Issues in the development of advance directives in mental health care

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Abstract

Background: Interest in advance directives in mental health care is growing internationally. There is no clear universal agreement as to what such an advance directive is or how it should function.

Aim: To describe the range of issues embodied in the development of advance directives in mental health care.

Method: The literature on advance directives is examined to highlight the pros and cons of different versions of advance directive.

Results: Themes emerged around issues of terminology, competency and consent, the legal status of advance directives independent or collaborative directives and their content. Opinions vary between a unilateral legally enforceable instrument to a care plan agreed between patient and clinician.

Conclusion: There is immediate appeal in a liberal democracy that values individual freedom and autonomy in giving weight to advance directives in mental health care. They do not, however, solve all the problems of enforced treatment and early access to treatment. They also raise new issues and highlight persistent problems.

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Introduction

Interest in advance directives in mental health in Britain has been stimulated by the planned reform of mental health legislation in both England & Wales (Department of Health, 1999a; Department of Health & Home Office, 2000) and Scotland (Scottish Executive, 2001a & b). Versions of advance directives have

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appeared in Bills before Parliament in both countries (Department of Health, 2002; Scottish Parliament, 2002). Previously the main interest in the UK was through some of the voluntary organizations which either proposed them (e.g. Manic Depression Fellowship), or recognized that their members were interested in them (e.g. National Schizophrenia Fellowship, National Schizophrenia Fellowship (Scotland), MIND). The National Institute for Clinical Excellence (NICE) has recommended the use of advance directives in relation to the use of atypical anti-psychotic drugs (NICE, 2002). The Health Technology Board for Scotland advises the use of advance statements in its advice on the same group of drugs (Health Technology Board for Scotland, 2002).

The United States has the longest history of their use and an evolved legal framework for managing them. Since, however, mental health legislation in relation to involuntary detention is a state responsibility, each state has its own, often different legislation. The US Patient Self-Determination Act of 1990 put a duty on all federally funded health care institutions to notify patients of their right to make advance directives for health care decisions or to appoint health care attorneys and to assist them in deciding whether to make such a directive (Pellegrino, 1992; Kapp, 1994).

The international literature on advance planning in mental health care makes frequent references to 'advance directives' in many guises to solve a variety of problems in patient management, including the suggestion that advance directives could be used to allow a person to participate in research even when they are incapable of consenting at the time (American Psychiatric Association, 1995; Backlar, 1998). Rarely, however, are the details of what is envisaged spelt out.

Advance directives are generally proposed as a way of increasing patient autonomy, one of the four basic principles traditionally viewed as underpinning medical ethics (e.g. Beauchamp & Childress, 1983; Downie & Calman, 1987). Indeed it has been argued that autonomy has become the most important principle in bioethics in America (Wolfe, 1998). O'Neill (2002), however, has argued that as traditionally constructed in medical ethics, autonomy amounts to little more than 'informed consent'. Furthermore, she suggests there are 'systematic limitations' to informed consent as it is 'always given to one or another description of a proposal for treatment.' (p. 43). If advance directives are seen as an expression of individual choice, no matter how circumscribed that choice may be, there is no problem in locating them in the traditional view of individual autonomy in medical ethics. The limitations of contemporary choice are merely echoed in planning for the future. Likewise, her preferred concept of 'principled autonomy' which requires principles that 'can be adapted by any, hence by all, ordinary agents' (p. 88) can accommodate advance directives since there is no reason why they could not be adapted by all. This might be deemed to be the position of the United States in respect of its 1990 Act.

This paper seeks to discuss the main areas for consideration in the formal involvement of advance directives in mental health services. It will do this by first reporting the varieties of advance directives and their terminology currently described in the literature, and then looking at the main issues arising from this, namely their legal status and the breadth of their remit. Although passing

reference will be made to potential impact on resources, this is not a major focus of the paper and has been discussed elsewhere (Halpern & Szmukler, 1997; Chan & Conacher, 1994; Brown, 1995).

