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ORIGINAL ARTICLE

A Review of Barriers to Using Psychiatric Advance Directives in Clinical Practice

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Abstract Despite advocacy and demand for psychiatric advance directives (PADs), uptake and implementation in clinical practice is low. We examine why PAD implementation has been difficult globally by reviewing barriers in existing evidence. The review includes 30 studies, and identified 13 barriers, clustered into system level barriers, health professional level barriers, and service user level barriers. The considerable barriers to uptake and implementation hamper PAD use. We propose several potential strategies for overcoming some of the barriers. In order to realise these strategies, additional research is needed, particularly more field-based and operational research to understand processes and difficulties experienced in clinical practice.

Keywords Psychiatric advance directives · Mental health legislation · Decision-making · Literature review

Introduction

Psychiatric advance directives (PADs) are legal documents detailing a person's preferences for future mental health treatment and care in advance of decisional incapacity (Campbell and Kisely 2009; Elbogen et al. 2006; Henderson et al. 2008) Traditionally, PADs have been used to document preferences in advance of a psychiatric crisis (Backlar 1997; Henderson et al. 2008; Swartz et al. 2006) but can be extended to plan for future routine care. PADs are seen as a tool for service users to exercise autonomy, choice, and control over treatment for their mental health problems (Atkinson et al. 2003; Thara and Rameshkumar 2012). PADs offer several ways of advance planning; service users can specify treatment preferences (e.g. preference for a particular medication or refusal of a medication), treatment setting (e.g. preference for a particular hospital or type of care), methods for de-escalating crises, life decisions (e.g. what to do with pets or the home while hospitalized, who to contact in case of emergency) or other care preferences (e.g. restraint and seclusion preferences, existing treatment details for comorbidities) or preferences/guidance for staff (e.g. staff should be friendly and understanding) (Srebnik and Russo 2007; Swartz et al. 2006). Service users can also allow for the appointment of a proxy decision maker for future care in a PAD (also referred to as health care agent, or power of attorney) (Henderson et al. 2008).

Apart from exercising autonomy, empowerment, and choice (Backlar et al. 2001; Jankovic et al. 2010; Kim et al. 2007; Peto et al. 2004), PADs offer some additional advantages. They can increase service user motivation to continue with planned treatment, thus improving treatment adherence (Elbogen et al. 2007; Srebnik 2005; Swanson et al. 2000), improve the patient-provider relationship,

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address practice-based issues in the organization of mental health care, and reduce coercion and involuntary care (Jankovic et al. 2010; Srebnik et al. 2003, 2005; Swartz et al. 2006). Advance directives are also seen as a form of supported decision-making (Weller 2010) and therefore in line with Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2006) which emphasises equal recognition before the law and the right to exercise legal capacity.

PADs do not necessarily require collaboration or agreement with health professionals, and are therefore seen as enhancing autonomy and choice in decision-making for the person with mental illness. A number of other advance planning tools are available (e.g. joint crisis plans, crisis cards, advance statements) requiring various degrees of collaboration with health care professionals, and some are legally binding, similar to PADs.

Legislation in a number of countries have provisions for PADs, however, only a small minority of people with mental illness actually write a PAD. Previous research on usage of PADs in the United States (US) shows that between 4 and 7 % of those surveyed have completed a PAD (Swanson et al. 2003), and only 12.5 % of health care professionals had seen clients with an existing PAD (Swanson et al. 2003). Despite the low completion rate of PADs, demand is high in the US, ranging from 66 to 77 % of service users surveyed (Swartz et al. 2006; Wilder et al. 2012). Similar data are not available for other countries, but given that the US is at the forefront of encouraging PADs completion and use, the situation in other countries is likely to be less developed.

This raises questions on two issues. First, why is the uptake of PADs so low despite the high demand from service users? Second, if PADs are seen as empowering for service users and promote the CRPD's goal of supported decision making, why are they not implemented more in practice? The gap between interest in and completion of PADs has been attributed partially due to the barriers facing service users and health professionals (Swartz et al. 2006). The perceived barriers to implementation and use of PADs in practice differ depending on the models of care they are based on, as well as the legislative and service contexts they have been developed in (Henderson et al. 2008).

The aim of this review is to obtain greater understanding as to why it has been so difficult to implement PADs globally. We aim to do this by reviewing the barriers highlighted in the existing evidence base and conclude with putting forward potential research questions, which can be tested to inform how particular barriers could be alleviated and how PAD uptake could be scaled up. In this paper we will only focus on barriers to using and implementing PADs and facilitated PADs. This review will not focus on the barriers to having a proxy decision-maker, or on the content of PADs; rather, we will look at structural and systemic barriers to using PADs. Facilitated PADs, for the purposes of this review, refer to support or assistance in completing a PAD, provided by someone who has received training on PADs and how to facilitate such a process for a person with a mental illness (Swanson et al. 2006a). Other forms of advance planning tools (e.g. joint crisis plans, crisis cards, advance agreements, treatment plans, wellness recovery plans) will not be covered in this review. The interactions between health care professionals and service users are different for PADs compared to other advance planning tools, as the power distinctions are different. In a situation where there are power differentials between different stakeholders, it is quite conceivable that the 'voice and desire' of the service user can be lost. PADs give the service user the greatest level of autonomy to have his/her wishes heard and respected. We endeavour to explore the controversies surrounding the legal backing of PADs, and whether this presents more barriers at a particular level (service user level, health professional level, or system level).

Methods

Search Strategy

We conducted a systematic search in the following databases: PubMed, PsycINFO, and Cochrane Library. Search terms included: advance directives, advance directive adherence, advance statements, advance agreements, Ulysses AND psychiatry, mental health services/legislation, mental competency, commitment of mental illness, crisis intervention. We also systematically searched through reference lists of included studies to identify any additional references for potential inclusion that our searches might have missed (see Fig. 1).

