

Review

Psychiatric Advance Directives as a complex and multistage intervention: a realist systematic review

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What is known about this topic

- Despite many supposed benefits, the take-up rates of Psychiatric Advance Directives (PADs) remain low.
- Results of randomised trials on PADs are equivocal.
- Clinical and organisational barriers to their use have been identified.

What this paper adds

- Different frameworks underlie the intervention and make the purpose of PADs unclear.
- Although designed to enhance the user's autonomy, PADs are more efficient in sustaining the therapeutic alliance.
- Much is known about types and functions of the directives document and how to complete it, but more research is needed on how to access the document and honour its contents; indeed, their effective use and evaluation depend on the overall intervention.

Background

Psychiatric Advance Directives (PADs) are documents that allow users with severe and chronic mental illnesses to notify their treatment preferences for future crisis

Abstract

Psychiatric Advance Directives (PADs) are documents that allow users with severe and chronic mental illnesses to notify their treatment preferences for future crisis relapses and to appoint a surrogate decision-maker for a period of incompetence. Despite many supposed clinical and organisational benefits, their take-up rate has remained very low and their clinical evaluation has given contradictory results for organisational outcomes. Intermediary results are available, however, which rely on different theoretical views about how PADs are supposed to work. We carried out a realist systematic review that considered the PAD as a multistage intervention including the definition of the document, its completion and its access and honouring. We identified the theoretical frameworks underlying this kind of intervention and examined the available evidence that supported or contradicted the expectations at each stage of the intervention. Forty-seven references were retrieved, ranging from 1996 to 2009. Three frameworks underlie a PAD intervention: enhancement of the autonomy of the user, improvement of the therapeutic alliance and integration of care through partnership working. Although designed in the first place with a view to sustaining the user's autonomy, results indicate that the intervention is more efficient within a therapeutic alliance framework. Moreover, much is known about the completion process and the content of the document, but very little about its access and honouring. The mixture of expectations makes the purpose of PADs unclear, for example, crisis relapse prevention or management, advance planning of long-term or emergency care, or reduction in the resort to coercion. This may explain their low take-up rates. Hence, frameworks and purpose have to be clarified. The shape of the whole intervention at each stage relies on such clarification. More research is needed, particularly on the later stages of the intervention, as the evidence for how PADs should be implemented is still incomplete.

Keywords: advance planning, autonomy, crisis plans, Psychiatric Advance Directives, therapeutic alliance

relapses and to appoint a surrogate decision-maker for a period of incompetence. Inspired by Szasz's 'Psychiatric Will', PADs were initially designed to enhance patient's autonomy by allowing them to state preferences for or against psychiatric treatments (Szasz 1982). Since then,

PADs have been introduced into the legislation of numerous states in the USA and into that of other western countries (Atkinson 2007). Psychiatric Advance Directives are supposed to offer a series of clinical and organisational benefits, such as improving the feeling of empowerment of the user; improving the relationships between users, health providers and families; reducing hospitalisations, bed days and the resort to coercion or inpatient compulsory admission (Sutherby *et al.* 1999, Swanson *et al.* 2000, Henderson *et al.* 2004).

However, at the same time, several authors have pointed out numerous clinical and operational barriers to their use (Van Dorn *et al.* 2008): the reluctance of a number of stakeholders including psychiatrists and service users (Srebnik & Brodoff 2003, Atkinson *et al.* 2004, Van Dorn *et al.* 2008), the lack of competence of clinicians or service users to implement or honour the statements in a PAD (Peto *et al.* 2004, Elbogen *et al.* 2007a), legal and ethical issues relating to the liability for implementing or overriding the statements (Swanson *et al.* 2007) and the capacity of the care system to organise partnerships and continuity of care around the user's preferences (Van Dorn *et al.* 2006).

A Cochrane systematic review of the effects of advance treatment directives for people with severe mental illnesses examined the effectiveness of PADs through two available randomised controlled trials (Campbell & Kisely 2009). Contrary to expectations, the review provided little evidence on the benefits of PADs for final outcomes, such as psychiatric admissions (voluntary or involuntary), bed days, compliance with mental health treatments, self-harm, violence, formal assessment under the Mental Health Act, or service use. However, it stated that PADs were well-suited for conveying patients' preferences in mental health and that more intensive intervention such as Joint Crisis Plans (a type of PAD involving the user, clinicians, and possible third parties in a negotiation process around its completion) may be more beneficial. In any case, PAD completion rates remain very low (Henderson *et al.* 2008).

Starting from that conclusion, we considered the PAD as a multistage intervention, including at a minimum: (i) PAD document definition, (ii) PAD completion and content and (iii) PAD access and honouring in times of crisis (Srebnik & La Fond 1999). Many results of PAD experiments are available in the scientific literature for intermediary outcomes at each stage. Consequently, in this article, we first set out to examine these empirical data. We also reviewed the different theories underlying PAD intervention: what is its main purpose and why should it work? We finally examined the question of whether the evidence retrieved supported or contradicted the theoretical expectations identified.

Method

In a first step, 295 references were retrieved (after eliminating duplicates) through ISI Web of Knowledge and Medline databases, using the terms: (advance directives OR advance statements OR advance agreement OR joint crisis plan OR crisis card) AND (psychiatry OR mental health). This initial step was performed in July 2009. In a second step, the abstracts of the 295 selected papers were reviewed. A total of 103 references appeared to be clearly outside the scope of this literature review and were rejected. The rejected references were about psychological aspects of end-of-life advance directives, directives on dementia, advance consent to research in mental health, and psychological dimensions of advance directives for physical illnesses. One hundred and ninety-two references remained.

