

# **Psychiatric Advance Directives:** *A Tool for Consumer Empowerment and Recovery*

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# Introduction

This presentation is based on a paper that explores the use of psychiatric advance directives (PADs) as a tool for empowerment and recovery for individuals with psychiatric disabilities. Individuals with psychiatric disabilities have stated that “choice and self direction” are important steps in recovery. When persons are in psychiatric crisis they may experience a feeling of loss of choice and self direction. PADs ensure that even when individuals are unable to make a decision about their treatment, they are still in control of their recovery and their personal choice is being respected.

# What are Psychiatric Advance Directives (PADs)?

- PADs are legal documents that allow individuals with psychiatric disabilities (consumers) to express their wishes for treatment and to communicate relevant information regarding their condition at a time of crisis when they may not be able to communicate such information to health care providers (Appelbaum, 2004; Backlar, McFarland, Swanson & Mahler, 2001).

# PADs: How Do They Work?

- In a PAD, consumers are able to state their preferences for care through:
  - Advance Instructions (AIs): A statement of consent or refusal of treatment with specific medical interventions during a crisis (e.g. specific medications, electroconvulsive therapy)
  - Health Care Power of Attorney (HCPA): A proxy decision maker appointed by consumers to make treatment decision for them when they are no longer able to make or communicate decisions (Appelbaum, 2004)

# PADs: What are the Benefits?

- Maintain autonomy of individuals with psychiatric disabilities during periods of psychiatric crisis
- Individuals with psychiatric disabilities are able to express their wishes for the treatment they know is most effective during a crisis
- Empower the individual who is in a psychiatric crisis
- Support the recovery process

# PAD Policy

- In most states in the US and provinces of Canada there is some form of PAD legislation (Ritchie, Sklar & Steiner, 1998; Swanson, Swartz, Ferron, Elbogen & Van Dorn, 2006)
- PADs are supported by the the U.S. Patient Self Determination Act of 1990
  - Mandates health facilities ask patients if they have advance directives, including a PAD, and provide them with information regarding advance directives upon request (Backlar, 2004; Backlar & MaFarland, 1998)

# PADs: Use and Demand

- In a survey of five urban US sites (N=200 at each site) researchers found:
  - Only 4%-13% of consumers had a PAD, BUT
  - 70%-83% were interested in one if someone would help them with the process (Swanson, Swartz, Elbogen et al., 2006)

# PADs and Recovery

- Individuals with mental illnesses can be the experts of their treatment, even in a time of crisis
- Improves working conditions between patient and case managers
- Patient is more self aware of treatment needs
- Use past experiences as a learning tool by “identifying preventive actions, coping skills and self management techniques”

# PADs and Recovery Components

- A collaborative workgroup organized by SAMHSA has identified the core components of recovery, and PADs support each of them (Center for Mental Health Services, 2006)

# PADs and Recovery Components

- Self-direction
  - Individuals are still able to direct care during a crises
- Individualized and Person-Centered
  - Individuals are able to learn from their prior experiences
- Empowerment
  - Individuals are empowered through creating the document and remaining in control of their treatment
- Holistic
  - PADs can include important information regarding treatment and contacting loved ones
- Non-Linear
  - Individuals are able to learn from their past experiences, gain coping skills, and learn preventive measures

# PAD Recovery Components

- **Strengths-Based**
  - Based on the fact that individuals know what they need when in a crisis
- **Peer Support**
  - Wellness Recovery Action Plan (WRAP) recognize PADs as a tool for “documenting and communicating the individual’s WRAP crisis plan” (Copeland, 2004)
- **Respect**
  - PADs ensure that the individual’s choice is respected by health professionals
- **Responsibility**
  - The individual is able to take responsibility in a crisis
- **Hope**
  - The individual is able to gain hope from past experiences

# Barriers to PADs

- Complexity of preparation for consumers
  - Understanding legal language
  - Finding witnesses for PAD and notarizing
  - Filling PAD with providers
- Ensuring that PAD is executed and accessible
  - Requires extensive coordination among health professionals
  - Difficult in fragmented mental health system
- Lack of knowledge or endorsement by providers
  - Widely varied levels of support and belief in their utility, ranging from 20% to 75% (Atkinson, Garner, & Gilmour, 2004; Backlar et al., 2001; Elbogen et al., 2006)

# Future Areas for PAD Research

- Peer Support to increase knowledge of PADs
  - Peer training sessions regarding PADs may be more comfortable and understandable for other consumers
  - Peers may be able to speak to professionals about the PAD process and about personal experience with a PAD
  - Peer support may increase the successful completion of a PADs
  - Peers may be able to offer suggestions on the PADs process and more personal support than health professionals

# Future Areas for PAD Research

- Holistic use of PADs
  - Currently there is a lack of coordination among health professionals and lack of awareness regarding PADs
  - Increased efforts have been made to have PADs on file when needed in a crisis by filing the PADs in a centralized protected web-based system
  - Currently there no holistic strategy to integrate the PADs in the patient's recovery plan

# Next Steps

- Research needed to evaluate the integration of PADs into the consumer's environment
  - Ensuring that all of the consumer's health care providers have access to the PADs
  - Identify all of the key players that need to be aware of the PAD during a crisis
  - Making sure that the health care providers work together and support the consumer's wishes
  - Explore how peer interventions and holistic approach can support the consumer's recovery

# Conclusions

- The use of a PAD can support the consumer's recovery process and empower the individual.
- But there are several barriers
  - The complicated process of creating a PAD
  - The lack of understanding and support by the mental health profession
  - Access to information when needed in a crisis
- Additional research is needed to address these barriers

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