

Advance statements in adult mental healthcare: an update

ARTICLE

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SUMMARY

In this article we re-examine the conclusions of our article on advance statements in adult mental healthcare that was published in 2010 in the light of new literature published in the intervening decade. We explore the results of studies on the implementation and effectiveness of advance statements in adult mental health services, and then summarise recommendations for legislative changes from the Independent Review of the Mental Health Act 1983 that are relevant for England and Wales.

LEARNING OBJECTIVES

After reading this article you will be able to:

- appreciate recent evidence regarding implementation, content and effectiveness of advance statements in adult mental health services
- demonstrate basic understanding of current legislation on advance statements in adult mental health in England and Wales
- apply the recommendations of the Independent Review of the Mental Health Act 1983 (England and Wales) on patient's choice and autonomy in making decisions about care and treatment.

DECLARATION OF INTEREST

None.

KEYWORDS

Advance statements in mental health; advance directives in mental health; advance choice in mental health.

In this article we use the term advance statement as a general description of wishes for future mental health treatment. This term encompasses:

- joint crisis plans, which are facilitated by mental health professionals external to the treatment team and engage both patients and member/s of their mental health team (Henderson 2015)
- psychiatric advance directives, which provide information on preferences (and refusals) to guide future healthcare decisions (which can be facilitated by, but do not necessarily involve, mental health professionals)
- legally binding advance decisions to refuse treatment and lasting powers of attorney for health and welfare (as defined in the Mental Capacity Act 2005)
- other forms of advance statement, such as crisis cards as an advocacy tool (Sutherby 1998) and the Wellness Recovery Action Plan (WRAP) as a self-monitoring system for early identification and treatment (Copeland Center for Wellness and Recovery 2018).

A helpful comparative typology of advance statements has been described in Henderson *et al* (2008).

Our 2010 article (Jankovic 2010), which gave a full discussion of the terminology, content, advantages and disadvantages of advance statements in adult mental healthcare, concluded that introducing formal structured discussions about wishes for future treatment through advance statements may help to actively involve patients in treatment planning and consequently raise standards of routine care. We also concluded that there was a need for mental health services to implement these discussions in routine practice in an appropriate manner and hoped that experience and future research would help to ascertain the general usefulness of advance statements, as well as identify which patients and in which therapeutic contexts advance statements would be particularly beneficial.

To reflect on whether these conclusions are still valid we have reviewed the literature on advance statements in mental healthcare over the past decade.

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The term 'advance statement' is used to describe an individual's wishes and decisions about future medical treatment that can be referred to when their mental capacity for making these decisions is impaired. Given that severe mental illness is often characterised by fluctuating mental capacity, the process of creating an advance statement can enable a person to reflect on past personal experiences during a period of incapacity and consider these experiences when planning their future care (Jankovic 2010).

Content, implementation and effectiveness of advance statements in adult mental health services

Content

The most common wishes recorded in advance statements refer to medication preferences and refusals of some medication. Refusal of all psychotropic medication is rarely recorded (Srebnik 2005), for example only 1 patient with psychotic disorder out of 221 stated in their joint crisis plan that they would prefer not to take any medication (Farrelly 2014a) and in 2 out of 55 advance statements presented to the Mental Health Tribunal for Scotland all medications were refused (Reilly 2010).

More recent research on the prevalence of treatment refusals includes a study on crisis treatment preferences of people with personality disorder (Borschmann 2014) that identified a theme regarding treatment refusals involving particular types of psychotropic medication and involuntary treatment, and a study on joint crisis planning that showed a significant increase in the number of treatment refusals – from 2.4% in baseline routine care plans to 45% following joint crisis planning (Henderson 2017). This raises an important question as to whether mental health professionals should routinely ask patients whether there are any treatments they wish to refuse.

Other aspects of healthcare planning are very important and these include methods of de-escalating a crisis (most often privacy or being offered time out), the appointment of a surrogate decision maker, wishes about whom to notify (and whom not to) about admission, assistive devices (e.g. corrective lenses, dentures), dietary preferences, and organising care of dependants and pets while in hospital (Srebnik 2005). It is particularly important to look at non-medication preferences, which can be easily overlooked in a crisis, as many aspects of advance statements can be respected even if a patient is detained and receiving treatment against their will, thus preserving some aspects of their autonomy (Jankovic 2010).