In a third step, three criteria were applied to restrict the sample of references. First, we included only references after 1991, when advance directives were incorporated into US legislation in the Patient Self Determination Act. Second, we restricted the sample to references that considered the PAD in the context of a clinical or social intervention. Third, we only kept references containing either quantitative or qualitative data on health and social outcomes. No other criterion, for example, regarding study design, was applied. Indeed, according to the realistic review methodology, multiple methods for primary studies are required to gain as comprehensive a picture as possible of the intervention investigated. An update of the search was performed in December 2009. Other sources of information were also consulted, but they failed to yield further relevant references. The final sample of study references contained 38 research papers. All the references included related to the period from 1996 to 2009. Moreover, nine conceptual papers on PADs were also consulted to assist in designing the categories for analysis (Table 1).

Data processing and analysis

The realist review is an iterative method designed to assess complex interventions by identifying the theoretical mechanisms through which the intervention is supposed to work, then by evidencing the actual conditions of its implementation, and finally, by assessing the integrity of the proposed theories (Pawson *et al.* 2005). Following these guidelines, we defined a set of key references within the sample, including the ten most-cited articles, the nine conceptual papers referred to above, and one monograph by Atkinson (2007). The analysis of the set of key references allowed us to draw up a list of thematic categories covering the issues relating to PADs that have been addressed in the literature. During the coding

Table 1 References included

Empirical studies						
Study	Country	Setting	Stakeholders involved	Method	Topic explored	
1 Campbell & Kisely (2009)	England	IPU + CMH	Users (N = 316)	Meta-analysis (Cochrane)	PADs vs usual care in terms of clinical and organisational outcomes	
2 Khazaal <i>et al.</i> (2009)	Switzerland	IPU	Users (N = 20)	Observational	Effects of a CBT intervention on PAD completion with bipolar users	
3 Khazaal <i>et al.</i> (2008)	Switzerland	IPU	Users (N = 20)	Follow-up	Follow-up of the previous CBT intervention for PAD completion	
4 Henderson <i>et al.</i> (2009)	England	CMH	Users (N = 62)	Follow-up	Users' and case managers' views on JCP	
5 Flood <i>et al.</i> (2006)	England	CMH	Case managers (N = 28)	RCT	Economic evaluation of JCP vs usual care	
6 Henderson <i>et al.</i> (2004)	England	CMH	Users (N = 160)	RCT	Effects of JCP vs usual care	
7 Sutherby <i>et al.</i> (1999)	England	CMH	Users (N = 42)	Observational	Users' preferences for JCP vs crisis cards	
8 Kim <i>et al.</i> (2008)	USA	Various	Social workers (N = 193)	Survey	Attitudes and decision-making of social workers regarding PADs	
9 Swanson <i>et al.</i> (2007)	USA	Various	Psychiatrists (N = 164)	Survey	Psychiatrists' views on overriding PADs	
10 Elbogen <i>et al.</i> (2006)	USA	Various	MH clinicians (N = 597)	Survey	Clinicians' attitudes to PADs	
11 Van Dorn <i>et al.</i> (2006)	USA	CMH	Psychiatrists (N = 164)	Survey	Clinicians' attitudes to barriers to PAD use	
12 Srebnik & Russo (2008)	USA	CMH + ED	Psychologists (N = 234)	Retrospective	Actual PAD access in crisis	
13 Srebnik & Russo (2007)	USA	CMH + ED	Social workers (N = 193)	Retrospective	Crisis care consistency with PADs	
14 Srebnik <i>et al.</i> (2005)	USA	CMH	Users (N = 35)	Observational	Competences to complete PADs and CAT-PAD testing	
15 Peto <i>et al.</i> (2004)	USA	CMH	Users (N = 106)	Survey + observational	f-PAD testing for completion	
16 Srebnik <i>et al.</i> (2003)	USA	CMH	Clinicians (N = 184)	Survey	Users' views on PADs	
17 Van Dorn <i>et al.</i> (2008)	USA	CMH	Users (N = 303)	RCT	Barriers to f-PAD completion	
18 Elbogen <i>et al.</i> (2007a)	USA	CMH	Users (N = 469)	RCT	Competences for f-PAD completion	
19 Elbogen <i>et al.</i> (2007b)	USA	CMH	Users (N = 469)	Survey	Perceived empowerment with f-PADs	
20 Kim <i>et al.</i> (2007)	USA	CMH	Users (N = 125)	Qualitative interviews	Users' views on f-PADs	
21 Swanson <i>et al.</i> (2006a)	USA	CMH	Users (N = 28)	RCT	Effect of f-PADs vs PAD	
22 Swartz <i>et al.</i> (2006)	USA	CMH	Users (N = 469)	Survey + document analysis	Contents of completed f-PADs	
23 Van Citters <i>et al.</i> (2007)	USA	CMH	Users (N = 150)	Observational	Hypothetical scenario for f-PAD completion	
24 Swanson <i>et al.</i> (2006b)	USA	Various	Users (N = 1100)	Survey	Comparative use of PADs in 5 US cities	
25 O'Connell & Stein (2005)	USA	CMH	Clinicians (N = 272)	Survey	Clinicians' views on PADs	
26 Amering <i>et al.</i> (2005)	Austria	Training programme	Users (N = 33)	Qualitative interviews	Service users' views on PADs	
27 Papageorgiou <i>et al.</i> (2004)	England	IPU	Users (N = 59)	Qualitative interviews	Service users' and clinicians' feedback on RCT results	
28 Papageorgiou <i>et al.</i> (2002)	England	IPU	Clinicians (N = 31)	RCT	Effects of PADs vs usual care	

Table 1 (Continued)