Inclusion Criteria

We restricted our search to inclusion of papers focusing on PADs (facilitated and non-facilitated), and we did not include studies on any other type of advance agreements or treatment planning tools. As studies in this field are often not conducted as randomized controlled trials, we broadened our inclusion criteria to include qualitative studies. We included studies as long as at least 50 % of the sample population reported having a mental illness. We included primary data and did not include reviews in the analysis. Included studies were restricted to English.

Exclusion Criteria

We excluded studies if they: focused on a sample population with predominantly physical health conditions or cognitive

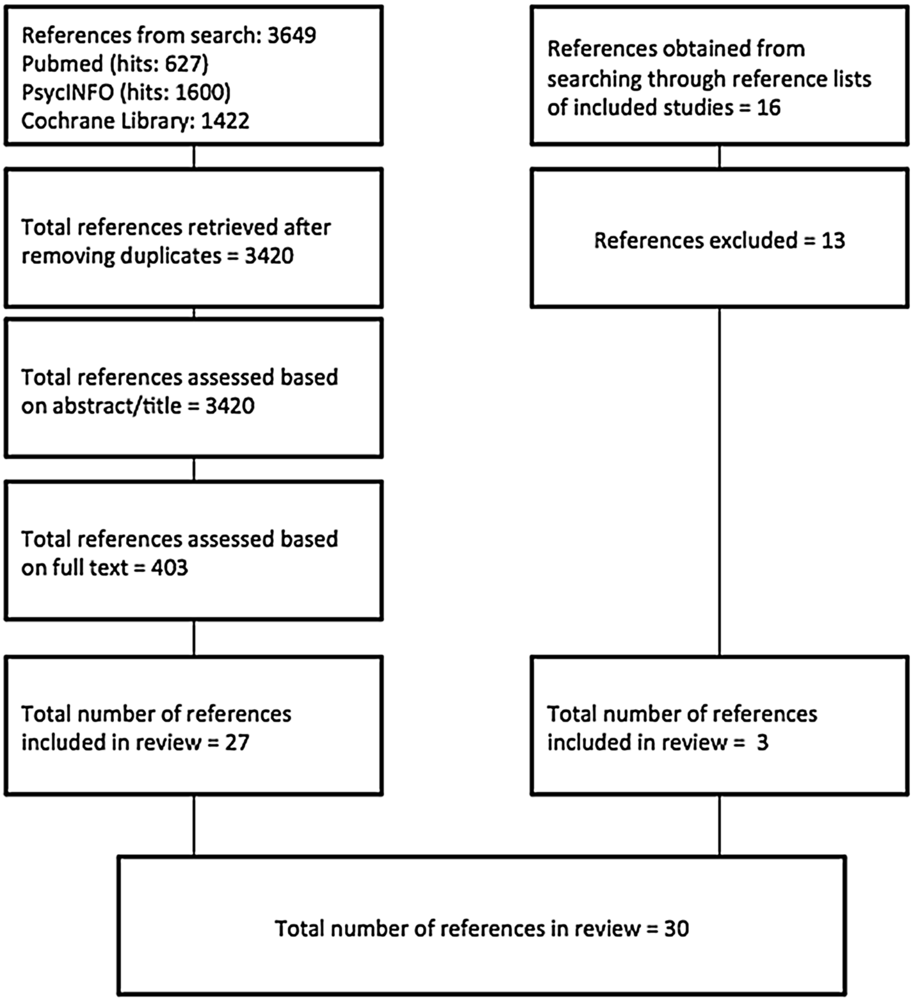

Fig. 1 Flow chart of study inclusion

impairment (Alzheimer's, dementia); focused on enduring powers of attorney; focused on other forms of advance planning tools (i.e. anticipatory psychiatric planning, joint care plans, joint crisis plans, crisis cards, and advance care planning).

Study Selection

One reviewer (LS) conducted the search and screened the abstracts of all publications obtained by the search strategy and sifted through the references to exclude irrelevant studies. Two authors (LS and SP) screened the remaining relevant abstracts to identify which papers met eligibility criteria. Disagreements were resolved by consensus and where necessary involving the third author. Records were kept for study exclusions. References were managed Reference Manager (version 11) on Windows.

Data Extraction and Study Appraisal

Study characteristics comprising study ID, setting, population characteristics, interventions and comparisons (if applicable) and outcome measures were extracted from all included studies and inserted into evidence tables in Microsoft Word. Two authors (LS and LVDH) extracted the data independently and SP checked for accuracy. LS and AVDH appraised the studies for methodological quality using a methodological checklist for qualitative studies. Disagreements were resolved by consensus or by consulting with external researchers.

Results

3,853 references were identified from the search, of which 403 were assessed based on full-text. Of those, 30 were included in this review (see Table 1 for included study characteristics). Common reasons for exclusion were: the article did not highlight concerns or barriers to PADs uptake or implementation, the article focused on other types of treatment planning tools or advance agreements aside from advance directives, or the article focused on medical advance directives and not on PADs. The study flow outlining the review process can be seen in Fig. 1.

Barriers were assessed at three levels: the system (both legal and health system) level, the health professional level, and the service user level. We describe the barriers at each level emerging from the evidence, as well as attempt to capture tensions and conflicting barriers between levels.

What are the Barriers to PAD Implementation/Uptake at the System Level?

Three main themes emerged from the literature on barriers to PAD implementation at the system level (including both the health and legal system): legal liability, legal provisions to override PAD, and resource implications associated with PAD implementation.