Concepts and terminology

All forms of advance directive have the aim of specifying a person's wishes when they are 'well' (capable) for what they want to happen when they are 'ill' (incapable) and unable to make decisions. A variety of terms are used in the literature, including 'advance refusal', 'Ulysses contract', 'advance agreement', 'advance statement' and the less common 'psychiatric will' and 'Mill's will'. These are not always clearly defined and there is no guarantee that the same term has a consistent meaning. Although all terms refer to planning the future management of an illness episode they reflect different types of relationship between service users and service providers. This may reflect different assumptions about what they should do, or be an effect of different cultures or health services.

'Advance refusals' allow a patient to opt out of treatment. In contrast, the 'Odysseus/Ulysses contract' or 'self-binding contract' allows a patient to opt-in to services (Howell *et al*., 1982; Dresser, 1984). A patient agrees in advance that they want services or medication when they are ill, even if at the time they refuse because of the illness. A self-binding contract could be used to specify where a patient will accept treatment (Bazelon Centre, 1999). This may be possible in countries with private health insurance but is unlikely to be acceptable in the UK.

'Advance agreement', the term preferred in the English review of legislation, (Department of Health & Home Office, 2000) implies that decisions are taken with clinicians and, crucially, agreed with them. This can be seen as a limit to patient autonomy. An 'advance directive' (Halpern & Szmukler, 1997; Dawson *et al*., 2001) on the other hand, might be seen as the embodiment of autonomy, in that they direct the clinician and their choices, and this may be considered to be stronger than an 'advance statement', the term preferred by the Scottish Executive (Scottish Executive, 2001b) whereby a choice is stated.

The term 'psychiatric will' was coined by Szasz (1982a) who, as a consequence of arguing that psychiatric treatment is oppression, argues for a legally binding document which prohibits compulsory treatment under mental health law. It is thus similar to advance refusal. He argues against compulsory treatment under any circumstances, preferring 'informal moral sanction such as social ostracism or divorce and formal judicial sanctions such as fine and imprisonment'. (Szasz, 1982b)

'Mill's wills', named after the philosopher John Stuart Mill, have been argued for by Rogers and Centifanti (1991) as a limit to paternalism and to allow the person to opt into or out of specific treatments. Mill argues that the 'only purpose for which power can be rightfully exercised over any member of a civilized community against his will is to prevent harm to others. His own good, either physical or moral is not a sufficient warrant.' (Mill 1859/1969).

Linked to the concept of future planning are 'joint crisis plans' (Sutherby *et al*., 1999) which require the individual to be a current user of services and to make plans in collaboration and agreement with their service provider.

'Crisis cards' are more like an advance directive which does not require the agreement of a service provider. Sutherby & Szmukler (1998) attribute their first use to Survivors Speak Out in England in 1989. This group also promoted their use during the debate in the UK on compulsory community treatment in 1998.

Other ways of determining patients' views and wishes have been explored. For example a 'values history' seeks to explore the person's value system to allow substituted judgments to be made using this as their basis (Lambert *et al*., 1990). Proxy decision makers can make judgements on either a 'best interests' or 'substituted judgement' basis. The approach intended should be stated at the outset.

Several of the state laws in America which relate to advance directives have an important role for proxy decision makers (Sales, 1993; Fleishner, 1998) and allow the nomination of an 'enduring power of attorney' (Gallagher, 1998). Some states explicitly prohibit the person's consultant psychiatrist or other clinician from whom they are receiving treatment from becoming a proxy. The expectation appears to be that the proxy will be a family member or friend.

The Adults with Incapacity (Scotland) Act 2000 has created a new 'welfare power of attorney' allowing the attorney to take medical and other decisions for an adult who has lost capacity. Similar provisions are contained in the Ontario Health Care Consent Act 1996 and Substituted Decisions Act 1992.

The potential variety of advance directives can be illustrated by locating a hypothetical advance directive in at least three dimensions: (i) its legal status, (ii) whether it is independently or collaboratively made and (iii) what interventions it may cover (including opt in and opt out of treatment). Plotting these dimensions as in Table 1 gives 32 potential types of advance directives. A fourth dimension, patient status, voluntary or detained, in-patient or community-based adds further potential varieties of advance directive and highlights the importance of clarifying what is intended when promoting advance planning.