Empirical studies					
Study	Country	Setting	Stakeholders involved	Method	Topic explored
29	Varekamp (2004)	Netherlands	Various	Qualitative survey	Stakeholders' views on UD in the Netherlands
30	Atkinson <i>et al.</i> (2004)	England + Scotland	IPU, NHS trusts, users' advocacy, MH casework	Stakeholders' analysis	Models of PADs and stakeholders' analysis
31	Atkinson <i>et al.</i> (2003a)	England + Scotland	IPU, NHS trusts, users' advocacy, MH casework	Qualitative stakeholders' analysis preparation	Models of PADs and stakeholders' analysis
32	Srebnik <i>et al.</i> (2003)	USA	Various	Survey	Clinicians' views on PADs
33	Swanson <i>et al.</i> (2003)	USA	Various	Survey	Stakeholders' views on PADs
34	de Haan <i>et al.</i> (2001)	Netherlands	Various outpatient	Qualitative survey + Rating	Preferences for PAD completion + competences needed
35	Backlar <i>et al.</i> (2001)	USA	CMH + Rehab. Centre	Qualitative survey	Stakeholders' use and understanding of PADs
36	Amering <i>et al.</i> (1999)	Austria	Psych. Dept. in University	Survey	Psychiatrists and psychiatric nurses' views on PADs
37	Sherman (1998)	USA	Clubhouse programme	Observational	Testing of a computer-assisted PAD completion
38	Backlar & McFarland (1996)	USA	Newsletter for users and carers	Survey	Actual completion of PADs
Conceptual references used to define the categories for analysis					
Study					
39	Henderson <i>et al.</i> (2008)	Topic explored			
40	Szmukler (2008)	A typology of PADs			
41	Henderson <i>et al.</i> (2007)	Description of several types of PADs			
42	Scheyett <i>et al.</i> (2007)	Expected different effects of the 'classic PAD' and the JCP on shared decision-making			
43	Thomas & Cahill (2004)	Expected benefits of PADs for empowerment and recovery			
44	Atkinson <i>et al.</i> (2003b)	Comments on expected effects of PADs on compulsory admissions			
45	Joshi (2003)	Issues in the development of PADs			
46	Swanson <i>et al.</i> (2000)	Description of PADs			
47	Srebnik & La Fond (1999)	Expected different effects of PADs and outpatient commitment			
		Description of a full PAD process			

CMH, community mental health; ED, emergency department; IPU, inpatient unit.

Table 2 Axial coding tree of categories (main issues addressed in the literature on PADs)

Users' views on and attitude to PADs
Empowerment, autonomy of the user
Seclusion – coercion
De-escalating methods/Early signs of crisis
Electro Convulsive Therapy
Non-medical statements
User reluctance
Profiles of users completing PADs
Clinicians' views on and attitude to PADs
Autonomy of clinicians' decisions – overriding
Clinicians' reluctance/concerns
Profiles of clinicians endorsing PADs
Competences required
Users' competence in relation to illness (morbid insight), functioning
Users' competence to fill in PAD/Consistency of statements/Utility
Clinicians' competence to negotiate/help filling in a PAD
Clinicians' competence to access/honour a PAD
Operational (system) features to access and honour a PAD
Information required
Clinicians' need for information
Users' need for information
Carers' and others' need for information
Content of PADs
Types and models of PADs
Classic PADs and crisis cards
f-PADs
JCPs
Functions of PADs
Prescription
Proscription
Surrogate
Advance consent to treatment (UD)
Interpersonal relations (Clinicians – users – carers)
Compliance
Crisis prevention and management
Health providers networking (Mental Health – General Health – Social Care)
Facilitation features for PAD completion
Technical features for registration and access
Ethical issues/Legal constraints and conflicts
Organisational outcomes
Length of stay/Admissions
Coercion, legislation use
Costs
Violence

process, some categories may have been merged or unmerged and reordered to produce the coding categories tree presented in Table 2.

We carried out a thematic qualitative analysis by axial coding of the 38 research articles. On the one hand, for each category of analysis, we identified the different theories underlying the purpose of and arguments developed about that specific category. We then synthesised these underlying theoretical expectations into three main frameworks that set out how the PAD is meant to work

throughout the whole set of categories. These frameworks were completed by taking into account the stakeholders' views as reported in the literature. On the other hand, within each category, we registered the corresponding empirical data when available. These data were classified according to their support for or contradiction of the theoretical expectations identified, and ordered along the proposed multistage intervention process. We paid specific attention to the context of and the features used during the randomised trials.

Results

The characteristics of the studies included are described in Table 3. A majority of studies involved service users: two studies were specifically dedicated to users with bipolar disorders, and 27 involved mixed groups of users with schizophrenia and other psychotic disorders, bipolar and major depression disorders. Sixteen studies involved clinicians in mental health, mainly psychiatrists, psychiatric nurses, psychologists, social workers in mental health settings and case managers. Five studies included carers. Twenty-seven references, reporting twelve different study processes, occurred in Community Mental Health settings in the USA and England. Fourteen references, reporting the results of nine different studies, related to inpatient psychiatric units, and twelve references reported results in other care settings.

Most studies concentrated on the early stages of the PAD process. Indeed, 18 articles focused on PAD document definition, whereas 24 investigated the PAD completion stage. Only two studies considered the access and honouring stage of PADs: one looked at PAD access in times of crisis and the other at the consistency of the actual care with PAD statements. Finally, four studies evaluated outcomes of PAD use: these include the Cochrane review mentioned above, the two available trials included in the review (Papageorgiou *et al.* 2002, Henderson *et al.* 2004, Campbell & Kisely 2009) and an economic assessment of Henderson's trial (Flood *et al.* 2006). The major topics investigated were the stakeholders' views on PADs (mainly clinicians and users) and the development and effects of features that facilitate the effective use of PADs.