Table 1 Included studies in the review

Study	Design	Sample/stakeholders	Sample characteristics
Ambrosini et al. (2008)	Qualitative interviews	Legal professionals and mental health professionals	$N = 200$
		Canada (Ontario and Quebec)	$N = 50$ legal professionals, $N = 150$ mental health professionals
Amering et al. (1999)	Questionnaire	Mental health professionals at a university-affiliated teaching hospital Austria	$N = 174$ mental health professionals ($N = 34$ psychiatrists, $N = 140$ nursing staff)
Amering et al. (2005)	Field observations from PAD training sessions, open-ended interviews; focus groups	Service users interested in completing a PAD US (New York)	$N = 20$ Interview Group; $N = 9$ in Focus Group
Atkinson et al. (2003)	Focus groups; interviews	Service users, professionals, carrers	$N = 28$ interviews; ($N = 10$ psychiatrists, $N = 6$ service users, $N = 4$ other mental health professionals, $N = 3$ carers, $N = 2$ representatives from voluntary organisations, $N = 3$ not stated interest group)
		Scotland	$N = 17$ group discussions ($N = 10$ with service users; $N = 6$ with health professionals, $N = 1$ advocates)
Atkinson et al. (2004)	Survey by mail (questionnaire using five models of PAD)	Service users, psychiatrists, nurses, social workers, voluntary organisations, directors of National Health Service (NHS) trusts, directors of social work England and Scotland	$N = 473$ ($N = 17$–20 Directors Social work Scotland, $N = 8$ Trust Scotland, $N = 130$ Psychiatrists Scotland, $N = 39$ Voluntary Organizations, $N = 68$–71 Trusts England, $N = 56$ Psychiatric Nurses, $N = 86$ Mental Health Officers, $N = 38$ Psychiatrist England, $N = 31$ Directors Social Services England
Backlar et al. (2001)	Qualitative interviews	Service users and their providers US	$N = 40$
Elbogen et al. (2006)	Questionnaire	Mental health professionals US	$N = 597$ (591 in results) professionals ($N = 164$ psychiatrists, $N = 234$ clinical psychologists, $N = 193$ clinical social workers)
Elbogen et al. (2007)	Follow-up data after 1 year of PAD intervention (quantitative and qualitative measures)	Service users with severe mental illness US	Subpopulation from a larger project on PADS (Swartz et al. 2006) $N = 125$ Subset for these analysis 125 participants who completed PAD via facilitation. Have had a PAD for at least 1 year to examine long-term effects of PADS
Foy et al. (2007)	Survey	Service users US	$N = 58$

Table 1 continued

Study	Design	Sample/stakeholders	Sample characteristics
Henderson et al. (2010)	Delphi method; questionnaire	Within the US Veteran Affairs Administration: Service users who have made PADs, consumer advocates who have helped others to do so, caregivers named as health care agents, clinicians support of PAD and researchers working on PAD	$N = 55$
		US	
Kim et al. (2007)	Qualitative interviews	Service users	Data collected as part of a larger longitudinal RCT examining FPAD ($N = 469$, Swartz et al. 2006)
		US (North Carolina)	$N = 28$
Kim et al. (2008)	Online self-report survey	Social workers providing services to adults with severe mental illness US (North Carolina)	$N = 193$
O'Connell and Stein (2005)	Self-report survey	Law professionals, health care professionals, clergy, mental health professionals, consumers, family members	$N = 272$
		US (Ohio)	$N = 64$ Legal professionals; $N = 52$ health care professionals $N = 44$ clergy; $N = 66$ mental health professionals; $N = 32$ consumers, $N = 14$ family members
Peto et al. (2004)	Follow-up Analysis of earlier study; Online interviews via PAD program, survey	Service users (outpatients) with severe mental illness US (Washington)	$N = 106$ (consists of those who completed a PAD, drawn from larger sample of $N = 303$)
Srebnik et al. (2003)	Interviews, and quantitative analysis of interest in PADs using clinical data and case histories	Service users US (Washington)	$N = 303$
Scheyett et al. (2010)	Qualitative interviews; Phone survey; part of a larger survey of North Carolina Jail administrators	Jail administrators US (North Carolina)	$N = 80$
Srebnik and Brodoff, (2003)	Field notes from 24 structured meetings on PAD	Mental health professionals	$N = 296$
		US (Washington)	$N = 115$ outpatient participants at 2 community mental health centres; $N = 78$ inpatient staff (nurses, social workers, medical staff, administrators) at 4 community psychiatric hospitals, $N = 39$ inpatient staff from 1 state hospital, $N = 16$ crisis service staff, including 1 triage unit, $N = 13$ from an after hours crisis program for 2 mental health centres, $N = 6$ crisis mental health program in a county jail, $N = 29$ county-designated mental health professionals in 2 counties
Srebnik and Russo (2008)	Interview; Chart review; Case history; Quantitative analysis of larger study sample	Service users who completed a PAD and had a psychiatric crisis event post-PAD completion US (Washington)	$N = 303$ (larger study, of which $N = 106$ completed a PAD). This analysis focuses on $N = 69$ of the $N = 106$ who had at least one psychiatric crisis even where their PAD could have been used
Swanson et al. (2003)	Interviews with service users and family members; mailed self-report questionnaire for clinicians	Service users with severe mental illness, family members (carers), clinicians who treat persons with severe mental illness	$N = 272$
		US	$N = 104$ service users; $N = 83$ family members; $N = 85$ clinicians