Competency and consent

Before discussing the concerns involved in giving legal status to advance directives, the issue of competency to make such a directive must be addressed. As with any other form of future planning, be it a 'living will' or 'last will and testament', the person doing the planning must be competent. The issues involved in measuring competency are extensive, beyond the scope of this paper, and reviewed elsewhere (Gunn, 1994; Roth *et al*., 1977; Atkinson & Patterson, 2001). Gunn (1994) suggests that for mental health decisions cognitive tests are not always enough and that in addition the person must be able to 'appreciate the treatment and its consequences.' The English courts have said that the person must 'believe' the information given and be able to make a 'true choice' (Re C, 1994). A mental illness may prevent this. A number of American States have criteria laid down to measure competency but again these vary from state to state (Atkinson & Patterson, 2001).

It is not just how competency is measured which is important, but the surrounding issues of who makes the judgement as to competency, and when and where it is made. Central will be the questions of whether this is a legal or clinical judgement and the form any

Table 1: Matrix of 32 possible varieties of advance directive

	Legally binding agreed with psychiatric staff	**Legally binding independently made**	**Not legally binding agreed with psychiatric staff**	**Not legally binding independently made**
(Opt-out) refusal of all treatment (Opt-out) refusal of a particular treatment (Opt-in) to specific treatment (Opt-in) to early detention Provisions for financial matters Provisions for social care Nomination of 'best interests proxy' Nomination of 'substituted judgement proxy'				

competency hearing takes. These will have resource implications, which may be greater if the advance directive is legally binding. There is also the related issue of who pays the legal costs of making, changing, invoking or challenging the use of an advance directive. If the costs fall to the individual then it is likely to exclude significant numbers of those with severe and enduring mental illness who might otherwise wish to make them.

Financial assistance may be made available for such cases but then we must consider the source of such aid. It is unlikely that hard-pressed clinical services will want their resources directed to this. Even insurance premiums for clinicians might increase if there is concern about the increased possibility of litigation. The reviews of the Mental Health Acts in both England & Wales and Scotland (Department of Health & Home Office, 2000; Scottish Executive, 2001b), although advocating advance directives in some form, do not deal with difficulties surrounding resource or funding issues.

The President's Commission (1983) argued that assessing capacity need not be unduly onerous. An 'informed layperson' should be able to make an assessment as to whether the patient understands the situation and can 'make a choice in the light of that understanding.' The judge who would make the decision would do so as a layperson, albeit on the basis of medical advice. Most legal jurisdictions will imply a *presumption* of capacity. A doctor who ignored an advance directive could not defend a charge of battery (assault) by arguing he did not know whether the patient had been competent to make the directive (Malette *v.* Shulman, 1990).

However, if a person has a pre-existing mental illness it will be more difficult for health care professionals to rely on the presumption of capacity.

Inherent in the notion of competency is that the person understands the issues involved. 'Informed consent' is the term used in American states but not, surprisingly, a concept known to UK law. In the context of 'living wills' or advance directives relating to end of life decisions, there has been some discussion of the amount of information the patient should have to allow a valid decision to be made. Dresser (1995) argues, for example, that planning for future dementia requires a sophisticated understanding of the options for care and treatment. We are not aware of similar discussions relating to the information needs of patients wishing to make advance statements in psychiatry.

In general medicine a person can make, when competent, an advance directive refusing a potentially life saving procedure for what may seem to others irrational reasons (Re T, 1992; Sidaway *v*. Royal Bethlem Governors, 1985). For mental health law to be consistent a competent patient would have to be able to refuse, for example, Electro Convulsive Therapy (ECT) for apparently irrational reasons, even if these stemmed from misconceptions about the procedure. Many tests of competency and informed consent require that the person be able to show that they understand the nature and purpose of the treatment. It is generally accepted in UK law that a higher standard of actual knowledge and understanding is required for a refusal to be valid (Re T, 1992). Moreover, if apparent 'irrationality' could be the result of mental illness, this has to be taken into account. Contrast two American cases where in one a patient's delusions prevented her from appreciating the facts of the case (Re Maida Yetter, 1973) while in the other the refusal of treatment by a woman with a degree of dementia was respected, notwithstanding that her reasons were not regarded as medically rational (Lane *v*. Candura, 1978).