Theoretical frameworks underlying PAD intervention

Across the literature, three main theoretical frameworks, or set of expectations were invoked to explain the many benefits expected from the use of PADs: (i) enhancement of the user's autonomy, (ii) improvement of the therapeutic alliance and (iii) integration of care through health providers working in partnership. These three frame-

Table 3 Characteristics of the studies (stakeholders involved, settings, country of study, main methodology, topics and stages of intervention)

Characteristic	Studies involved	Total
Stakeholders involved		
Service users ($N \cong 3634$)	1–7, 12–24, 26–29, 33–35, 37–38	29
Clinicians ($N \cong 2077$)	4, 8–11, 15, 25, 27, 29–36	16
Carers ($N \cong 327$)	29, 33–35, 38	5
Settings		
Community Mental Health (CMH)	1, 4–25, 29, 32–33, 35	27
Inpatient units (IPU)	1–3, 8–10, 24, 27–33	14
Other outpatient	30–31, 34–35, 37	5
Emergency and crisis departments (ED)	12–13	2
Other	26, 30–31, 36, 38	5
Country		
USA	8–25, 32–33, 35, 37–38	23
England	1, 4–7, 27–28, 30–31	9
Scotland	30–31	2
Switzerland	2–3	2
Austria	26, 36	2
The Netherlands	29, 34	2
Methodology		
Quantitative surveys	2, 8–11, 15–19, 21–22, 24–25, 30, 32–36, 38	21
Qualitative interviews, focus groups, content analysis, observations	3, 20, 26–27, 29, 31, 34	7
Quantitative randomised controlled trials	5–6, 17–18, 21, 28	6
Quantitative observational studies	7, 14–15, 23, 37	5
Quantitative retrospective studies	12–13	2
Quantitative meta-analysis (Cochrane)	1	1
Stages		
PAD document definition	1, 4, 7–11, 16, 20–21, 25–26, 29–33, 36	18
PAD completion	1–4, 6–7, 14–24, 27–29, 34–35, 37–38	24
PAD access and honouring	12–13	2
PAD process evaluation	1, 5–6, 28	4
Topics		
Clinicians' views on and attitudes to PADs	8–11, 25, 27, 29–36	13
Competences needed for f-PAD use, and f-PAD effects	15–23, 37	11
Users' views on and attitudes to PADs	4, 7, 16, 26–27, 29–31, 33, 35	10
PAD clinical process evaluation (clinical trial)	1, 6, 28	3
PAD completion and understanding	2–3, 38	3
Carers' views on and attitudes to PADs	29, 33	2
PAD access and honouring	12–13	2
Economic evaluation of the use of PADs	5	1
Comparative actual PAD completion	24	1
Competences of users for PAD completion	14	1

The total number of references for each characteristic may be higher than 38 as many categories are not exclusive.

Table 4 Main expected benefits of a PAD intervention within its three levels of action and the three underlying theoretical frameworks identified

	Theoretical framework		
Level of action	User's autonomy	Therapeutic alliance	Integration of care – partnership working
Intrapersonal	Involvement of the user	Compliance	Continuity of care
Interpersonal	Empowerment	Shared decision-making	Sharing information networking
Organisational	Recovery	Early intervention Reduction of involuntary treatment	Reduction of hospitalisations

works may, moreover, affect the three levels of action of a complex intervention, as described by Pawson *et al.* (2005): the level of the user, or intrapersonal level; the level of the relations between the user, his/her friends and relatives, and the clinicians around him/her, or interpersonal level; and the level of the organisation of care. Cross-referencing the three frameworks identified and the three levels of action of the intervention made it possible to classify the main expected benefits of PAD intervention, as summarised in Table 4.

The first framework underlying the PAD intervention is the enhancement of the user's autonomy, which was its original goal (Srebnik *et al.* 2003, Elbogen *et al.* 2007b, Szmukler 2008). At an intrapersonal level, allowing the user to express his/her treatment preferences and to make statements about his/her life and illness should be a way to develop his/her involvement in the treatment (Amering *et al.* 1999, Papageorgiou *et al.* 2004, Elbogen *et al.* 2007b). Many clinical outcomes in psychiatry have been associated with an improvement in the user's insight, self-esteem, or accountability or with his/her satisfaction with treatment (Trivedi & Wykes 2002, McCabe *et al.* 2007). At the interpersonal level, the enhancement of the user's autonomy supposes the development of his/her feeling of empowerment (Backlar & McFarland 1996, Atkinson *et al.* 2004, O'Connell & Stein 2005, Kim *et al.* 2007), and hence should be a tool for recovery, reducing symptoms, reducing crisis relapses and improving the social integration of the user at the organisational level (Sutherby *et al.* 1999, Backlar *et al.* 2001, Scheyett *et al.* 2007).

The second set of expectations is the improvement of the quality of the therapeutic alliance between the user and the clinicians and possibly of the global relationships involving the user, the user's family/friends and the clinicians (Summers & Barber 2003, Priebe & McCabe 2006). In this context, the PAD document is perceived as a tool for the exchange of information (Atkinson *et al.* 2003b). An improved information exchange between the clinicians and the user should have an effect on mutual understanding and sustain compliance with treatment at the intrapersonal level (Henderson *et al.* 2004, 2009), facilitate access to the information needed by all the stakeholders and the sharing of decision-making on treatment at the interpersonal level (Srebnik & La Fond 1999, Papageorgiou *et al.* 2004, Khazaal *et al.* 2009, Drake *et al.* 2010), and, hence, improve the overall quality of care (Adams *et al.* 2007). From an organisational point of view, it should help early intervention and have an impact on reducing compulsory admissions (Swanson *et al.* 2000, Papageorgiou *et al.* 2002, Henderson *et al.* 2004, Thomas & Cahill 2004).