In terms of the content of advance statements, the summary (Box 1) from our 2010 article has been included here. In addition, a recent study on joint crisis plans (Farrelly 2014a) used thematic analysis to identify two major categories of preferences: (a) the manner in which crisis care would be delivered and (b) treatment-specific interventions. Most participants requested full involvement in decisions about their care, clear and consistent treatment plans, access to familiar clinicians who knew them well, and to be treated with respect and compassion. Some requested hospital admission, but the majority preferred alternatives. The most frequently

BOX 1 Wishes commonly recorded in advance statements

- Medical treatment instructions
- Medication preferences
- Medication refusals (and reasons why)
- Preference/refusal of ECT
- Preferred method of de-escalating crisis
- Preference of hospitals/hospital alternatives
- Information on side-effects and allergies
- Description of crisis symptoms and response to hospital admission
- Appointment of a surrogate decision maker
- Personal care instructions
- Individuals to be notified of hospital admission
- People not authorised to visit during hospitalisation
- Assisted devices (e.g. corrective lenses or dentures)
- Persons to notify about care of finances, dependants or pets
- Dietary preferences

preferred intervention was care by a home treatment team. Just under half refused a particular treatment, and the majority of refusals concerned specific medications where alternatives were offered.

Implementation

The implementation of advance statements in routine mental healthcare – both their completion by patients and access and honouring by staff – continues to encounter difficulties.

Patients' completion of advance statements without active help was low a decade ago, and this continues to be the case. A US study from 2006 indicated that the rate of completion of psychiatric advance directives in a control group that did not receive active facilitation was only 3% (Swanson 2006). In a more recent multi-site study in England, a review of routine crisis planning at baseline before any intervention showed that only 15% of participants had a crisis plan containing any information specific to that individual (Farrelly 2014b). One study (Henderson 2010) that looked at psychiatric advance directives within the US Veterans Health Administration showed preferences for non-medical settings for completion and assistance with completion independent of the treatment team.

Several studies have shown that, with intense facilitation, completion rates can be improved both for psychiatric advance directives – to 50% (Easter 2017) and 61% (Swanson 2006) – and for crisis plans – to 64% (Ruchlewska 2016). The form of facilitation varied and included external facilitation

of joint crisis planning with clinicians (Thornicroft 2013), using a manualised intervention combining motivational interviewing with advance directives (Kisely 2017), and patient-advocate and clinician facilitated crisis planning (Ruchlewska 2014). However, a large number of eligible patients did not take part in these studies – 60% in Ruchlewska *et al* (2014) and 64% in Henderson *et al* (2004). Some refused to participate whereas others were not contactable. Such a high percentage of non-participation raises the question of generalisability of these results to routine care.

Despite evidence that facilitation increases completion rates, a question remains as to how this can be maintained in routine practice without extra financial investment. Furthermore, significant problems remain with accessing and adhering to advance statements at times of crisis. Although much is known about the completion process and the content of advance statements, very little is known about accessing and honouring them (Nicaise 2013). A recent study in The Netherlands revealed that individual crisis plans were consulted for only 34% of patients in crisis and where this involved an involuntary admission, an even smaller proportion was accessed (Ruchlewska 2016). Similarly, in a recent multisite randomised controlled trial (RCT) in England, many patients complained that the agreements made in their joint crisis plan were not honoured in practice; only 5 of 28 care coordinators questioned reported referring to or using joint crisis plans during the follow-up period (Thornicroft 2013). It is unclear how much of the problem is related to organisational difficulties such as out-of-area in-patient admissions and functional models of care (a model where care in the community is provided by a different team than care in in-patient settings or in crisis) or how much is related to a culture in mental health services of not considering advance choices an essential part of crisis care. Qualitative exploration of joint crisis plans shows that, although clinicians endorsed shared decision-making approaches and believed that they were enacting them in routine care, reports from patients contradicted this view (Farrelly 2015).

