

# Advance directives in mental health care: evidence, challenges and promise

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Psychiatric advance directives (PADs) are written documents or oral statements that allow adults with decision-making capacity to declare their treatment preferences and/or to designate proxy decision makers to act on their behalf should they be deemed incapable in the future of making informed choices on their own.

In the U.S., the Patient Self-Determination Act (1) created momentum for recovery-oriented care, which has led to the enactment of mental health-related advance planning legislation in about two-thirds of the states (2,3). Internationally, increasing attention to such tools is found in the U.K., Ireland, Germany, Belgium, Canada, New Zealand, Australia and India.

## EVIDENCE

A recent theoretical framework (4) discerned from the existing literature three complementary facets of the PAD intervention process: a) enhancement of consumer autonomy; b) improvement of consumer and treatment provider therapeutic alliance; c) integration of care through system partnerships.

### Enhancement of consumer autonomy

PADs improve psychiatric and recovery-oriented outcomes by empowering consumers with serious mental illness to take an active role in their own care (5), choosing among high-quality, evidence-based treatments in the least restrictive setting possible.

PADs are thought to embody a recovery-oriented philosophy by encouraging consumers to preselect their treatments for times of future crises. Research has shown that consumers who have executed PADs endorse feelings of self-determination, autonomy, and empowerment (6-9).

### Improvement of consumer and treatment provider therapeutic alliance

PADs also facilitate communication between providers and consumers about future treatment choices, and these discussions improve therapeutic relationships (7) as well as provide clinically relevant treatment information (10,11). In fact,

research suggests that 95% of PADs are rated both clinically useful and consistent with clinical treatment standards (7,10).

In the context of completing PADs, facilitation refers to a collaborative process between a consumer and a provider that informs the consumer about PADs, engages the consumer in a discussion of past treatment experiences, and helps the consumer work through the process of documenting future treatment preferences and instructions.

Clinician- or treatment provider-facilitated PADs may also improve consumer uptake of PADs. Up to three quarters of consumers indicate they would complete a PAD if provided the choice and support (6,7,12). Thus far, the facilitation process has significantly reduced barriers to PAD completion, with increases in completion of almost 30 times compared to non-facilitated PAD models (7,13).

PADs may also reduce negative coercive treatment experiences. Compared to consumers without PADs, consumers with facilitated PADs were approximately half as likely to require a coercive intervention during a mental health crisis over a 24-month follow-up period (12). This is particularly important because consumers' fear of coercive treatment interventions reduce their willingness to interact with the mental health system and engage in treatment (14).

### Integration of care through system partnerships

Despite these positive signs, mixed or even no evidence exists about the impact of PADs on primary outcomes such as psychiatric admissions, compliance with treatment, harm to self or others, or treatment utilization. Henderson et al (15) demonstrated a reduced number of involuntary psychiatric admissions for PAD completers when facilitated by the individual's clinician; however, similar outcome research showed no effect on psychiatric admissions with non-clinician facilitated PADs (16).

Similarly, there is a lack of research and evidence on the use of PADs to coordinate care across providers/institutions. There is mixed evidence, though, about the thoughts and practices of providers within single institutions (e.g., 17).

## CHALLENGES IN IMPLEMENTATION

Experience has demonstrated that many barriers interfere with implementation and use of PADs. Opponents and

proponents alike acknowledge the low usage rates of PADs, which fall below the usage rates of advance directives focused on only end-of-life care (18). Low usage rates are not attributable to a lack of interest, however, as the same study that showed usage rates of 4-13% across five cities also found that 66-77% of consumers reported interest in PADs when told about them (18).

An important recent advance in the consideration of barriers is the use of taxonomies. Barriers can be identified by the intervention stage at which they occur: intervention design, PAD completion, or PAD access and honoring (4,19). Barriers can also be identified by the level at which they occur: system level, agency level, and individual level (19,20). Arguably, barriers begin even before PAD services are created, as many stakeholders continue to hold misperceptions or conflicting perceptions about PADs and their use (e.g., 21-23).

Once implementation is undertaken, system-level barriers include legal impediments (e.g., unauthorized practice of law, misunderstanding of legal duties and ramifications) and obstacles to communication (e.g., lack of cross-system collaboration) (19,20).

Agency-level barriers include difficulties in integrating a new practice into existing agency culture, need for training, lack of resources (e.g., overworked staff, lack of payment for facilitation services), and impediments to coordinating services (e.g., creating a referral system, engaging doctors as needed for portions of PADs, electronic health record integration).

Individual-level barriers can include engaging clients (both initially and over time, because advance care planning is a process), understanding difficult material, communicating with one's providers and loved ones, and taking steps to ensure that the PAD will be readily accessible (19,20).

Finally, it is well worth noting that, although low- and middle-income countries may be expected to face additional barriers, recent research suggests that completion of PADs is feasible in those countries (24).

## PROMISE

The continuing appeal of PADs in the face of many challenges is likely based on several factors, one of which is the growing attention to patient autonomy across health care systems in several countries (25) and treatment ideologies that advance such moral principles – namely, recovery-oriented models (26-30).

As noted earlier, the U.S. increased its attention to patient autonomy beginning in the early 1990s, with additional developments such as the New Freedom Commission on Mental Health report that prompted national administrative attention to recovery (31). The last decade and a half has seen similar policy and practice developments in the United Nations (32); European countries, such as Ireland, U.K. and Belgium (33,34); Australasian countries, such as Australia and New Zealand (35,36), and India (24,37).

In the U.S., the Commonwealth of Virginia has enacted a particularly forward-thinking revision to its health care decision laws: mental health care was woven into the language of the general Health Care Decisions Act, thus treating it on par with other major domains of health care about which an individual can document decisions (38). Virginia also adopted a presumption that all adults have capacity to make legally binding advance directives, and that a determination of incapacity cannot be based upon diagnosis alone (38). Another innovation that expands individuals' ability to make treatment decisions is Virginia's full inclusion in its law of a "Ulysses Clause" (the person authorizes the doctor in advance to ignore him/her, during future crises, when he/she is saying "No" to treatment) (38).

On the international stage, the United Nations Convention on the Rights of Persons with Disabilities supported a similar approach to individuals' right to autonomy and control over treatment (32).

The fact that PADs instantiate several desirable principles and concepts of care also lends to their appeal. The many facets of PADs may appeal differentially to various user groups: health care consumers benefit from the advancement of autonomy; consumers and clinicians benefit from improved working alliance; and consumers, providers and care systems benefit from coordination of care.

Some individuals and cultures value independence highly, so there is a natural draw to the self-determination that PADs can create. In comparison, some other individuals and cultures value family or group dynamics more highly, in which case PADs are also desirable because they allow for decision making among loved ones and/or for an individual to take a burden off of loved ones by planning ahead (e.g., 39). Thus, PADs have the ability to appeal to multiple audiences simultaneously (4,19).

## CONCLUSIONS

As the many challenges noted above suggest, implementation of PADs has been difficult despite their intuitive appeal. A PAD is a single tool embodying multiple principles and care concepts meant to be used in different ways by several types of stakeholders across multiple providers in what are typically disjointed health care systems (19,20).

Efforts to embed use of PADs in routine mental health care can benefit from research on strategies for increasing their usage and a burgeoning literature on dissemination and implementation of health care innovations (e.g., 40-43), as well as from studies on health behavior change (44-46).

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DOI 10.1002/wps.20268