The third framework, finally, concerns the integration of care through health providers working in partnership.

As advance planning for what is to be done in times of crisis, the PAD document is here seen as a tool for coordinating tasks between several health and social providers and clinicians. Thereby, it makes it possible to plug gaps in the organisation of health and social care delivery around the user (Swanson *et al.* 2000, Backlar *et al.* 2001, Swartz *et al.* 2006). At the intrapersonal level, this should improve the continuity of care for the user (Heslop *et al.* 2000). At an interpersonal level, the dissemination of information among health providers should contribute to networking between health providers (Fleury & Mercier 2002, Glasby & Dickinson 2008), and hence reduce the numbers and length of stay of hospitalisations (Papageorgiou *et al.* 2002, Atkinson *et al.* 2004, Henderson *et al.* 2004).

Stakeholders' expectations

There have been important discrepancies in stakeholders' views (those of mental health clinicians, especially psychiatrists, service users and families) in terms of their expectations as to the use and utility of PADs. Users generally asked for more equality in their relationship with health providers (Atkinson *et al.* 2004, Elbogen *et al.* 2006) and hence saw the PAD as a tool for persuading clinicians of their wishes and avoiding conflicts in treatment decisions (Amering *et al.* 2005). They usually preferred legally binding forms of PADs (Atkinson *et al.* 2003b). In users' views, the PAD has clearly been understood as a tool to support their autonomy.

As for clinicians, they endorsed conceptually the importance of a greater involvement of users in their treatment and the value of PADs as a tool to facilitate this (Atkinson *et al.* 2004, Elbogen *et al.* 2006). However, there were significant differences between professions. Psychiatrists were generally far more reluctant to perceive PADs as beneficial (Swanson *et al.* 2003, Atkinson *et al.* 2004, Papageorgiou *et al.* 2004, Elbogen *et al.* 2006, Van Dorn *et al.* 2006). They were concerned with the reduction in their own autonomy and power in decision-making; they argued, for example, that legally binding, prescriptive directives would not offer anything useful, as statements would be consistent with actual practice, while legally binding proscriptive directives would be used to refuse all treatments (Atkinson *et al.* 2004). They were also concerned with their liability and possible decisional conflicts in case of legally binding PADs (Atkinson *et al.* 2003b), with the administrative burden of the intervention (Papageorgiou *et al.* 2002), and with the competences of users to make adequate statements, fill in the PAD document, and understand the intervention process (Backlar *et al.* 2001, Van Dorn *et al.* 2008). Most of them said that those users who most need a PAD would be the least inclined to make one, whereas

relatively healthy and stable patients, competent to use it, would not really need it (Swanson *et al.* 2000). Although they doubted the capacity of the care system to correctly implement PADs (Van Dorn *et al.* 2006), some psychiatrists and other clinicians were interested in the document as a reminder of the care plan and process for the user (Swanson *et al.* 2000). This view is more oriented towards an improvement of the therapeutic alliance.

Finally, family members appeared to be in an intermediary position, supporting the idea of empowering users and involving them more in their treatment, but at the same time, concerned about the liability of clinicians when the stated preferences are not followed (Swanson *et al.* 2003). Family members were even more supportive of compulsory treatment than clinicians (de Haan *et al.* 2001) and of the irrevocability of the PAD during a crisis and supported the function of surrogate decision-making, which would give them more input in the treatment (Swanson *et al.* 2003). This view is hence oriented towards an improvement of the therapeutic alliance that includes the carer as a decision-maker.

First stage: types of PADs

The literature describes different types of PADs with a variety of names: psychiatric will, advance directives, advance statements, advance agreements, advance instructions, crisis cards, among many others (Szasz 1982, Atkinson 2007). Henderson proposes a typology of PAD documents (Henderson *et al.* 2008). The range of stakeholders involved in their completion is one key variable among types of PADs. In its origins, the PAD was meant to be produced by the user on his/her own. This first type of PAD, which we refer to as the 'classic PAD', was the most common in the United States and was considered to be a legal document. However, because its take-up rate remained very low, several features were introduced to help users complete PADs: for example, information and training sessions (Srebnik & Brodoff 2003, Amering *et al.* 2005), structured booklets to fill in (Papageorgiou *et al.* 2002, Swanson *et al.* 2006b), the use of a hypothetical scenario (Van Citters *et al.* 2007), trained facilitators (Swanson *et al.* 2006b, Elbogen *et al.* 2007a, Khazaal *et al.* 2009), and a computer-assisted directive (Sherman 1998). This second type of PAD is called a 'facilitated PAD' (f-PAD), as the user is helped to state his/her preferences, but still without the involvement of clinicians. The third type is the Joint Crisis Plan (JCP), which has been experimented with in the United Kingdom (Henderson *et al.* 2004, 2009). This type of PAD involves the user and mental health clinicians in a negotiated completion process, as well as third parties such as friends and relatives of the user or a case manager.

Of the 38 retrieved references, 17 used a 'classic PAD', 15 used an f-PAD and 4 used a JCP. Moreover, one randomised trial compared the effects of an f-PAD with those of a 'classic PAD' and concluded that f-PADs significantly increased the rate of PAD completion within 2 months of the baseline compared with the control group (Swanson *et al.* 2006b). The two randomised trials included in the Cochrane review compared a booklet to fill in (f-PAD) with usual care, and a JCP with usual care (Campbell & Kisely 2009). Letting the user produce a PAD alone (Classic PAD) or helped by facilitation without clinicians (f-PAD) is underlain by the users' autonomy framework, whereas the negotiation process of the JCP fits in more with the therapeutic alliance framework (Henderson *et al.* 2008).