Effectiveness

Looking at the effectiveness of advance planning, results of three trials have been published in the past decade. In the Dutch system, where there are emergency involuntary admissions and court-ordered involuntary admissions and where, for court-ordered involuntary admissions, dangerousness criteria mostly include self-neglect or social breakdown, Ruchlewska *et al* (2014) showed that crisis planning may be an effective intervention for

reducing planned court-ordered admissions of people with psychotic and bipolar disorders but not emergency admissions. Thornicroft *et al* (2013) published results of a large multi-centre RCT in England, CRIMSON, that failed to demonstrate that joint crisis planning is significantly more effective than treatment as usual in reducing compulsory admissions for people with psychosis. However, there was evidence that crisis plans had not been fully implemented at all study sites. The same study identified an improvement in the therapeutic relationship of the intervention group. Borschmann *et al* (2013) showed that joint crisis planning had high face validity in a sample of people with borderline personality disorder in London (UK), but there was no evidence of clinical efficacy in this feasibility study (the primary outcome was self-harming behaviour).

Although single studies have yielded inconsistent results, a meta-analysis (de Jong 2016) of studies that examined effects of advance statements on compulsory admissions of adult psychiatric patients showed a statistically significant reduction (23%) in such admissions. The authors concluded that this is a clinically relevant figure because of the effect that compulsory admissions have on psychiatric patients and the human rights issues involved. Results highlight the fact that, by advocating patients' desires and preferences regarding a future crisis and by involving family and friends, advance treatment planning is an important and helpful process.

There is evidence pointing towards the importance of these interventions for specific groups of patients. A US study by Elbogen *et al* (2007) showed that an increased sense of autonomy at 1 year following completion of psychiatric advance directives was predicted by ethnicity. The paper concluded that psychiatric advance directives hold promise in helping empower African American people with mental illness. Furthermore, economic evaluation of the CRIMSON trial showed a 90% probability of joint crisis plan intervention being more cost-effective than treatment as usual in the Black ethnic group (Barrett 2013). This outcome is potentially of great importance given that the rate of detention in England for the 'Black or Black British' group has been found to be over four times that for the 'White' group (Community and Mental Health Team, NHS Digital 2017). Thus, any interventions that may reduce compulsory intervention in this group deserve particular attention and consideration for clinical practice.

Legislation regarding advance statements

Recent changes in mental health legislation in different parts of the world have sparked an interest in

advance statements, and a number of articles have been published describing implementation challenges and early results from evaluations of adopting advance directives into routine care. In India, psychiatric advance directives have been incorporated into the Mental Health Care Act 2017 (Ratnam 2015) and a number of studies explored different aspects of this process (Sarin 2012; Kumar 2013; Shields 2013; Pathare 2015; Inamdar 2016; Gowda 2018; Tekkalaki 2018). In Australia, psychiatric advance directives have now been incorporated into four jurisdictions (Ouliaris 2017), and the Commonwealth of Virginia, USA, has undertaken efforts to incorporate the completion of psychiatric advance directives into routine mental health services for individuals with severe mental illness (Wilder 2013; Kemp 2015, Zelle 2015).

The law in England and Wales and the Independent Review of the Mental Health Act

In England and Wales, the Code of Practice for the Mental Capacity Act 2005 (Department for Constitutional Affairs 2007) defines an advance decision to refuse medical treatment as legally binding if it is made at a time when a person has mental capacity to make such a decision and the decision is applicable to the given situation. For refusal of life-sustaining treatment, an advance decision has to be in writing, signed and witnessed, and a clear statement must be included stating that it is applicable even if life is at risk. The Code of Practice states that 'People can only make advance decisions to *refuse* treatment. Nobody has the legal right to demand specific treatment, either at the time or in advance' (Department for Constitutional Affairs 2007: para. 9.5). Therefore, unlike treatment refusals, advance statements regarding treatment preferences are not legally binding. Nevertheless, they should be taken into consideration when deciding on the treatment options that are in the best interests of the patient if that patient lacks capacity.