If a person has to be competent to make an advance directive, the question arises whether they also have to be competent to change it. It is generally assumed that advance refusals for treatment in end of life situations will be waived if the patient, even if not deemed competent, is giving indications that they wish to live. There is legislation in the US which allows revocation even after the loss of capacity. In the UK, Age Concern and the Centre of Medical Law and Ethics (1988) argued that, despite the apparent illogicality, that if a patient, however confused, requested treatment, it would be inhumane to refuse this on the grounds that they had previously made an advance directive refusing treatment. If this is followed through in advance directives in the mental health context then the patient, competent or not, should be able to accept treatment even after an advance directive refusing this. There is more of an issue however, if a person who may now be incompetent is allowed to refuse treatment that an opt-in advance directive was specifically set up to avoid them refusing. The Mental Health Bill currently before the Scottish Parliament will require a patient to be competent to revoke an advance directive.

If we assume that the desire to live, no matter how it is displayed, should outweigh any advance directive, then changing one's mind in this direction should not be a problem and the potentially

terminal consequences of an advance directive should be overruled. In mental illnesses, particularly depression, the situation may be less clear. Depression, for example, may make a person believe that they do not deserve to live. While they are ill their ability to change their mind may be taken from them. What might be seen as the 'natural safeguard' in a person's fighting for life has been lost.

Legal status of advance directives

As previously noted, a number of American states have laws relating to advance directives in mental health care (Fleishner, 1998). In Canada, the Ontario Health Care Consent Act 1996 gives statutory effect to advance statements in medicine, including psychiatry. The European Convention on Human Rights and Biomedicine, signed by 29 European states (excluding the UK), requires advance statements to be 'taken into account' if a patient is not able to express his or her wishes at the time medical interventions are made (Article 9). In England & Wales, in general medicine, advance refusals of treatment have common law status (Airedale NHS Trust *v.* Bland, 1993). The British Medical Association (1995) has advised doctors that an 'unambiguous and informed advance refusal is as valid as a contemporaneous refusal' and doctors must comply with it. The BMA gives no guidance on how the doctor ascertains that the refusal is 'informed'. An advance directive refusing treatment would appear to be valid for a voluntary patient refusing psychiatric treatment or medical treatment, but the refusal could be over-ruled if the patient was detained under mental health legislation. Normally only treatment for the mental illness can be enforced under this legislation and only within the safeguards of the legislation. Refusals of treatment for physical illness will generally be honoured unless the refusal was thought to be a consequence of mental illness. In a case in England, a man who had a diagnosis of schizophrenia and was described as 'delusional' nevertheless had his refusal of treatment for life threatening gangrene upheld by the court, because it was satisfied that he understood the 'nature, purpose and effects' of the treatment proposed for him and had made a 'clear choice' to refuse it (Re C, 1994).

The ability of the law to override competently made decisions for detained psychiatric patients can be seen as discriminatory as already noted. The Adults with Incapacity (Scotland) Act 2000 now specifically provides that professionals 'take account' of statements, however formulated. There is similar provision in the Mental Health (Scotland) Bill (Scottish Parliament, 2002) whereby psychiatrists and mental health tribunals have to pay 'due regard' to advance statements. Thus, for advance directives in mental health, the crucial legal issue is as much their relationship to mental health law as their general legal standing.

The legal standing of an advance directive will affect many of the decisions taken; for example, proof of competency procedures might be more rigorous for a legally binding directive than one which was seen as merely suggestive. To avoid future litigation a competency hearing might be required, with the problems attendant in assessing competency to make or change an advance directive.

There is also a question of how long an advance directive should remain in force. Again this might be more im-

portant if it is legally binding, particularly if it has been made by someone with no experience of the illness or if treatment options become available that have not been envisaged. As Halpern & Szmukler (1997) point out, a legally binding advance directive might require, as part of the competence to make it, a discussion of its inherent 'risks'. A non-legally binding agreement, on the other hand, might simply require a discussion which emphasizes possible negative outcomes.