Table 1 continued

Study	Design	Sample/stakeholders	Sample characteristics
Swanson et al. (2007)	Structured self-report questionnaire	Psychiatrists US (North Carolina)	$N = 164$ (psychiatrists)
Swanson et al. (2008)	Prospective study	PAD completers vs non completers (service users) US (North Carolina)	$N = 147$ (PAD completers) and $N = 92$ (PAD non-completers)
Swartz et al. (2005)	Self-report mailed questionnaire to assess clinician attitudes	Psychiatrists US (North Carolina)	$N = 167$
Swartz et al. (2006)	Follow-up quantitative analysis of F-PAD RCT	Service users US	Additional analysis based on original F-PAD trial ($N = 469$) (Swartz et al. 2006) to look at preferences for completed PAD This analysis used two samples: A) Full sample with non-missing data for preference measure ($N = 456$) B) Subsequent analyses ($N = 381$) who were those who indicated prior to randomization that they did not already have a PAD or a power of attorney and wished to complete a PAD
Van Dorn et al. (2006)	Survey	Mental health professionals (psychiatrists, psychologists, social workers) US	$N = 591$ ($N = 167$ psychiatrists, $N = 237$ clinical psychologists, $N = 193$ clinical social workers)
Van Dorn et al. (2008)	Secondary analysis of Swartz et al. (2006) and Swanson et al. (2003) to examine barriers	Service users US	$N = 469$ (based on sample of Swartz et al. 2006)
Van Dorn et al. (2008)	Researcher-administered questionnaire	Service users coming from a Latino background in the US and their family members and their treating clinicians US	$N = 140$ ($N = 85$ service users, $N = 25$ family members, $N = 30$ clinicians)
Varekamp (2004)	Qualitative interviews	Service users and carers, psychiatrists Netherlands	$N = 51$ ($N = 19$ service users, $N = 17$ psychiatrists, $N = 15$ relatives/friends)
Wilder et al. (2007)	Mailed self-report or online questionnaire	Mental health professionals US	$N = 597$ ($N = 167$ psychiatrists, $N = 237$ clinical psychologists via mail questionnaire $N = 193$ clinical social workers) via online self-report survey
Wilder et al. (2012)	Internet based self-report questionnaire	Administrators, Clinicians, Consumers, Family Members, Advocates US	$N = 460$ ($N = 67$ administrators, $N = 268$ clinicians, $N = 40$ consumers, $N = 60$ family members, $N = 25$ advocates)

Legal Liability

Legal liability was one important barrier voiced by health professionals in five studies. The legal liability concern is two fold: First, health professionals are concerned that overriding provisions made in a PAD in line with community practice standards could result in a potential lawsuit by the service user or nominated representative (Srebnik and Russo 2008). These findings were corroborated by 18 % of professionals surveyed in a later study (Wilder et al. 2012). Second, there is a worry that if health professionals honour a PAD, it could lead to poor treatment outcomes and a potential legal liability for this poor outcome. It is interesting that these barriers were identified in studies conducted in the US, where clinicians have the legal right to override PADs if (a) the PAD is incongruent with acceptable community practice standards, or (b) if the service user poses a risk to themselves or others (e.g. high risk of suicide or violence). Results from Swanson et al. (2007) revealed that psychiatrists concerned about being sued for adverse outcomes from treatment decisions were more likely to override the PAD. In addition, psychiatrists most likely to override treatment refusals outlined in a PAD were more resigned to the necessity of involuntary treatment and held more negative views about the availability of community-based mental health services for people with mental illness (Swanson et al. 2007).

In this same study, 48 % of mental health professionals articulated that involuntary treatment would rarely be necessary if quality services were available and accessible in the community (Swanson et al. 2007). This pertains to the perceived lack of quality and accessible community-based services in that particular health care system. Should these services exist, involuntary treatment would be infrequently required, creating less legal liability for health professionals and less need to override PADs due to involuntary treatment.

In some countries (e.g. the US, Australia) an involuntary admission overrules a PAD. This provision in the law has been said to weaken the utility of PADs overall (Swanson et al. 2003). The laws authorising PADs are the same laws enabling health care professionals to decide to ignore PADs. In the US, for example, the laws on involuntary treatment and admission overrule PAD laws in nearly every jurisdiction (Swanson et al. 2003). Service users in another study (Atkinson et al. 2003) held the view that unless PADs are legally binding, clinicians would not devote attention to them. This view differed from the clinician views in the same study, who stated that PADs would be unworkable if made legally binding in the United Kingdom (Atkinson et al. 2003).

Difficulty Communicating About PADs

There were 4 studies identifying difficulty with communication between staff working in clinical settings once PADs are accessed (Kim et al. 2007, 2008; Srebnik and Brodoff 2003; Van Dorn et al. 2006). These studies found that mental health professionals in the US were concerned about how staff could access PADs, how crisis/inpatient staff would know whether someone has a PAD, how the PAD would be made available, and who informs the crisis/inpatient staff that a service user has a PAD (Van Dorn et al. 2006; Kim et al. 2007). For example, 66 % of health professionals in one study cited this as a barrier between different cadres of staff (e.g. between emergency room (ER) and psychiatric unit) (Van Dorn et al. 2006), whereas another study found that limited communication between outpatient and inpatient providers and limited communication between outpatient and ER was a highly significant barrier perceived by both consumers and non-consumers (on a scale of 1–9, 1 being highly significant barrier, 9 = insignificant, this barrier received a mean score of 2.4 (1.7) and 2.3 (1.6) respectively) (Henderson et al. 2010).

Resource Implications

A third barrier concerns resource implications resulting from PAD implementation. This was primarily expressed in terms of taking into account the time that PADs will take to complete. Different stakeholders (71 % of administrators and 52 % of clinicians) believed clinicians will not have sufficient time to help consumers with severe mental illness understand and complete PADs, or manage the extra paperwork they perceived to be associated with PADs (57 and 48 %, respectively) (Wilder et al. 2012). Logistical difficulties (e.g. storing and retrieving PADs at the critical time, incorporating PADs into routine documentation and making them easily accessible) was another system-level barrier identified by 25 % of respondents in O'Connell and Stein's study (2005). In another study, 80 % of the sample showed little confidence in the ability of institutions (e.g. clinics, hospitals) to have a system in place to facilitate access to PAD information (Backlar et al. 2001).

What are the Perceived Barriers to PAD Implementation/Uptake at the Health Professional Level?

Lack of Knowledge and Training

A lack of knowledge and awareness about PADs among mental health professionals emerged as one of the most frequently cited barriers in the literature, both from the health professional and service user perspective. O'Connell and Stein (2005) found that 55 % of health professionals had never heard of PADs, and only 11 % considered themselves "very familiar" with PADs. (O'Connell and Stein 2005) Similar results emerged from another study finding that only 37 % of health professionals correctly answered the question that the PAD statute in North Carolina does not require a clinician to follow a patient's advance refusal of treatment inconsistent with community practice standards (Elbogen et al. 2006), showing that 63 % of health professionals were therefore not familiar with PAD-relevant provisions in the law. O'Connell and Stein (2005) found that health professionals in the region which did not receive PADs education had significantly higher scores on the Obstacles to Success scale compared with informants in the pilot region (who received PAD education) ($p < 0.001$) (O'Connell and Stein 2005). Thus, health professionals who received training on PADs perceived fewer obstacles to PAD implementation.