Regarding involuntary treatment, the Mental Capacity Act Code of Practice states that, under the Mental Health Act 1983, healthcare staff can treat patients for their mental disorder, even if they have made an advance decision to refuse such treatment. An exception to this is electroconvulsive therapy (ECT). A person who has made a valid and applicable advance decision under the Mental Capacity Act to refuse ECT, or for whom a decision has been taken by their health and welfare attorney to refuse ECT, cannot be given that treatment. However, a significant clarification has been made on this point in the most recent edition of Code of Practice for the Mental Health Act, which states that an advance decision to refuse ECT can be

overridden under the Mental Health Act in an emergency where it is necessary to save life or prevent serious deterioration: 'A person who has made a valid and applicable advance decision under the [Mental Capacity Act 2005], or for whom a decision has been taken by their attorney, to refuse ECT, cannot be given that treatment under section 58A of the Act although treatment can be given in specific emergency situations under section 62(1A)' (Department of Health 2015: para. 13.3). This issue of overriding valid and applicable refusal of ECT has been raised as contentious and discussed during the recent Independent Review of the Mental Health Act (Mental Health Act Independent Review Team 2018).

Significant changes are likely to happen in the near future, as the report from the Mental Health Act Independent Review Team makes very important recommendations for the enhancement of the statutory framework for advance care planning in mental health services. The report states that 'The concepts in the Mental Capacity Act of advance decision-making and welfare powers of attorney should also apply in the context of the Mental Health Act' (Mental Health Act Independent Review Team 2018: p. 21).

It also makes a number of recommendations (under Principle 1) about choice and autonomy in making decisions about care and treatment (Box 2). It recommends that statutory 'advance choice documents' (ACDs) should be created in which patients are encouraged to voice their views about any future in-patient care and treatment. It is hoped that, where a person is recorded as having capacity at the time the choice is made, the presumption will be that the choice will be honoured unless there are compelling reasons not to honour it. Linked to this is the recommendation that it should be harder for treatment refusals to be overridden (for example that an advance refusal of ECT can be overridden by a judge or Court of Protection on strict criteria involving immediate risk to life). Other recommendations emphasise the importance of respecting patient choice and the right of patients to request a review by a second opinion appointed doctors (SOAD).

In addition, recommendations are made in the advocacy section of Principle 1 that the statutory right to an independent mental health advocate (IMHA) should be extended to include all mental health in-patients, including informal patients and people preparing their advance choice documents that refer to detention under the Mental Health Act (Mental Health Act Independent Review Team 2018: p. 23).

In an initial response to the review report by the government (under the then Prime Minister

BOX 2 Recommendations from the Independent Review of the Mental Health Act 1983 (MHA) for England and Wales

Principle 1 – Choice and autonomy

Making decisions about care and treatment

- Shared decision-making between clinicians and patients should be used to develop care and treatment plans and all treatment decisions as far as is practicable.
- It should be harder for treatment refusals to be overridden, and any overrides should be recorded, justified and subject to scrutiny.
- Statutory advance choice documents (ACDs) should be created that enable people to make a range of choices and statements about their in-patient care and treatment. These should be piloted to identify the detail needed to inform/influence practice.
- Decisions about medication should, wherever possible, be in line with the patient's choice and patients should have a right to challenge treatments that do not reflect that choice.
- Patients should be able to request a review by a second opinion appointed doctor (SOAD) from once their care and

treatment plan has been finalised or 14 days after their admission, whichever is the sooner; and another review following any significant changes to treatment.

- Patients should be able to appeal treatment decisions at a mental health tribunal following a SOAD review.
- The government and the Care Quality Commission should consider ways to resource the likely increase in SOAD reviews, looking at how the model of SOADs can evolve.
- The government should consult on:
 - whether the MHA should provide that a person can consent in advance to confinement for medical treatment for mental disorder, or to empower an attorney or court-appointed deputy to give consent on their behalf; and
 - what safeguards would be required.
- Mental healthcare providers should be required to demonstrate that they are co-producing mental health services, including those used by patients under the MHA.

(After Mental Health Act Independent Review Team 2018: pp. 297–298)

Theresa May) committed to introducing a new Mental Health Bill and accepted recommendations (a) that those detained under the Mental Health Act will be allowed to nominate a person of their choice to be involved in decisions about their care and (b) to introduce statutory advance choice documents so that people will also be able to express their preferences for care and treatment (Department of Health and Social Care 2018).

