

## Correspondence

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The principle of informed consent is basic to medical practice. It requires that the patient be informed of the reasons for the proposed intervention, including medication, the expected outcome and any and all potential adverse reactions. As has been pointed out many times, informed consent – and informed refusal – does not consist merely of the signing of a form but the discussion between patient and physician. In the UK, USA and Canada, the right of informed refusal is well established but there persists a misunderstanding of the role of competence. The Supreme Court of Canada, in *Starson v. Swayze* [2003],<sup>1</sup> allows informed refusal of medications even by a patient with a diagnosed psychiatric disorder. The presiding judge stated that:

'The HCCA [Health Care Consent Act] confronts the difficult problem of when a mentally ill person may refuse treatment. The problem is difficult because it sets in opposition fundamental values which we hold dear.

The first is the value of autonomy – the ability of each person to control his or her body and consequently, to decide what medical treatment he or she will receive. The second value is effective medical treatment – that people who are ill should receive treatment and that illness itself should not deprive an individual of the ability to live a full and complete life. A third value – societal protection – comes into play in some cases of mental illness. Where the mentally ill person poses a threat of injury to other people or to him- or herself, it may be justified to impose hospitalization [...]. The right to refuse unwanted medical treatment is fundamental to a person's dignity and autonomy. This right is equally important in the context of treatment for mental illness [...]. Few medical procedures can be more intrusive than the forcible injection of powerful mind-altering drugs which are often accompanied by severe and sometimes irreversible adverse side effects [...]. A competent patient has the absolute entitlement to make decisions that any reasonable person would deem foolish [...]. The right knowingly to be foolish is not unimportant; the right to voluntarily assume risks is to be respected. The State has no business meddling with either. The dignity of the individual is at stake. [...] In this case, the only issue before the Board was whether Professor Starson was capable of making a decision on the suggested medical treatment. The wisdom of his decision has no bearing on this determination [...] The Board must avoid the error of equating the presence of a mental disorder with incapacity. Here, the respondent did not forfeit his right to self-determination upon admission to the psychiatric facility [...] The reviewing judge properly held that the Board's finding of incapacity was unreasonable, and that the Board misapplied the statutory test for capacity. There is no basis to find that either of the courts below erred on the evidentiary issues that were raised by the appellant. Accordingly, I would dismiss the appeal.'

The patient was granted the right to refuse medications and seek psychotherapy.

1 *Starson v. Swayze* [2003] 1 S.C.R. 722, 2003 SCC 32.

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As a researcher, doctoral student and service user (with a diagnosis of schizophrenia), I commend Morrison and colleagues<sup>1</sup> for their brave and timely editorial. In addition to the adverse effects they mention, a small but robust literature attests to the often overlooked impact of subjective or psychological side-effects on service users' quality of life and ability to pursue meaningful, socially valued roles (e.g. Awad & Voruganti,<sup>2</sup> Deegan,<sup>3</sup> Jones,<sup>4</sup> Roe & Swarbrick<sup>5</sup>).

In a focus group project on medications and treatment engagement that I recently completed, many service users reported that, in their experience, treating psychiatrists almost always refuse to even see patients who decline pharmacotherapy. Likewise, help with coming off medications is rarely available from medical professionals, leading to the deeply ironic fact that virtually the only comprehensive guide to psychotropic medication discontinuation widely available in the USA is the non-academic, activist-published *Harm Reduction Guide to Coming Off Psychiatric Drugs*.<sup>6</sup> Similarly, I have yet to meet an American service user with a diagnosis of psychosis who has ever been actively offered targeted intermittent (*v.* continuous) treatment. Clearly, research documenting the representative 'real-world' availability of treatment choices and alternatives, as well as the actual extent of autonomy support in psychiatric settings (or the lack thereof), is urgently needed.

