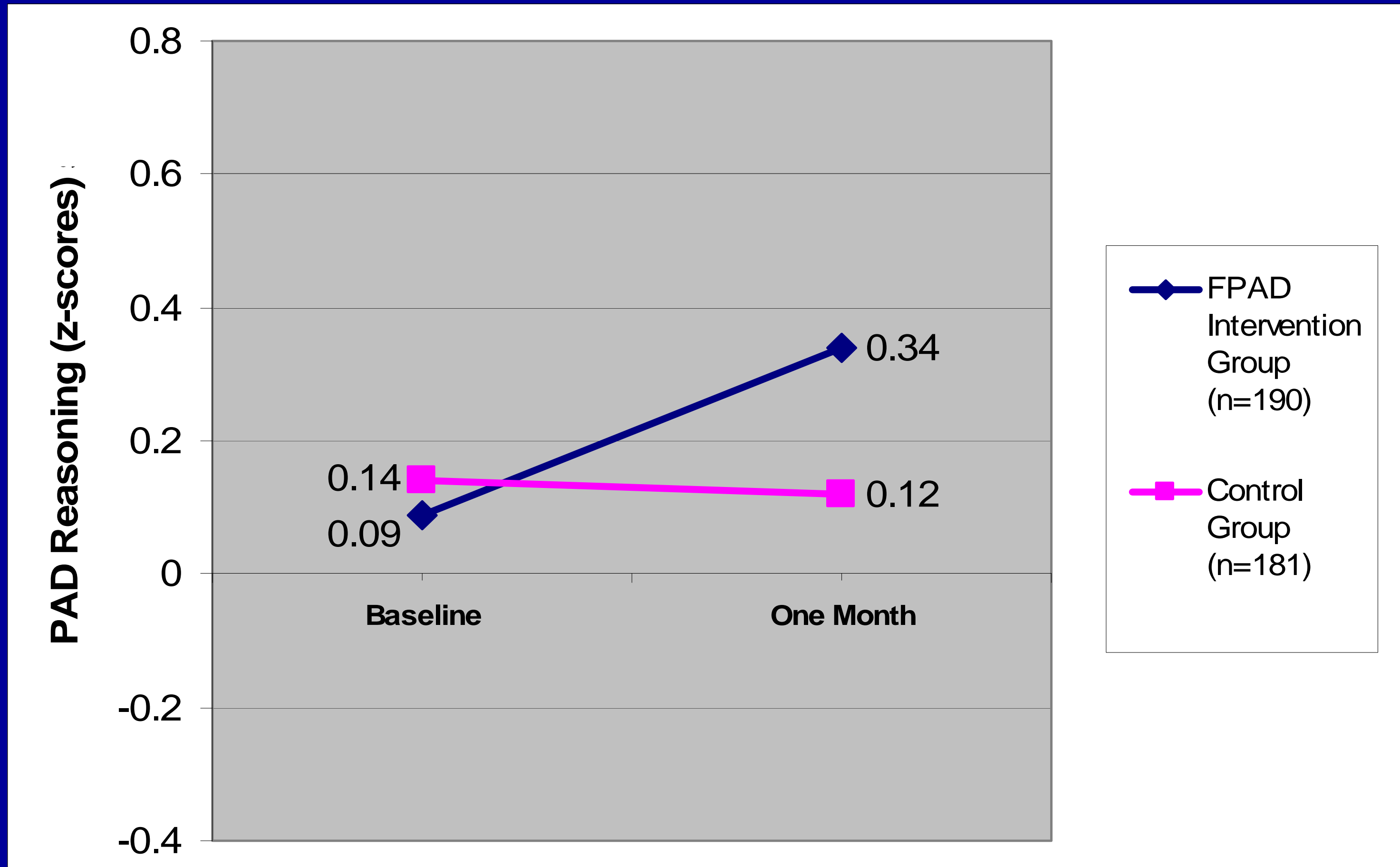
- Baseline
  - Control group: 1/230 (0.5%)
  - F-PAD group: 3/239 (1%)
- By two months
  - Control group: 8/230 (3%)
  - F-PAD group: 149/239 (62%)

F-PAD effect on working alliance with clinician

- Correlation between F-PAD intervention and Working Alliance Inventory change score from baseline to 1 month follow-up:

  $r=0.10$ ($p<0.05$)

F-PAD effect on decisional capacity



Participants in the intervention group showed greater improvement on reasoning about effects of PADs at one-month compared to controls (F (1, 368) = 8.65., p = 0.003).