Six studies (Amering et al. 1999; Van Dorn et al. 2006; Ambrosini et al. 2008; Kim et al. 2008; Wilder et al. 2012) found that between 29 and 54 % of health care professionals had prior knowledge of PADs. The extent of PADs knowledge appears to differ by health care professional, as social workers and nursing staff had more PADs knowledge compared to psychiatrists and psychologists (Amering et al. 1999; Van Dorn et al. 2006). Furthermore, inpatient and outpatient clinicians received less training compared to inpatient and outpatient administrators (30 % and 100 %, respectively (Wilder et al. 2012). More administrators (100 % of inpatient and 88 % of outpatient) had heard of the relevant law governing health care decisions in the US compared to clinicians (67 % of inpatient and 62 %of outpatient) (Wilder et al. 2012). However, administrators working in specialized mental health contexts (e.g. prisons) reported limited knowledge of PADs; only 10 % of administrators surveyed in one study reported having any knowledge of PADs (Scheyett et al. 2010). Finally, emergency care and inpatient care providers having limited knowledge of PADs was cited as a significant barrier to PAD implementation (on a scale of 1–9, 1 being highly significant barrier, 9 = insignificant, this barrier received a mean score of 1.7(.9) and 1.9 (1.1) respectively) (Henderson et al. 2010).

Fear of Complete Treatment Refusals

Mental health professionals in two studies expressed concern that PADs will be used by persons with mental illness as a tool to refuse all treatment (Backlar et al. 2001; Srebnik and Brodoff 2003). In one study this was articulated as a fear that PADs might be used to refuse either all medications or hospitalizations, which could compromise treatment (Srebnik and Brodoff 2003). Another study found that 45 % of professionals believed that the benefits of PADs could be outweighed by the disadvantages of a patient potentially using PADs to refuse medications (Elbogen et al. 2006). Professionals who accepted and emphasized service user autonomy were most likely to follow a PAD where treatment was refused (Elbogen et al. 2006). In two studies (Kim et al. 2008; Van Dorn et al. 2006) 41 % of psychiatrists, 36 % of psychologists, and 33 % of social workers believed that there could be a risk of violence arising from treatment refusal in a PAD, determined by their agreement on a scale assessing obstacles to PADs implementation. In this same study, 51 % of psychiatrists, 44 % of psychologists and 31 % of social workers believed that inappropriate treatment requests in a PAD would constitute a substantial barrier.

Fear that PADs will Interfere with Clinical Aspects of Care

Several studies found that health professionals felt PADs could interfere with various aspects of care. For example, 31 % of mental health professionals in one study agreed with the statement that people with mental illness would not take responsibility for updating their PAD over time (O'Connell and Stein 2005).

Health professionals also appeared to fear that once a PAD is completed, the service user will not be able to change their mind and update their PAD, compromising care and clinical outcomes (Kim et al. 2008; O'Connell and Stein 2005; Van Dorn et al. 2006). To illustrate, 96 % and 81 % of crisis staff and inpatient clinicians (Wilder et al. 2012) and 55 % of psychiatrists, 46 % of psychologists and 48 % of social workers (Van Dorn et al. 2006) surveyed believed that the service user would request to change their mind about PAD content in a crisis, posing a barrier to PAD implementation. Related to this was the fear that the service user will not be able to receive "current" or "up to date" treatment as they are bound to the outdated treatment listed in the PAD (Srebnik and Brodoff 2003).

Professionals' Reluctance to Facilitate PAD

Srebnik and Brodoff found that mental health professionals were reluctant to spend a substantial amount of time to create PADs with service users (Srebnik and Brodoff 2003). This is likely linked to health professionals' worry that they may influence the PADs process, as well as service user choices articulated in a PAD. This was found in a qualitative study conducted in the Netherlands (Varekamp 2004). Fourteen percent of mental health professionals highlighted that it would be difficult to help people fill out a PAD in an unbiased manner (O'Connell and Stein 2005). Front line workers' resistance towards sharing power with the service user (Kim et al. 2008) and reluctance to work with PAD models allowing service users to opt out of treatment (Atkinson et al. 2004) were also mentioned as barriers to professionals facilitating PADs.

Concerns About Service User Capacity

Three studies found mental health professionals to be concerned whether service users have decisional capacity to complete a PAD and make treatment decisions (Srebnik and Brodoff 2003; Swanson et al. 2007; Wilder et al. 2012). Ninety percent of professionals surveyed thought that a service user might be too psychotic during a crisis to remember to notify staff that they have a PAD. Accordingly, patient insight was among the most important facts that clinicians considered when deciding whether or not to support patient preferences (Wilder et al. 2012).

What are the Perceived Barriers to PAD Implementation/Uptake from the Service User Perspective?

Trust

One theme emerging from the service user perspective was trust. Several studies cited that service users did not have someone they trust enough to make a decision on their behalf. This translates to electing someone as a surrogate decision maker, a healthcare power of attorney, or appointing a nominated representative to make decisions as stated in an advance directive. The lack of having someone to trust is also associated with a low preference for surrogate decision-making, another barrier mentioned in two studies (Swanson et al. 2003, 2006b). To illustrate, 43 % of service users did not feel they had someone they could trust to help them complete a PAD (Van Dorn et al. 2009). Service users expressed that they had limited trust in their health care professional (Swanson et al. 2003; Swartz et al. 2006). In one Dutch study, 11 % of service users did not trust their mental health providers enough to draw up a Ulysses directive[1] (Varekamp 2004). This distrust was related to the doubt that PADs would have any treatment effect (Swartz et al. 2006; Van Dorn et al. 2008).