Most studies point out that users actually report a feeling of self-determination and empowerment when completing a PAD; this was, however, the case with all three types: the 'classic PAD' (Backlar *et al.* 2001, Srebnik *et al.* 2003, Amering *et al.* 2005), the f-PAD (Amering *et al.* 2005, Elbogen *et al.* 2007a, Kim *et al.* 2007) and the JCP (Henderson *et al.* 2009). In other respects, most users involved in the studies with a 'classic PAD' reported a lack of information and for the need for help in completing it (Backlar *et al.* 2001, Srebnik *et al.* 2003, Swanson *et al.* 2003). The various facilitation features examined were all found to be of interest to users and feasible. Some showed higher take-up rates of PAD completion with f-PADs than with 'classic PADs' (Swanson *et al.* 2006b, Elbogen *et al.* 2007a).

There is no evidence available that one type of PAD would be more effective than another for increasing user autonomy. However, f-PADs seem to significantly increase the working alliance as compared with the 'classic' PAD (Swanson *et al.* 2006b). There is no evidence available that makes it possible to compare the effect of the different types of PADs, as against the usual care, on therapeutic alliance. The two randomised trials measuring the effects of PADs on clinical and organisational outcomes did not actually directly assess these outcomes. However, Henderson's trial showed positive results in terms of the number of involuntary inpatient admissions (Henderson *et al.* 2004). That outcome is related to the therapeutic alliance framework at the organisational level. The type of PAD in use in this trial was a JCP. As for Papageorgiou's trial, it showed no significant result with an f-PAD (Papageorgiou *et al.* 2002).

First stage: functions of PADs

Preferences for treatment can be stated in the form of advance instructions or in the form of the designation of

a proxy with surrogate decision-making capacities during the period of incompetence (Elbogen *et al.* 2006). According to Swartz *et al.* (2006), there are four basic functions of PADs: prescription (choice of options), proscriptive (rejection of options), surrogate decision-maker designation and irrevocability during a crisis. The latter, which gives advance consent to involuntary treatment, is also known as a self-binding or 'Ulysses' directive (Varekamp 2004). This function raises specific legal and ethical issues that will not be discussed here.

Prescription is one basic function of PADs and is supported within all the theoretical frameworks. However, proscriptive, which was the main purpose of Szasz's psychiatric will, is still one major contentious issue in the literature. In a study comparing several models of PADs, Atkinson showed that the option of refusing treatment is mainly supported by users and members of users' advocacy organisations, especially when the PAD is legally binding; psychiatrists are less keen on that option (Atkinson *et al.* 2004). Several other studies focused specifically on clinicians' opinions regarding proscriptive PADs. They reported that a majority of clinicians would not endorse PADs containing refusals of treatment; social workers were more supportive, and psychiatrists less supportive (Elbogen *et al.* 2006, Van Dorn *et al.* 2006, Swanson *et al.* 2007, Kim *et al.* 2008). Hence, the function of proscriptive is mainly underlain by the users' autonomy framework.

However, clinicians were less likely to override treatment refusals when they are not legally binding, when they had more professional experience, when they were more aware of the legislation on PADs, or when a surrogate decision-maker was appointed. Psychiatrists were also more likely to follow opting-out instructions when these were endorsed by the family (Elbogen *et al.* 2006) or when mental health professionals were involved in producing the instructions, which is the case with some f-PADs and with JCPs (Srebnik *et al.* 2005).

Most clinicians underpin their reluctance to follow proscriptive PADs by pointing to the fear that they could be used to refuse all treatments. Such concerns are not confirmed by available evidence: users are generally interested in helping clinicians to make decisions; they give treatment indications to that end and are willing to argue their treatment refusals (Amering *et al.* 1999, 2005, Elbogen *et al.* 2007b). Moreover, these are generally consistent with clinical practice (Swartz *et al.* 2006, Van Dorn *et al.* 2006). A second concern of clinicians about proscriptive PADs is that users could not be sufficiently aware of the possible consequences of their refusals. Once again, this situation is less likely to happen when a facilitator or a clinician is involved in drawing up the PAD document (Atkinson *et al.* 2004, Van Citters *et al.* 2007). All these results indicate that the proscriptive

PAD is more likely to be taken into account within an improved therapeutic alliance framework.

The function of surrogate decision-making in times of incompetence also raises controversial issues. Although the option of a proxy designation is not available in the United Kingdom (Atkinson 2007), the appointment of a person with 'Durable Powers of Attorney' is the most used function of PADs in the USA and receives the highest rates of endorsement by clinicians (Elbogen *et al.* 2006, Swanson *et al.* 2006b, Kim *et al.* 2008). Having a surrogate decision-maker is a key predictor of having an instructional PAD accessed and of consistency of care (Srebnik & Russo 2008), but at the same time decreases the likelihood of having the instructions followed (Srebnik & Russo 2007). These results indicate that the surrogate decision-maker function is supported within the framework of the therapeutic alliance or the framework of the organisation of care.

Users are also very interested in designating a proxy (Amering *et al.* 2005, Swanson *et al.* 2006b, Swartz *et al.* 2006), particularly with a view to enforcing proscriptive preferences (Backlar *et al.* 2001, Kim *et al.* 2007). In such cases, the surrogate designation function is perceived from the point of view of user autonomy. However, some users report that they would like to appoint a surrogate decision-maker and cannot find one, as legislation in some US states forbids appointing their own physician (Backlar *et al.* 2001). This observation indicates that, even in users' views, the designation of a surrogate decision-maker could also be considered within the therapeutic alliance framework.