As things stand, 'choice' and 'self-determination', at least in the USA, often appear to involve little more than the choice between a variety of antipsychotics and other psychotropic medications. As Morrison *et al* suggest, it is high time we began to take the profound heterogeneity of treatment response, outcome and symptom trajectories, as well as individual needs, preferences and risk assessments, seriously.

- 1 Morrison AP, Hutton P, Shiers D, Turkington D. Antipsychotics: is it time to introduce patient choice? *Br J Psychiatry* 2012; **201**: 83–4.
- 2 Awad AG, Voruganti LP. Neuroleptic dysphoria: revisiting the concept 50 years later. *Acta Psychiatr Scand* 2005; **111**: 6–13.
- 3 Deegan PE. The importance of personal medicine: a qualitative study of resilience in people with psychiatric disabilities. *Scand J Public Health* 2005; **66**: 29–35.
- 4 Jones N. Antipsychotic medications, psychological side effects and treatment engagement. *Issues Ment Health Nurs* 2012; **33**: 492–3.
- 5 Roe D, Swarbrick M. Recovery-oriented approach to psychiatric medication: guidelines for practitioners. *J Psychosoc Nurs Ment Health Serv* 2007; **45**: 35–40.
- 6 Hall W. *Harm Reduction Guide to Coming off Psychiatric Drugs*. The Icarus Project and Freedom Center, 2012.

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Morrison and colleagues<sup>1</sup> highlight the important issue of patient choice in relation to the prescription of antipsychotic medication. They argue that patient choice should be considered because of the uncertainty regarding potential benefits and increasing awareness of potential risks of both older and newer types of antipsychotic medication. I agree that patient choice, along with consideration of the evidence, should be an essential part of the decision-making process and believe that shared decision-making is an ideal way in which to do this.

Shared decision-making involves a collaborative approach to treatment decision-making whereby the clinician presents information about suitable treatment options along with details about the potential risks and benefits of each option.<sup>2</sup> In return, the patient provides information about their personal values and preferences, so that a decision can be made on both evidence and patient preferences and values.

In areas where evidence is limited or ambiguous, shared decision-making offers an opportunity to be explicit about what is known about likely treatment outcomes and therefore encourages realistic expectations. Having frank and collaborative discussions as part of the decision-making process may also encourage patients to be more open about sources of decisional

conflict and lead to greater knowledge, adherence and satisfaction, whatever the chosen treatment option may be.

Decision-making tools called decision aids (usually online or paper-based tools) can facilitate shared decision-making. A systematic review of decision aids across all health areas found that they: increase patients' knowledge of treatment options; give patients more realistic expectations about the potential risks and benefits of these treatment options; help patients to make a decision that is more in line with their personal values and to be more involved in the decision-making process.<sup>3</sup>

There has been a growing interest in shared decision-making for mental disorders.<sup>4</sup> Shared decision-making interventions, usually involving decision aids, for treatment decision-making in areas of mental health have shown promising preliminary results and include one study for adult in-patients diagnosed with schizophrenia faced with a decision about treatment with antipsychotic medication.<sup>5</sup> The shared decision-making intervention was feasible for this population and significantly increased patients' knowledge about schizophrenia, uptake of psychoeducation and feelings of involvement in consultations, without increasing consultation time.

In areas where there is uncertainty or ambiguity in the available evidence for treatment options, it is imperative to inform patients of the potential risks and benefits and support them to explore their preferences and values around these outcomes. Shared decision-making is one way in which to do this and is well suited to the provision of antipsychotic medication for psychotic (and other) disorders.

- 1 Morrison AP, Hutton P, Shiers D, Turkington D. Antipsychotics: is it time to introduce patient choice? *Br J Psychiatry* 2012; **201**: 83–4.
- 2 Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med* 1999; **49**: 651–61.
- 3 Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, Holmes-Rovner M, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2011; **10**: CD001431.
- 4 Simmons M, Hetrick S, Jorm A. Shared decision-making: benefits, barriers and current opportunities for application. *Australas Psychiatry* 2010; **18**: 394–7.
- 5 Hamann J, Langer B, Winkler V, Busch R, Cohen R, Leucht S, et al. Shared decision making for in-patients with schizophrenia. *Acta Psychiatr Scand* 2006; **114**: 265–73.