Lack of Support

Lack of support from others (e.g. from health care workers) was also mentioned as discouraging access, completion or demand for PADs in three studies. One study found that 24 % of the population found it hard to get help with a PAD (Swartz et al. 2006). Elbogen et al. (2007) found that 94 % of those surveyed indicated they would be unable to complete a PAD without assistance or having a facilitator (Elbogen et al. 2007). The tendency to support PADs can directly influence the interest level of the service user. In one study, case managers' support for PADs was positively related to service user interest in PAD (Srebnik et al. 2003).

Lack of Knowledge of PADs

Another main barrier that emerged was a lack of knowledge and information about PADs, how to complete a PAD, and what to put in a PAD. This lack of knowledge and information could stem from limited access to PADs. There was a general lack of knowledge among service users and their carers about the existence of a PAD, how PADs could benefit them and their treatment, and how to access a PAD once the service user is interested. For example, as little as 9–58 % of service users were aware of the existence of PADs (Foy et al. 2007; Swanson et al. 2003; Van Dorn et al. 2008). The comparative figures for advocates and carers was 72 and 52 %, respectively (Van Dorn et al. 2008).

Understanding and Completing a PAD

Some service users (56 and 50 % of those sampled) had problems with understanding and comprehending the PAD (Swartz et al. 2006; Van Dorn et al. 2008). Once interest is expressed, some service users were uncertain as to what to write or articulate in a PAD (Foy et al. 2007; Swanson et al. 2003; Van Dorn et al. 2008). Some also felt that PADs posed too much of a burden, expressed by 79 % of clients interviewed in one study (Van Dorn et al. 2008). Finally, four studies (Foy et al. 2007; Swanson et al. 2003; Swartz et al. 2006; Van Dorn et al. 2008) highlighted a reluctance to sign legal documents, which is necessary when signing legally binding PADs.

Fear of Negative Attitudes from Health Professionals

Service users mentioned that a key barrier was getting their health care professional to actually use and access the PAD they had completed. A follow-up study on a randomized controlled trial found that among participants with PADs who experienced episodes of decisional incapacity, only 35 % reported being aware that a clinician had read their PAD (Swanson et al. 2008). These tie in with the notion that patients are afraid or reluctant to tell their doctor they even have a PAD. One study found that service users were apprehensive to tell their doctor they have a PAD (Elbogen et al. 2007), whereas in another study, discomfort was expressed in even mentioning the existence of a PAD, for fear of a negative response from the doctor or involuntary treatment during future hospitalisations (Kim et al. 2007). Health professionals' negative attitudes towards PADs in general was rated by both service users and professionals as a significant barrier (on a scale of 1–9, 1 being highly significant barrier, 9 = insignificant, this barrier received a mean score of 3.4 (SD = 1.4) (Henderson et al. 2010). Service users went on to further express that they were afraid to inform hospital staff they had a PAD for fear of not being paid attention to, or receiving a punishment for broaching topics such as seclusion and restraints. Service users were reluctant to approach their doctor in the first place in another study, fearing rejection (Amering et al. 2005). A later study found that service users communicated the fear that clinicians might intimidate them during a psychiatric crisis, deterring them from introducing their PAD (Kim et al. 2007).

Revocability and Enforceability of PADs

Service users who were uncertain about what to document in a PAD expressed a higher preference for irrevocability (Swartz et al. 2006). In another study, 74 % of participants were concerned about the enforceability of PADs and whether they carried any legal weight (Srebnik and Russo 2008). Building on this, participants in the same study worried about the legal validity of PADs, particularly as to whether the remaining parts of a PAD were still legally valid if health care professionals had overridden others

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[1] The authors define a Ulysses directive as a subset of PADs, where a client with recurrent psychiatric episodes not yet deemed dangerous provides permission in advance for admission and treatment, thus forfeiting the right to refuse them. The key issue with Ulysses directives is the notion of irrevocability (Varekamp 2004).

(Srebnik and Russo 2008). Conversely, in one Dutch study, all 18 service users interviewed mentioned that a specific disadvantage of the Ulysses directive is being committed to something agreed on in periods of decisional capacity (Varekamp 2004).

Discussion

This review aimed to capture the barriers to PAD uptake and implementation from a broad group of stakeholders within the research literature. The purpose of conducting such a review was to better understand the barriers blocking the uptake of PADs and implementation despite high demand and extensive advocacy. The results from this review point to a number of barriers expressed at the system, health professional and service user level, and highlight both perceived and real barriers, as well as barriers to PAD completion as well as PAD activation/compliance.

Capacity as a Barrier to Completion of PADs?

The discrepancy between the interest in and completion of PADs have been attributed to a wide range of barriers such as the service user's understanding of PAD documents, scepticism about whether PADs will be beneficial, and difficulty obtaining proxy decision-makers (Swanson et al. 2003). Health professionals felt that a service user's competency to complete a valid PAD could be a barrier. This is despite nearly all service users in a number of studies being able to complete a valid PAD (for example, Backlar et al. 2001; Peto et al. 2004). Even in low-resource settings like India, it is possible to complete a PAD, both facilitated and independently, even when service users have active symptoms (Kumar et al. 2013). In this particular Indian pilot study, 65 % of service users completed a PAD without assistance, 29 % required prompts, and 6 % required assistance to write the PAD (Kumar et al. 2013). This study lends support to the view that decisional incapacity is not an 'all or nothing' phenomenon, but rather a fluctuating occurrence throughout the course of mental illness (Patel and Bloch 2009). PADs embrace the idea of decisional incapacity as a transitory phenomenon, as they are specifically intended for completion during a period in which the service user has decisional capacity, to plan for periods when they may experience decisional incapacity.