If joint crisis plans are to become legally binding advance directives, this might change their nature. For example, the proposals by Sutherby *et al*. (1999) suggest that the plan involves, where possible, an independent advocate in addition to the mental health professionals, the patient and 'anyone else who might be helpful'. If one of the members of this group were a lawyer we might suspect that the nature of the discussion would change. If the purpose is to produce a formal, possibly legally binding document, there may arise occasions where the views of the patient and staff differ and agreement cannot be reached. It is also likely that staff would be cautioned against writing into crisis plans promises of certain services in case their provision became problematic because of limited resources. Service providers might feel vulnerable to litigation if they are unable to provide an agreed service at an agreed time. Of course, in such a case another debate might be opened about what constitutes 'agreed time' and the nature of the crisis. Thus, if advance directives were legally binding, staff, and possibly patients, would have to be cautious in their care planning to make sure they were not inadvertently making an advance directive. This might result in a disclaimer on every care plan – 'This is not an advance directive'.

If advance directives were to be legally binding, this would raise the very real issue of whether they should permit refusal of treatment, even if death ensued. A directive might include refusal of resuscitation after a suicide attempt or allowing someone suffering from anorexia to starve to death. In most cases to allow someone to die through refusal of treatment for a mental illness would mean that mental health legislation could not be used to overrule the advance directive.

Independent or collaborative directives

If promoting or protecting a person's autonomy is the prime concern for advance directives there is no reason why the person needs to have experience of mental illness when they make such a directive (Szasz, 1982a). They will, however, of necessity be a patient when it is invoked.

Some of the models for future planning, such as advance agreements and joint crisis plans, are only appropriate for those currently engaged with services. Other forms of advance directives are, however, available to people who have not experienced the condition for which they are planning. We need to consider if there is any reason why people should not be able to refuse, for example, ECT even if they have no previous experience of ECT or even severe depression. It is possible to envisage a situation where it is possible to make a less well informed advance directive before any onset of mental illness and without competency being challenged, than it is after experience of both mental illness and specific treatments when a more informed choice

can be made but competency is more likely to be challenged.

UK policy documents encourage jointly negotiated decision making about treatment and management (e.g. advance agreements, joint crisis planning) as leading to improvements in the patient-clinician relationship, through greater discussion between the parties, including consideration of choices and statements of preference. Patient autonomy, however, is only supported in so far as preferences are accepted by staff. The Scottish Executive (2001b) promotes the use of advance statements as supporting 'the principle of *participation'* (their emphasis). They are not seen as altering the legal relationships between service users and service providers.

The English White Paper, 'Reforming the Mental Health Act' (Department of Health & Home Office, 2000) anticipated advance agreements coming from people who have already experienced care and treatment for a serious mental disorder. Clinical teams would be expected to help patients make such statements and consider them when planning treatment if they are recent and made in consultation with specialist mental health services. The BMA (1995) shows how the distinction between advance directives and good care planning can become almost indistinguishable. They suggest 'health professionals have a key role in assisting the patient to evaluate and reconcile the advantages and disadvantages of the treatment and make decisions about future management accordingly. Anticipatory statements authorizing treatment or expressing preference between equally viable treatments can be discussed at times when the patient retains insight ... and these should be reflected in subsequent treatment plans ...'.

What should advance directives cover?

As previously mentioned in relation to table 1, there is a range of matters that could potentially be covered by advance directives including opting in or out of medical treatment and instructions for social, family and personal issues.