Nonetheless, many clinicians expressed concerns about possible conflicts between the user and his/her proxy, especially with legally binding forms of PADs. First, this legal power could affect the relationship between the user and the family (Atkinson *et al.* 2004). Indeed, it appears that proxies are more likely to use a 'best interest' standard rather than a 'substitute judgement' standard of decision, that is, to decide according to the proxy's perception of the user's interest rather than according to the proxy's interpretation of the user's likely preference (Srebnik & La Fond 1999). Second, there could be legal conflicts between the proxy's decisions and the user's statements. This could lead to litigation against the health providers (Srebnik & Brodoff 2003). These arguments weaken the case for the possible benefits of the function of surrogate decision-maker designation within the therapeutic alliance framework.

Second stage: PAD completion and content

There is a great variety of forms and information contained in the PAD documents that were used in the studies reviewed. Some of these studies focused specifically

on investigating the type and form of the information that should be included in a PAD document. In some US states, the content of the PAD document is determined by the law (Backlar *et al.* 2001, Swanson *et al.* 2006a). The basic information in all PAD documents covers the user's preferences in relation to medication and hospitals, information on crisis and relapse symptoms, persons to be notified (generally the user's usual clinicians and his/her relatives or friends), and when the option applies, the designated surrogate decision-maker. The following additional clinical information can be included: protective factors and de-escalating methods, instructions for inpatient staff, supplementary information on allergies and the side effects of medication, specific choices regarding Electro Convulsive Therapy (Swanson *et al.* 2006b, Elbogen *et al.* 2007b), and recent medical history (Papageorgiou *et al.* 2004). There seems to be a consensus on the value of this type of information across the three main groups of stakeholders (de Haan *et al.* 2001, Atkinson *et al.* 2004).

In addition, some studies show that users are also interested in adding non-treatment directives to the PAD: care for dependents, persons prohibited from visiting, assistive devices, instructions regarding finances, pet care, dietary preferences or other people to contact (Sherman 1998, Srebnik & Russo 2007). In Henderson's trial, up to 20 percent of the completed JCPs contained such non-treatment directives. The value of non-treatment directives is described as particularly relevant to the enhancement of user autonomy.

All this information is relevant within the three theoretical frameworks underlying the PAD intervention. However, the form in which the information is presented within the document is related to its use and hence points to the theoretical framework that underlies it. In Papageorgiou's trial, the f-PAD document contained contact details of the user and of his/her usual clinicians: a general practitioner, a community psychiatric nurse, a keyworker, a psychiatrist and a social worker. It also contained seven sentences to be completed by the user, in the form of: 'I notice I am becoming ill again when I...', 'If I do seem to be becoming ill again I would like...'. The sentences covered: (i) early signs of crisis, (ii) wishes for preventing the crisis, (iii) recent events, (iv) refusals, (v) persons to be contacted, (vi) instructions for hospital admission and (vii) instructions for inpatient staff (Papageorgiou *et al.* 2002). Although the information may be relevant irrespective of the theoretical framework, the two-first pieces of information are relevant to the prevention of a crisis to avoid inpatient admission, while the remainder are relevant to the management of the crisis when it has occurred and the user is admitted to hospital. Consequently, the information on crisis prevention is more concerned with the improvement of the therapeutic

alliance, while the information on crisis management is more oriented towards the organisation of care among clinicians.

In Henderson's trial, the JCP contained the information chosen by the user under four suggested headings: contact details, current care and treatment plan, care in a crisis and practical help in a crisis. The most frequent options actually chosen by users were: (i) contact details of the user, the consultant, the general practitioner, the psychiatric nurse and the nominee (trusted person nominated by the user); (ii) mental health problem or diagnosis; (iii) current medication and dosage; (iv) early signs of crisis; and (v) instructions to follow at the beginning of a crisis (Sutherby *et al.* 1999, Henderson *et al.* 2004). The JCP is thus more clearly designed for the crisis management, and is underlain by the framework of the organisation of care among clinicians.

Third stage: PAD access and honouring

Very little is known about the PAD access and honouring stage, as only two references, both in relation to the same study, focus on this stage (Srebnik & Russo 2007, 2008). In the study, 106 users in Washington State completed a computer-assisted PAD. This f-PAD was disseminated among stakeholders via multiple strategies: it was mailed to persons chosen by the user, copies were given to the designated surrogate decision-makers and placed in the user's medical records; a flag was added to the user's electronic registry, psychiatric crisis units in the county also received a copy of it, and it was stored at a 24-hour crisis clinic. Users were provided with a crisis card to carry with them and also with a bracelet. All these features were set up during an experimental period in which clinicians were informed and trained in the use of PADs. Over the following 2 years, 69 users had a total of 450 crisis events. In spite of the numerous strategies described above, the PAD document was accessed in just 90 events. Access to the document does not indicate that it was actually used or honoured (Srebnik & Russo 2008). In the second reference, results indicated that the average rate of consistency of care with the directives contents was 67% during the 90 crisis events. However, as this study was retrospective, there is no indication whether care was consistent because the PAD was honoured or simply as the result of the usual care being given (Srebnik & Russo 2007).

The PAD access and honouring stage has not been specifically investigated elsewhere. No information has been collected on the actual access or use of the completed PADs in the two randomised trials identified. However, for each of the trials, results were published with feedback from the participants (Papageorgiou *et al.* 2004, Henderson *et al.* 2009). Two thirds of the JCP

holders in Henderson's trial made no further use of it. Six of 13 audits following hospital admissions showed that at least some stated preferences were not followed (Henderson *et al.* 2009). And most of the users involved in Papageorgiou's trial had forgotten to use their f-PAD, while clinicians reported that they did not find it useful, did not refer to it and did not take it into account in subsequent care (Papageorgiou *et al.* 2004).