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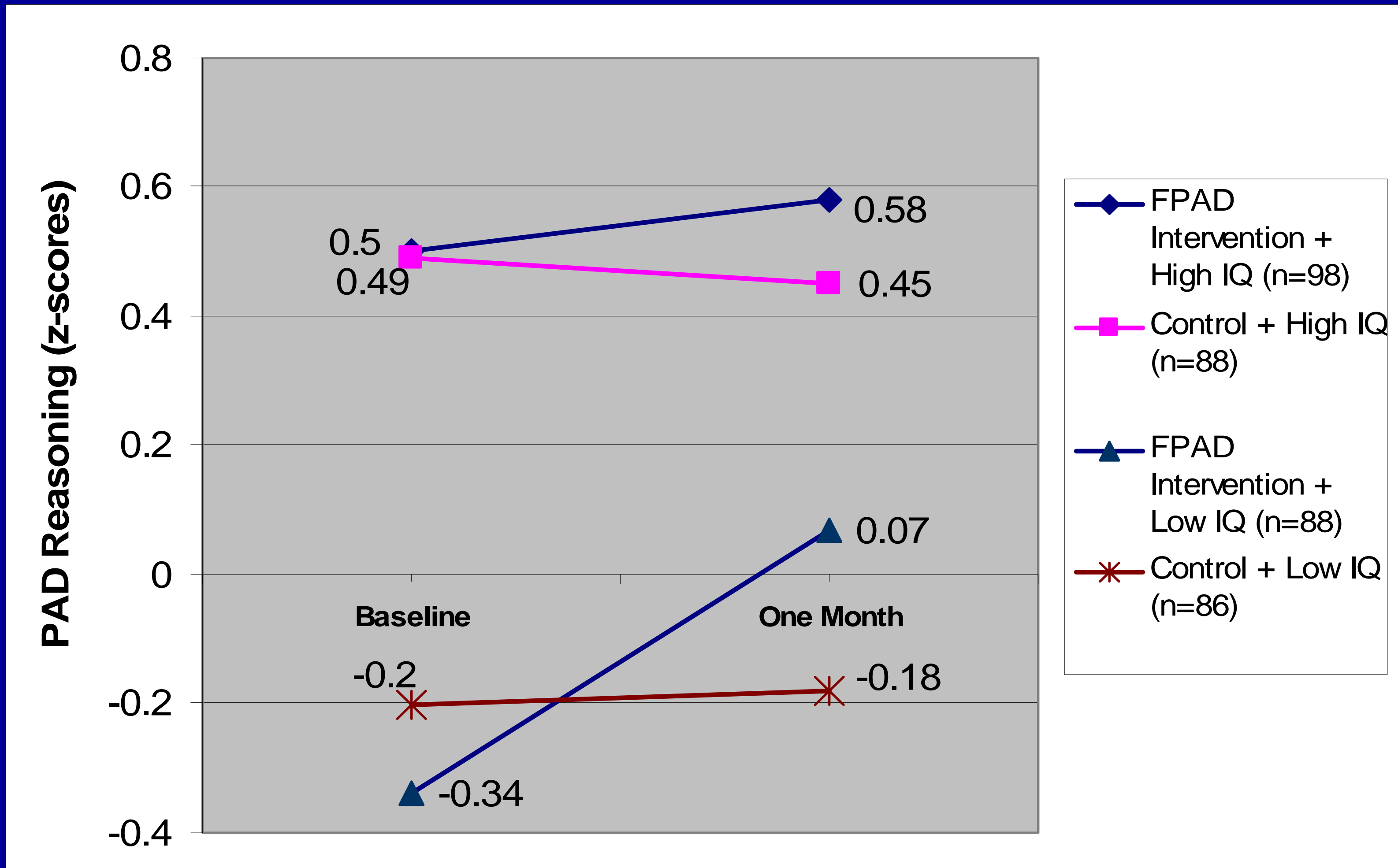
F-PAD effect on decisional capacity



Participants in the intervention group < IQ of 100 showed improvement compared to their counterparts in the control group ($F(1, 171) = 7.36$, $p = 0.007$).

