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## Beyond patient-centered care: Enhancing the patient experience in mental health services through patient-perspective care

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### Abstract

Delivering mental health services as patient-centered care has been an international priority for more than 50 years. Despite its longevity there is still not widespread agreement regarding how it should be defined or how it should guide the delivery of services. Generally, though, prioritizing the patient's values and preferences seem to be at the core of this particular approach. It is not clear, however, that services attend to patient values and preferences as closely as they should. Terms such as "treatment resistant" and "noncompliant" seem to belie an attitude where the therapist's opinion is privileged rather than the patients. To improve the effectiveness and efficiency of mental health services a move from patient-centered care to patient-perspective care is recommended. An attitude of patient-perspective care would require service providers recognizing that help can only ever be defined by the helpee rather than the helper. A patient-perspective service that was structure around the preferences and perspectives of patients might finally help to end the long-term suffering of many people who experience mental health problems.

### Keywords

Patient-centered care; patient-perspective-care; mental health, treatment effectiveness and efficiency

"Patient-centered care" is a widely used term in the health field generally and in mental health specifically. While the familiarity of the concept is undisputed, the way in which it is defined, understood, and used to inform service delivery is much less clear.<sup>1</sup> References to patient-centered care can be found as early as the 1950s but there is still no universally accepted definition of the term.<sup>2</sup> Indeed, there is ongoing debate in the literature regarding what patient-centered care actually is with some arguing that its use is an example of tokenism.<sup>3</sup> Regardless of how well-known the patient-centered approach is reported to be, it seems much more challenging to recognize it in clinical practice.<sup>3</sup>

The patient-centered care initiative has been useful for highlighting the importance of patient preferences and values. For example, the Institute of Medicine<sup>4</sup> defines patient-centered care as "providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions". Unfortunately, while the patient-centered care initiative emphasizes the patient's values and preferences, it provides less information about what to do with these values and preferences once they have been identified. In particular, what should be done about them if they are discrepant from the clinician's values and preferences? Typically, the way patient-centered care is currently delivered, it seems that the most common approach adopted is to attempt to persuade patients to alter their views until they are more consistent with the views of the clinician.

Evidence indicates, however, that adopting a patient-centered approach to treatment can assist in reducing the length of stay in hospital, the number of readmissions, and also the number of emergency department visits.<sup>2</sup> While these achievements should not be discounted, there are many aspects of mental health service delivery that seem to be at odds with a patient-centered ethos. Perhaps it is these aspects of service delivery that make the realization of an authentic patient-centered service so problematic on a widespread scale. These difficulties provide a compelling rationale to consider alternatives to patient-centered care.

At its most literal, the term "patient-centered care" refers merely to geography. McCance et al.,<sup>3</sup> for example, argue that patient-centered care requires placing the client at the center of care delivery. Placing the patient at the center of a clinician's deliberations, however, does not preclude that clinician making decisions on behalf of the patient.

It seems entirely incongruent to discuss issues of compliance and engagement within a patient-centered approach yet these are common concerns for many services. Indeed, one of the stated benefits of a patient centered approach is that it can improve patient compliance with their care plans.<sup>2</sup> Furthermore, increasing patient engagement in services is often considered a priority. Patients who do not attend as many appointments as a clinician thinks they should attend are typically described as treatment "drop outs"<sup>5,6</sup> or "treatment resistant". If services, however, were thoroughly focused

on delivering their care according to the preferences and values of patients, it is difficult to understand how issues such as noncompliance, disengagement, and resistance would be relevant topics.

Perhaps the presence of these difficulties in services reveals a more fundamental problem in terms of the way in which the nature of patients is considered. One example is the idea that patient-centered care requires the activation of patients.<sup>7</sup> This may imply a conceptualization of patients as entities that can be “switched” on or off. From this perspective, it is logical to assume that it might be the responsibility of the mental health clinician to “ignite” or engage the patient. Another perspective, however, is that patients are always “on” or active. Considering the situation in this way would provide scope for clinicians to understand even disengaged and noncompliant patients as active agents. Patients might or might not be “dropping out” of treatment. When patients end their treatment before clinicians think they should, they may have achieved the results they wanted even if those results don’t match the results the clinician thinks they could have achieved.

Concepts such as engagement, noncompliance, resistance, and treatment drop outs are even more puzzling when one considers that most mental health patients are voluntary users of a service. Many ethical and professional codes recognize the patient’s right to self-determination including their right to withdraw from treatment.<sup>8-10</sup> In Australia, for example, the *National Practice Standards for the Mental Health Workforce 2013*<sup>11</sup> say that mental health practitioners should advise “the person and their family or carer of their right to informed consent for treatment and of their right to refuse treatment” (p. 17). Yet, if patients do withdraw before the clinician thinks they should they can be regarded as disengaged, resistant, non-compliant, or a treatment drop out.