Opt-out options mean that the person can refuse any, or all, psychiatric interventions. It is not possible to opt-out of detention under mental health legislation, although some North American states or provinces allow detained patients to refuse medication if not a danger to others. Currently, in the UK, a detained patient cannot opt-out of treatment. The Millan Committee in Scotland (Scottish Executive, 2001a) while not recommending that detained patients be allowed to refuse medication does recommend allowing competent patients to refuse ECT, even if they are detained. The main treatments which patients are likely to want to refuse are all or specific medication and ECT. One concern in respect of refusals is not only that patients limit what may be beneficial to them, but that there might be an increase in detention if psychiatrists felt compelled to detain patients who appeared to accept proposed treatment which they had previously rejected in an advance directive. (Dawson *et al.*, 2001). Previously such patients would have been treated as voluntary patients. Concern that their current agreement or change of mind might not be competent could lead to detention. This would protect psychiatrists from litigation and provide the patient with the protection of the review procedures detailed in legislation. This concern is based on the belief that advance refusals have status in common law which can be over-ridden by the

Mental Health Act. As mentioned earlier, in some circumstances honouring the patient's change of mind to accept treatment, where this preserves their life or health, might be seen as appropriate.

In those US states which have a narrow committal criterion, for example dangerousness only, opt-in advance directives have been seen as a potentially useful way of gaining access to treatment for a person who was becoming unwell and refusing treatment but was not yet legally detainable or, for those who do not become dangerous but who would otherwise be denied treatment. This could be particularly useful for people with a recurring condition, who when well have good insight, but this is lost at the onset of another episode. Such opt-ins might reduce detentions for some people, and thus the stigmatisation which comes with detention, and give patients some ownership of the admission process. Under Scottish incapacity legislation a patient can request their attorney to arrange for hospital admission. However, if they later resist admission when ill, formal mental health act detention procedures will have to be used. The advance directive does not allow the use of force or detention. The Ontario legislation, on the other hand, allows an appointed proxy to consent to involuntary detention in a psychiatric hospital, provided that the document appointing him or her gives that power.

Although the main focus for advance directives has been on medical interventions, there is some interest in extending the scope of the directive to include other aspects of the person's life. Examples include: specifying with whom the psychiatrist or staff may discuss the patient's case; removal of credit cards or other measures to curtail overspending; arrangements for child care; and naming the person with whom staff may liase to maintain tenancy or other home agreements (Manic Depression Fellowship, 2001; National Schizophrenia Fellowship, 1999). At first glance, these might seem straightforward matters for advance directives to deal with. As with medical care however each area would necessitate careful consideration, not least in its relationship to pre-existing legislation governing credit and child-care, for example. The same issues relating to competency, information and revocation as apply to medical treatment would also have to be considered.

Conclusion

There is immediate appeal in a liberal democracy that values individual freedom and autonomy in giving weight to advance directives in mental health care. This is especially so at a time when both government and voluntary sector are saying patients should have more control over their psychiatric treatment. There are, however, as we have indicated, difficulties in incorporating advance directives into mental health law and practice.

The Richardson Committee (Department of Health, 1999a) was positive in its assessment of what advance agreements can achieve: 'such agreements would greatly assist in the promotion of informal and certainly consensual care. Patients and care teams would become used to negotiating an agreed package of care to be implemented in the case of relapse'. As we have demonstrated, this is only one version of what an advance directive might be.

The legally binding model gives more autonomy to the competent patient. Its

application in practice would, of necessity, be rather different to the less formal crisis plan. Advance directives could be seen as having at least two different aims. On the one hand, there are legally binding advance directives, particularly relating to refusing treatment and probably not intended to be over-ruled by mental health law. These might be seen within the framework of legal restrictions on the power of the psychiatrist, so that patients have a more equal relationship with psychiatrists. On the other hand, there are crisis plan type arrangements where the aim is to improve communication. Changes in the power relationship may come more from increasing the power of the patient, through giving them information and a negotiating framework, rather than restricting the power of the psychiatrist. The emphasis could be on changing patient behaviour as much as the psychiatrist's behaviour.

Far from being an easy solution to ethical issues of enforced treatment and early access to treatment, advance directives introduce new issues and highlight persistent problems, not least regarding the allocation of resources. This does not mean, however, that advance planning with patients is inappropriate. Anything which allows patients and mental health professionals to work more harmoniously together for the patients' greater good should be welcomed.

Postscript

Since writing this article the Scottish parliament has passed *The Mental Health (Care and Treatment) (Scotland) Act 2003* (Edinburgh: The Stationery Office). Its provisions in relation to advance statements are broadly similar to those included in the Bill.

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