Embracing patient choice

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],1 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 value is the principle 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.


As a researcher, doctoral student and service user (with a diagnosis of schizophrenia), I commend Morrison and colleagues1 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,2 Deegan,3 Jones,4 Roe & Swarbrick5).

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.6 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.

Morrison and colleagues1 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 medications. 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.7 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...