Shared-decision making has become another priority in health care delivery.<sup>7,12</sup> Legitimate shared-decision making, however, is questionable given the power differential between a patient and a mental health clinician. One service user emphatically pointed out in a documentary that it was his life he and his clinician were discussing so there could be no “shared” decision making.<sup>13</sup> This man argued passionately and persuasively for “supported-decision making” as opposed to shared-decision making.

The power differential between clinician and patient may also be an important consideration in the provision of psychoeducation and mental health literacy. While there can be much value in providing people with more information and greater knowledge, there is a sense that mental health programs of information provision are very much about inculcating patients with a particular way of understanding mental health problems. The understanding

that is most often the content of these information provision programs is a Western, biomedical conceptualization of mental health. The patient is very clearly at the center of these learning programs, however, it is not at all clear that the programs are developed with the patient’s beliefs, values, and preferences in mind. Rather, the information seems to be presented with a view to educating the patient about a particular model of mental health so that compliance with the treatment regime will be more likely.

Other aspects of service delivery that can appear to be promoting a patient-centered approach yet are often more about the organization and convenience of services are stepped care and appointment reminders. While the logic of stepped care may be sound, it is routinely the clinician who makes the stepping decision for the patient. If the patient receives a particular level of service and is judged to need a higher level of service then it is arranged for the patient to see another therapist for a different kind of treatment. A modification to the current stepped care approach would be for individual clinicians to vary the intensity of the service they provide depending on the needs of particular patients. It is also not routine practice to ask patients if they require appointment reminders before they are issued. It is not clear that appointment reminders are even helpful for patients<sup>14</sup> but, of more importance here is the imposition of the reminders according to the clinician’s preferences rather than the patients.

Given these difficulties it is perhaps not surprising that a shift away from emphasizing patient centeredness has started with an acknowledgement that patient experience is the foundation for effective treatment.<sup>15</sup> Rather than focusing on whether the patient is at the center of care or in some other position it is time to ensure that the perspective of the patient provides the framework for the organization and provision of services. Rather than patient-centered care, patient-perspective care needs to become the new attitude of clinicians, service managers, and policy makers.

When considering the ways in which a service could be improved, it is instructive to reflect on the definitions of the term “service”. The first two meanings provided by dictionary.com are: 1) an act of helpful activity; help; aid: to do someone a service; and 2) the supplying or supplier of utilities or commodities, as water, electricity, or gas required or demanded by the public. In some ways it seems as though mental health services have implicitly adopted the second definition whereas a patient-perspective approach would require that the first definition was observed.

Rather than mental health services providing the commodity of mental health treatment, a patient-

perspective mental health service would be operated by clinicians and managers who understand that “help” can only ever be defined by the helpee not the helper. That is, it is the recipient of the help, not the provider, who is the arbiter about whether or not what they are receiving is actually helpful. If it is not experienced as helpful by the receiver of the help then it is not helpful.

A patient-perspective framework requires attitudes of humility and curiosity. Such a framework necessitates clinicians accepting that they will never fully understand their patients so they guard against assuming that they do understand and they routinely check with the patient that what is happening is what should be happening from the patient’s perspective. In this way, the patient-perspective approach provides a useful orientation point to ensure current practices are being delivered according to what the patient finds most acceptable. Hyde,<sup>16</sup> for example, describes being strongly motivated to do what’s best for the patient. Unfortunately, however, from a patient-centered perspective, there are no guidelines for deciding what “best for the patient” actually means. This can be highly problematic in mental health services when patients may be considered to be thinking irrationally. In these situations, it is not uncommon for the clinician to decide what is best for the patient. A patient-perspective approach, however, would insist that time is taken to consider the patient’s current experiences and the perspectives associated with those experiences. Even with nonverbal patients it is possible to use dedicated and systematic observation to learn how they spend their time, who they spend it with, what activities they avoid or engage in, and so on.

Patient-driven healthcare is a current priority in the Veteran’s Administration of the United States where healthcare is driven by what matters to the patient.<sup>17</sup> This initiative appears entirely consistent with a patient-perspective imperative. The patient-perspective attitude could assist clinicians in ensuring the healthcare they are providing is consistently patient-driven. A patient-perspective approach even accommodates and respects those situations in which the patient’s decision is to withdraw from treatment.

In order for the effectiveness and efficiency of mental health services to improve it is recommended that the priority of patient-centered care shifts to one of patient-perspective care. Indeed, even the definition of what effectiveness or efficiency means should be defined from the patients’ perspectives. A patient-perspective service would be one in which clinicians and managers understood that help is defined by the receiver not the provider of the help. It would also be a service where the full implications of an individuals’ right to self-determination were acknowledged, accepted, and promoted. The patient experience is prioritized in a

patient-perspective framework with an understanding that no-one else can ever fully appreciate another’s experience so helpers must be led by the helpees to ensure the acceptability of service provision. Designing mental health services that are more acceptable to patients from patients’ perspectives might finally help to reduce the long-term suffering of many people experiencing mental health problems and enable them to live the lives they would wish for themselves.

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