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Helping Consumers Understand PAD Definition and Limits

- When assisting a consumer complete a PAD, it is important to ensure the consumer understands the limits of PADs.
- Studies show that consumers report not understanding how PADs work; thus, consumers may develop false expectations that these legal documents will ensure they get what they want.
- By educating consumers about PADs, facilitators can best foster empowerment realistically.

Overcoming Logistical Barriers to Completing PADs

- Finding Witnesses
- Consumer is personally known to witness.
- Consumer is not related to witness by blood, marriage or adoption.
- Consumer is not a person for whom witness directly provide care as a professional.
- What if the consumer has no one else that meets these criteria?

Overcoming Logistical Barriers to Completing PADs

- Registration and/or Notarization in many states
- Concern about confidentiality might arise regarding submitting mental health advance directive to registries.
- Choosing a password to permits access for consumer and others to PAD. What barriers might consumers face?

Documenting Preferences and Writing Useful PADs

- Documenting a consumer's preferences could conflict with helping to write a useful PAD.
- Consider a consumer wishing to document a request unlikely to be followed (e.g., "I want to smoke in the Emergency Room").
- In such cases, facilitators could provide some feasibility testing (e.g., "I don't think the hospital policy would allow you to smoke in the Emergency Room.").

Documenting Preferences and Writing Useful PADs

- At this point the consumer could either not document the preference (e.g., “You’re right, there’s no way they’d let me smoke in the ER.”) or write it down in the PAD anyway (e.g., “I know, but I want doctors to know how important my smokes are.”).
- Although a PAD facilitator can prompt consumers to assess the feasibility and appropriateness of PAD instructions, the facilitator first should strictly support consumers’ preferences in recording any instructions they wished.

Ensuring PADs are read by Providers and Family

- Make copies of PAD and send to relevant outpatient and inpatient facilities.
- Encourage consumer to discuss PAD preferences with Health Care Agents, clinicians and other family members.
- File PAD at the U.S. Living Will Registry and other state registries.
- Consumers should keep a copy of their PADs on their person at all times.

Excerpts from unfacilitated PAD:

"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."

I do not consent to being admitted to a health care facility for mental health treatment.

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 my head, 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 liver function tests were once affected. Depakote

Advance Directives for Mental Health Treatment page 1 of 10

Facilitated PAD facility preferences:

3. Facility Preferences.

A. I agree to admission to the following hospital(s):

I want to go to [redacted] because [redacted] is there and my team of seven medical doctors are there.

B. I do not agree to admission to the following hospital(s):

I don't want to go to [redacted] because they can't follow my diet or provide me with appropriate access to my medical doctors (I was forced to take medication the last time I was there).

Conclusion

- PADs can help empower consumers with mental illness when they experience crises.
- PAD facilitation is most helpful when:
  1. consumers are educated about how these legal documents work, and;
  2. efforts are made by the facilitator to both honor consumers' preferences and assist in writing a feasible crisis plan.

National Resource Center on Psychiatric Advance Directives

http://www.nrc-pad.org

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PAD STORIES

"....it was really crowded in the ER so I showed intake my psychiatric advance directive and told them that I needed to go somewhere quiet....so that I could calm down....The intake nurse sat with me in a quiet room until I calmed down." Click for more...

Home

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....

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.

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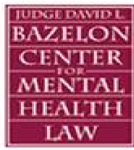
FAMILY MEMBERS AND FRIENDS

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

More details...

State-by-State Information

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.



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