Discussion

It remains to be seen which recommendations for change made in the Independent Review of the Mental Health Act (Mental Health Act Independent Review Team 2018) will be enshrined in mental health law, but given the evidence summarised in the first part of this article about limited use of individualised advance care planning in routine mental healthcare, as well as divergent views between clinicians and patients as to whether shared decision-making is happening in routine practice, recommended changes to the statutory framework appear needed.

The hope is that, with time, changes to legislation will improve completion, access and honouring of advance choices, and that this process will be regularly reviewed by mental health tribunals. How effective these recommendations will be in practice will need to be assessed, as even though legislative changes are likely to be helpful, it is recognised that these are not enough to achieve a patient-

centred care (Mental Health Act Independent Review Team 2018). It has been emphasised in research settings that, for complex interventions such as joint crisis planning, an extended formative stage is needed in order to discuss the attitudes of clinicians to adoption in routine clinical care (Thornicroft 2013). Similarly, for recommended changes in law to be truly integrated into mental health services, facilitation of a change in culture and organisational readiness is important and should be addressed in the implementation phase of the recommendations of the Independent Review of the Mental Health Act (Department of Health and Social Care 2018).

Conclusions

The past decade has seen a number of initiatives for changing practice and some advances in research in the field of advance statements. Nevertheless, the overall conclusion is similar to that in our 2010 article: introducing formal structured discussions about wishes for future treatment through advance statements may help to actively involve patients in treatment planning and consequently raise standards of routine care (Jankovic 2010). Importantly, this is likely to be enshrined in mental health legislation in England and Wales. The hope is that such legislation will facilitate implementation of advance statements, which so far has not happened on a large scale. Advance statements may be particularly beneficial for patients from ethnic minorities and contribute to

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rectifying inequalities in the provision and outcomes of mental healthcare across ethnic groups.

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MQs

Select the single best option for each question stem

1 Advance statements:

- a are used to describe an individual's wishes and decisions about their future medical treatment that can be referred to when their mental capacity for taking these decisions is impaired
- b are irrevocable, and once drawn up, cannot be altered even when a person has mental capacity
- c always prevent involuntary admission
- d must be completed together with the member of the care team
- e all of the above.

2 As regards advance refusals:

- a a person who has made a valid and applicable advance decision, or for whom a decision has been taken by their attorney, to refuse ECT can be given ECT in specific emergency situations under section 62(1A) of the Mental Health Act
- b they are the only important aspect of advance statements, because treatment preferences are not legally binding and therefore not important in treatment planning

- c psychotropic medication can be given against a person's valid and applicable advance decision to refuse it regardless of whether the patient is detained under the Mental Health Act or not
- d advance decision to refuse treatment can be revised by the patient at times of incapacity
- e all of above.

3 As regards research into the effectiveness of advance statements:

- a a multicentre RCT comparing joint crisis planning and treatment as usual in people with psychosis found no effect on improvement in the therapeutic relationship of the intervention group (Thornicroft 2013)
- b joint crisis planning did not have high face validity in a sample of patients with borderline personality disorder (Borschman 2013)
- c single studies have yielded inconsistent results, but a meta-analysis (de Jong 2016) of studies that examined effects of advance statements on compulsory admissions of adult psychiatric patients showed a statistically significant reduction in compulsory admissions
- d none of the above
- e all of the above.

4 Content of advance statement can include:

- a medication preferences
- b medication refusals (and reasons why)
- c personal care instructions, for example people not authorised to visit while the person is in hospital
- d dietary preferences
- e all of the above.

5 In 2018, the Independent Review of the Mental Health Act 1983 recommended:

- a that shared decision-making between clinicians and patients should be used to develop care and treatment plans and all treatment decisions as far as is practicable
- b that it should be harder for treatment refusals to be overridden, and any overrides should be recorded, justified and subject to scrutiny
- c that decisions about medication should, wherever possible, be in line with the patient's choice and patients should have a right to challenge treatments that do not reflect that choice
- d that patients should be able to request a SOAD review from once their care and treatment plan has been finalised or 14 days after their admission, whichever is the sooner; and again, following any significant changes to treatment
- e all of the above.