Legal Tensions and Impact on PAD Use and Implementation

In many states in the US, involuntary care or admission gives the health professional the right to ignore or overrule PADs. The paradox with this provision is that a PAD is most valuable precisely in crisis situations and in situations when the person is not in a position to make decisions. If PADs are overruled in these situations, what is the motivation for service users to write a PAD? The basic philosophy that laws enable this to happen points to a sort of discriminatory practice towards people with mental illness. The objective of having a PAD is that in times of crisis, when a person with a mental illness lacks decisional capacity, the PAD and preferences come into effect. It is therefore counter-productive to overrule a PAD precisely in the times that it's intended to be utilised. There is also an inconsistency between medical advance directives and PADs—while medical advance directives enable someone to refuse potentially life-saving procedures based on personal reasons, this logic is not applied to PADs (Atkinson et al. 2003). Medical treatments can be refused based on personal beliefs (based on emotional decision-making rather than on scientific facts) or based on religious beliefs (e.g. Jehovah's Witnesses refusing blood transfusions) and persons with mental illness are often not offered a similar option for refusing specific treatments, even when the PAD is written in periods when the person has full decisional capacity. In this light, the law's ability to override competently made decisions made by persons with mental illness can be seen as discriminatory (Atkinson et al. 2003). It is not the case however that all mental health professionals want to overrule PADs that refuse some form of treatment. In Wilder et al. (2007), a number of mental health professionals endeavoured to honour their patients wishes outlined in a PAD, particularly if the PAD presents evidences of conventional medical reasoning behind treatment refusal. The study points to the notion that mental health professionals are more sophisticated in their decision making as opposed to automatically overriding treatment refusals (Wilder et al. 2007).

The difference between advance directives and other types of advance agreements lies inherently in the fact that it is the expressed wish of the person with mental illness which is legally binding, which ultimately offers substantial autonomy to the service user (Atkinson et al. 2003). Furthermore, a legally binding PAD may require both competence and consideration about potential risks, whereas a non-legally binding agreement often requires a discussion with health professionals and service users and their carers, and involves more agreement and compromise. Non-legally binding types of advance agreements potentially offer less perceived risk to health care professionals (and have more of a focus on communication and collaboration). Legally binding PADs are perceived to potentially impose restrictions on the influence of the health professional by offering more power to the service user in the client-patient relationship (Atkinson et al.

2003). However, Atkinson et al. (2003) comment that service user autonomy is only supported so far as health care professionals accept their client's preferences. It may be imperative to change both service user behaviour and health professional behaviour (Atkinson et al. 2003). Wauchope et al. (2011) suggests that the amount of legal weight attributed to PADs constitutes a complex issue and requires more debate (Wauchope et al. 2011).

Provisions for PADs in Global Mental Health Legislation

Another consideration is that a number of countries have outdated mental health legislation, and close to no laws in low and middle-income countries (LMICs) offer the option of PADs. It is crucial that a strong policy and legislative framework is in place (and implemented) as a backbone to support treatment and care structures in a country. Another potential consideration not exclusive to LMICs but poignantly so is that in order to optimally implement PADs, a strong public health system and linkages are necessary, as well as good continuity of care (Thara and Rameshkumar 2012). It is therefore important that the provisions for PADs and strategies to enable completion and uptake are adapted to reflect the local health, legal and social context (Thara and Rameshkumar 2012). As an example, the current Mental Health Care Draft Bill in India specifically covers the issue of liability, serving as an example of overcoming the barrier of legal liability expressed by mental health professionals.

Furthermore, the roles and responsibilities that health professionals hold and the extent to which individual rights and principles such as autonomy vary by both context and by country. For example, in some states in the US, health professionals are required by law to discuss the topic with service users, while in India the draft Mental Health Care Bill does not mandate PADs but offers it as an option for service users. Underlying this are also differentiations in prioritising autonomy and individual rights, which differ between Western and non-Western countries. In non-Western contexts and in more collectivist societies, the smallest autonomous unit is often the family as opposed to the individual (Alem et al. 2002; Hanlon et al. 2010). This means that family members are often responsible for their family member's ongoing mental health care (Hanlon et al. 2010) and thus are key stakeholders in facilitating and assisting their relative with a mental illness in drafting a PAD. These types of differing support structures and contextual factors impacting autonomy need to be viewed in light of provisions for, and facilitating access to, PADs. One study in India found that there was strong evidence of coercion; 73 % of relatives believed electroconvulsive therapy (ECT) would have been administered by professionals with force even if they had refused (Hanlon et al. 2010; Rajkumar et al. 2006). This highlights the importance of mental health sensitization for both families and service users in such contexts, to communicate the added value of creating a PAD.

Despite the worry that PADs may be used to refuse some or all treatment, a number of studies report that service users do not refuse all treatment. Several studies (Amering et al. 2005; Elbogen et al. 2007; Kim et al. 2007) found that none of the participants refused all treatment, or refused very few treatments, and Kumar et al. (2013) found that out of 92 PAD completers, all wanted to continue treatment, while Reilly and Atkinson (2010) found that only one person refused all treatment (out of 55 PADs) completed in Scotland (Reilly and Atkinson 2010). In fact, Swartz et al. (2005) found that service users placed the highest value on continuity of care, doing so by taking treatment recommendations of their doctors (Swartz et al. 2006). This interest in following treatment recommendations sharply contrasts with the fears of health professionals that a high proportion of patients will use PADs to refuse recommended treatment. This is also supported by studies showing that treatment preferences were consistent with practice standards over 95 % of the time PADs were reviewed (Srebnik et al. 2005; Swartz et al. 2005).

From the service user perspective, another issue is the degree to which the service user wants their doctor involved in drafting a PAD (Ambrosini et al. 2012). Service users can sometimes complete a PAD in order to limit the doctor's freedom to make decisions (Atkinson et al. 2004). Health professional involvement in PADs may therefore depend partially on the level of trust in the doctor and dynamics arising from prior interactions (Laugharne and Priebe 2006). Scheyett et al. (2009) in the US found that social workers struggle with power, responsibility and professional tensions that exist between using PADs and supporting autonomy of their clients. From the health professional side, if PAD implementation barriers are to be reduced, it must be acknowledged that there may be valid reasons for mental health professionals to be reluctant to change their established practices and alter their responsibilities to embrace PADs (Backlar 1997). It seems that despite the advocacy for PADs and existing legislative framework for PADs, there is a lack of buy-in from health care professionals (Amering et al. 2005; Atkinson et al. 2004; Backlar et al. 2001; Miller 1998; Srebnik and Brodoff 2003; Swanson et al. 2003), 2007. In an effort to further action on PADs implementation and acceptance, we attempt to synthesise a number of potential solutions to the barriers we examined in this review.