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In any other branch of medicine today, the question 'Is it time to introduce patient choice?' would sound absurd: the only appropriate answer would be an incredulous, 'Has this not happened already?' For a significant number of readers of the *British Journal of Psychiatry*, this question in relation to the matter of antipsychotics is likely, in contrast, to be provocative and controversial. That this is the case shows just how far there is to travel before discrimination on the grounds of mental ill health can be said to have been extinguished.

I welcome the publication of the important editorial by Morrison *et al*,<sup>1</sup> which makes clear the extensive levels of coercion surrounding antipsychotic medication for people with diagnoses of psychosis. (Let us recall that the UN Convention on the Rights of Persons with Disabilities 'require[s] health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent'.)

The authors provide strong arguments and evidence with which to counter the 'prevailing opinion that all service users with psychosis require antipsychotic medication in order to recover'.

What is notable is how the editorial reprises arguments that writers from the service user and survivor movement have been making for some decades. For example, Morrison and colleagues argue in their editorial that 'some decisions to refuse or discontinue antipsychotic medication may represent a rational informed choice rather than an irrational decision due to lack of insight or symptoms of suspiciousness';<sup>1</sup> Judi Chamberlin, one of the leading American activists in the psychiatric survivors movement, reflected in 1998 on 25 years of activism in the consumer/survivor movement, and wrote, 'A patient who refuses psychiatric drugs may have very good reasons – the risk of tardive dyskinesia [...] or the experience of too many undesirable negative effects. But professionals often assume that we are expressing a symbolic rebellion of some sort when we try to give a straightforward explanation of what we want and what we do not want'.<sup>2</sup> (See also writings documented by the Survivors History Group, available at: <http://studymore.org.uk/mpu.htm>.)

The growing convergence between service user/survivor perspectives and those of parts of the mental health establishment on issues of such critical importance to many mental health service users' lives is to be celebrated. At the same time, it is important to keep in view the uneven ways in which arguments and evidence originating from different sources are treated and weighed. This will allow us better to understand why service users' writings are not as frequently referenced – even as they are central to the arguments being made – in mainstream mental health publications.

- 1 Morrison AP, Hutton P, Shiers D, Turkington D. Antipsychotics: is it time to introduce patient choice? *Br J Psychiatry* 2012; **201**: 83–4.
- 2 Chamberlin J. Confessions of a noncompliant patient. *J Psychosoc Nurs Mental Health Serv* 1998; **36**: 49–52.

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The editorial by Morrison *et al*<sup>1</sup> is timely in suggesting we should re-evaluate the way in which antipsychotic medication is used in the treatment of psychosis, particularly for those very early in the course of illness. Since the beginning of the early psychosis reform period, we have consistently advocated for low-dose antipsychotic treatment of first-episode psychosis complemented with comprehensive psychosocial care. More recently we have argued<sup>2</sup> that the success of early detection efforts means that young people are being seen much earlier in the development of their symptoms, and this alters the risk–benefit ratio associated with treatments. As proposed by the clinical staging model,<sup>3</sup> there is a strong rationale for beginning treatment with more benign, but evidence-based psychological approaches and reserving pharmacological agents, which despite their efficacy, can have significant adverse effects for (psychological) treatment-resistant cases. Treatment should be proportional to severity and need. Factors that support the call for change in the use of antipsychotic medications include the well-documented metabolic side-effects of most antipsychotic medications, the possibility that some of the structural brain changes seen in psychosis may actually be produced by antipsychotic medications (although the significance of these changes in relation to course and outcome is still unclear), and the widespread non-adherence to prescribed antipsychotic