Several studies mention service users' worries about a 'backfire effect', i.e. their fear that PADs would be ignored, as being a barrier to their use (Backlar *et al.* 2001, Atkinson *et al.* 2004); clinicians also mention the lack of health providers' partnerships as an organisational barrier to their implementation (Van Dorn *et al.* 2008).

As a result, there is no sufficient evidence available to assess the different theoretical frameworks underlying PAD intervention at the access and honouring stage. However, the endorsement of the PAD by clinicians and organisational steps to honour the directives in times of crisis appear to be decisive in terms of the actual use made of it.

Discussion

We considered the PAD as a complex and multistage intervention, and not just as a single document: this included the definition of the document, its completion, and the accessing and the honouring of its contents. By carrying out a systematic realist literature review, we identified the frameworks underlying the PAD and the stakeholders' views, and reviewed the evidence that confirmed or contradicted expectations.

Three frameworks have been identified that underlie the PAD: the enhancement of the user's autonomy, the improvement of the therapeutic alliance, and the integration of care through health providers working in partnership. Although these expectations are mentioned throughout the scientific literature, none of these outcomes has been assessed within the available randomised trials. Instead, these trials have focused on outcomes at the organisational level and have not considered the intrapersonal and interpersonal levels of action of the intervention. Moreover, trials have not taken into account how the PAD was actually used, once completed.

Our main finding is that although the PAD was designed in the first place to enhance the user's autonomy, the many results collected strongly suggest that it produces its best results as a tool for improving the therapeutic alliance. First, as the authors of the Cochrane systematic review stated, the best measured outcomes have been obtained with JCPs, where the document definition and content are negotiated among the user, clinicians, and third parties. Similarly, many studies show that

f-PADs, where facilitation features are designed to assist users in completing the PAD, are feasible, respond to user's interest and needs, increase the rates of uptake and improve the working alliance.

Secondly, even if the PAD was designed in the first place to enhance user's autonomy, its endorsement by clinicians is decisive for its effectiveness. Studies indicate that the endorsement of the PAD is higher when mental health professionals are involved in producing the document, and that they are less likely to override the directives in such cases, especially in relation to treatment refusals. Indeed, clinicians are concerned with the possible consequences of refusals and this concern is lessened when other clinicians have been involved in completing the PAD document.

Thirdly, another decisive element in supporting the use of the PAD is the designation of a surrogate decision-maker. While this designation may produce conflicts in relationships and thus contradict the theoretical expectation of a therapeutic alliance improvement, it still indicates that the PAD is being used to facilitate relationships. Moreover, many users opted to designate their own physician as surrogate decision-maker, although that option is not allowed in many US States. All these elements indicate a PAD that aims to improve the therapeutic alliance.

The mixture of expectations makes the purpose of PADs unclear and may explain the low take-up rate. This has been mentioned as an operational barrier to their use (Van Dorn *et al.* 2008). The shape of the intervention at each stage relies on the clarification of these expectations. In terms of the definition of the PAD document, while evidence indicates that those types of PAD conceived in terms of therapeutic alliance are more feasible than the 'classic PAD', concerns have been raised about proscriptive PADs, as users may refuse treatments and the consequences of such refusal, as well as about possible conflicts arising from surrogate decision-making. However, these concerns can be addressed when a PAD is completed in consultation with health professionals within a therapeutic alliance framework. In terms of the completion of the PAD, a consensus may be reached among groups of stakeholders as to the information to include. However, the indiscriminate accumulation of information that could possibly be relevant for the three different frameworks can make the PAD document unusable, e.g. for preventing a crisis relapse, for managing the crisis in outpatient or inpatient settings, for planning in advance the organisation of care among clinicians during an emergency or for avoiding the resort to coercion. Finally, in terms of the access to the document and the honouring of its contents, very little has been investigated. The few available results are quite disappointing. More research is needed to determine

how these later stages of the intervention could be implemented. For example, the actual role of a carer as a surrogate decision-maker at the honouring stage remains unclear. This may also depend on the adjudication between frameworks.

The realist systematic review is designed to examine what works, for whom, and how in a complex intervention, to test the integrity of the underlying theories, and finally to adjudicate between them (Pawson *et al.* 2005). However, our review indicates that there is no sufficient evidence available to allow us to understand the whole intervention, and therefore, that the evidence on how PADs should be implemented is still incomplete, as suggested elsewhere (Henderson *et al.* 2010). Further comparative studies will have to address the contextual issues of the intervention, for example, the care setting, or the whole care and legal system, in more detail. The shift from the framework of the user's autonomy to the framework of the therapeutic alliance might in fact be correlated with national characteristics of the mental health systems. Indeed, one limitation of our review is that the legal contexts underlying the whole intervention were not examined. Moreover, as a narrative method relating to a complex intervention, another major limitation is the lack of access to more informal and contextualised information about practical and relational elements of the intervention that are not reported in the formal scientific literature.

Therefore, we suggest that more research is needed among stakeholders to determine their theoretical expectations and preferences as to the implementation of a multistage intervention process. A stakeholders' analysis (Brugha & Varvasovszky 2000, Varvasovszky & Brugha 2000) would help examine the choices and possible differences between groups of stakeholders and determine a consensual scenario of PAD intervention. This type of analysis has already been carried out to determine models of PAD documents (Atkinson *et al.* 2004), and should be extended to the whole intervention process, for example, the moment when and the care setting within which it should be proposed to the user, the process for its completion, and above all, the ways in which PAD documents are registered and disseminated, the conditions of access to their contents and steps to be taken to honour them. The feasibility of such a complete multistage scenario should then be tested by its actual implementation, and only at that point should a randomised trial be considered.

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