Potential Solutions to Barriers

The type of barrier (e.g. systemic, structural, or perceived barrier) shapes solutions and implementation efforts. For example, perceived barriers may be alleviated by educating stakeholders and dispel doubts about the utility of PADs, while addressing structural barriers may entail changing cultures, structure and practices within organisations and systems (e.g. reconfiguring information systems). Furthermore, a number of barriers can be overcome with critical reflection and a deeper knowledge and understanding of the basic utility of a PAD for service user empowerment and autonomy. For example, lack of support and concerns from health professionals that additional time is required to help patients complete PADs could be tackled by offering facilitators or peer support workers to facilitate and assist with completing a PAD, as has been demonstrated in studies evaluating the efficacy of facilitated PADs (Elbogen et al. 2007; Swartz et al. 2006). While facilitated PADs can be seen as resource intensive, one solution could be to utilise non-professional health workers or support workers as a facilitator. A more recent study in the Netherlands found that quality aspects (completeness and specificity) of crisis plans were better when the plan was facilitated by a patient advocate than by a clinician alone (70 vs. 57 % completion rate, respectively) (Ruchlewska et al. 2012). Patient advocates confirmed that a completion rate of 70 % was consistent with crisis plans facilitated outside of a controlled trial setting. Using non-health professionals to facilitate crisis cards was also found to be effective in the Netherlands (Van der Ham et al. 2013). This solution reduces burden on health professionals, offers opportunities for informal support in the care process, while offering therapeutic benefits for the client and carer and enabling autonomy and increasing PADs completion to match high demand from service users. Facilitation can reduce a number of the reported barriers (Peto et al. 2004; Van Dorn et al. 2006) especially system-level barriers such as hampering clinician time, interfering with care, and reluctance from the service user side to approach their doctor about a PAD.

In terms of accessibility to PAD at the systems level, having information systems in place (e.g. computerised medical records that will alert the present of a PAD) seem a promising route to making PADs more accessible. This may be a significant barrier in under-served settings or in countries where there is a poor public health information management system. However, working on attitude changes and acceptance of PADs by mental health professionals needs to happen simultaneously with investing in a information system to store/retrieve PADs (Srebnik and Russo 2008).

One way to solve the lack of knowledge and awareness of PADs is brief, practice-based training programmes targeted at sensitising a broad range of health and law stakeholders on the utility and implementation of PADs (e.g. social workers, administrators, community health workers, general practitioners, psychiatrists, psychologists, lawyers, judicial officers, policymakers). This training could also be incorporated into undergraduate and continuing professional education to minimize the knowledge gap on PADs. Increasing awareness of tools like PADs could additionally help reduce stigma as they improve perceptions around the capacity of people with mental illness to be involved in their treatment (Wauchope et al. 2011). Training can also help service users and health professionals to understand the conditions under which PADs can be optimally used, as well as conditions where PADs need to be overridden.

While effective strategies need to be realised in order to alleviate barriers, future research exploring these strategies requires some thought. Practice-based trials can help to better understand what type of training benefits health professionals and service users best, whether PADs can be completed and used in non-Western contexts where autonomy is understood differently, and how logistical issues can be tackled. Outcome measures could aim to focus more on service-user centred measures such as quality of life, participation in care, and empowerment post-PAD completion.

In sum, it appears that while some barriers are relatively straightforward to address (such as the lack of knowledge and training issue for service users and health professionals), other barriers, such as changes to legislation are more difficult and require more debate and input from multiple stakeholders. Changes to legislation such as laws allowing overriding PADs in the case of involuntary care will require substantial input, as it is related to attitudinal change about power equations in client-provider relationships. If the more addressable barriers are tackled, it leaves more room to negotiate and deliberate the more difficult barriers.

Limitations

There are several limitations to this review. First, it is possible that our narrow search may have missed some studies and in addition, reviewing other forms of advance planning tools (which we excluded from this review) could have yielded more studies providing insight into barriers experienced by stakeholders. Second, the methodologies in systematically reviewing both quantitative and qualitative studies need further refining and examination. It is possible that the barriers/concerns reported across the studies were the most significant themes, and others were not highlighted, as has been found in other systematic reviews of barriers in health care (Mills et al. 2005). Third, some barriers were explicitly cited in the literature, whereas others were implicitly stated in the form of statements in a questionnaire that stakeholders agreed or disagreed with, or expressed concerns rather than explicit barriers. Thus, there is a substantial amount of variance and heterogeneity in the compilation of the barriers in this review. Fourth, all studies were from select high-income countries, primarily the UK or US, with very few studies from other middle or high-income countries and none from LMICs. Consequently, this biases our review and limits the ability to make explicit recommendations to countries with legal and health care systems different than high-income, Western countries. Fifth, generalizability beyond these studies can be seen as limited, as many papers use the same sample population or employ small sample sizes. Finally, while we assessed barriers at 3 levels, they are in actuality interlinked, and the categorization we used in this review is in a sense quite artificial. The barriers should be viewed not as three distinct levels of barriers but rather as lying along a continuum.

Conclusion

Reviewing the barriers to PAD uptake and implementation adds great understanding to the debate on how we can develop strategies to address these barriers experienced by service users, carers, health professionals and policymakers. Evidently, tensions exist between service users and health care professionals that appear to concentrate around dilemmas concerning power relations, capacity and reluctance to use PADs. There are potential strategies that can be applied to alleviate these tensions and dilemmas, although additional research (especially field-based and operational research) will be useful to capture the processes and challenges experienced in clinical practice as well as point to best practices in countries with existing PAD provisions.

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