

What is the importance of the patient's voice in mental health care?

Introduction

The patient's voice in mental health care has historically been relatively ignored, within a culture of paternalism and coercive treatment (Campbell, 1993). However, societal changes in recent decades have led to the expectation – from patients and policy makers alike - that the patient's voice should be listened to when planning and delivering health care (Stickley, 2006). This approach assumes that the patient's voice is important in all contexts, with little explanation or justification for this claim (Charles and DeMaio, 1993). The word "voice" is construed in various ways, but this essay uses Craig's (2012: 125) definition: "Legitimate participation in dialogue", because it combines definitions from several sources. While it is intuitive that the patient's voice is important in mental health care, intuition alone should not be the sole driver of medical practice; it must be "developed and defended" (Duggan et al, 2006: 272). This essay aims to address this shortcoming by exploring key arguments for the importance of the patient's voice in mental health care. These arguments fall into two broad categories: rights-based and outcomes-based. Do patients have an inherent right to a say in decisions that may affect them? Or should the importance of the patient's voice depend on potential benefits it provides? I conclude that neither a rights-based nor outcomes-based approach sufficiently accounts for the importance of the patient's voice in mental health care, and further work is needed if either account is to become sufficiently comprehensive.

Historical Background

In the United Kingdom (UK), various societal changes have facilitated increasing recognition of the patient's voice in health care generally, as well as mental health care specifically (Campbell, 2005). Appreciating these developments is key for understanding current ideas regarding the patient's voice (Charles and DeMaio, 1993).

In the 1960s and 1970s, patients and service providers began to reject medicine's traditional paternalism (Stickley, 2006). Psychiatric practice was steadily de-institutionalised, reintegrating patients into society and potentially creating opportunities for their voices to be heard (Stickley, 2006). Patient groups were formed, and advocacy for the patient's voice began to feature in policy. For example, the World Health Organisation (WHO, 1978: 1) noted that "people have a right and duty to participate individually and collectively in the planning and implementation of their health care".

Following this, increasingly popular neoliberal market economics recast patients as consumers. In this political economy, consumer feedback became more important to service providers, to facilitate maximally appealing services (Tritter and McCallum, 2006). Furthermore, higher levels of education and access to information technology allowed patients to challenge the traditional dominance of healthcare professionals in medical decision making (Marent et al, 2015). Combined, these factors created an environment in which incorporating the patient's voice into healthcare became expected by both patients and service providers – at personal consultation and policy levels (Stickley, 2006). This was reflected in The National Health Service (NHS) Plan of 2000, which stated: "NHS care has to be shaped around the convenience and concerns of patients...patients must have more say in their own treatment and more influence over the way the NHS works." (Department of Health, 2000: 88).

Despite strong statements that patients "must" have more say, authors have argued that such policies are based on poorly articulated ideas about the inherent value of the patient's voice, lacking robust justification (Charles and DeMaio, 1993; Rise, 2012; Walker, 2009). Therefore, this essay will address this deficit by critically examining the main arguments regarding the importance of the patient's voice in mental health care.

Arguments for patient voice

Several arguments have been presented in the literature to justify the importance of the patient's voice in mental health care. These arguments broadly fall into two categories: rights-based arguments and outcomes-based arguments (Rise, 2012). Rights-based arguments are grounded in the normative assumption that individuals

should have a say in decisions that affect them (Hickey and Kipping, 1998). Outcomes-based arguments posit that the patient's voice provides valuable input which causes positive change in measurable outcomes (Rutter et al, 2004). While the literature frequently conflates these two approaches, distinguishing them is important because they are rooted in different views of what good health care is, and therefore direct us to contrasting approaches to optimal care.

Rights-based arguments

Beauchamp and Childress's Four Principles of Biomedical Ethics¹, first developed in 1979, are foundational works in biomedical ethics. (Beauchamp and Childress, 1979; 2013). Many authors (e.g. Gillon, 2003; O'Shea, 2012; Walter and Ross, 2013) argue that within medicine, autonomy is the default governing principle - the "principle to be appealed to when principles conflict" (Wolpe et al, 1998: 43). Though interpretations of autonomy vary, clinical medicine tends to focus on freedom of choice – specifically, that a competent patient has the right to influence decisions that may affect them with minimal interference (Schermer, 2003). The patient's voice is arguably necessary to exert this influence, and rights-based justifications of the importance of the patient's voice are typically predicated on respect for this form of autonomy (Sullivan, 2003).

Various reasons for the importance of autonomy are suggested in the philosophical literature. Dworkin (1988) argues that making autonomous decisions defines people as individuals and gives them ownership over their lives. This ownership is conducive to self-respect, and allows others to respect them as individuals. Similarly, Rachels and Ruddick (1989) argue that exercising freedom is a prerequisite of having a life in the biographical sense - with coexistent history, relationships and direction – rather than just the biological sense of being alive. Autonomy is therefore argued to be an intrinsically important component of living (Schermer, 2003). Though these compelling arguments exist in the philosophical literature, they are rarely used to ground defences of autonomy in healthcare (Walker 2009). Walker (2009) argues that within clinical medicine, autonomy is commonly celebrated without sufficient moral justification, and it is likely that similar inadequacies exist in mental health care. Those accounts that do exist focus on the independence of individuals, emphasising freedom of choice

¹ Autonomy, Beneficence, Non-Maleficence, Justice

(Entwistle et al, 2010). Henceforth when I refer to autonomy, I am referring to this individualistic medical account of autonomy. In this context, the patient's voice is interlinked with the notion of autonomy, because patients exercise their autonomy through expression of their thoughts and opinions (Schermer, 2003).

Though a right to autonomy may partially justify the importance of the patient's voice, the narrow focus on individual choices undermines the associated arguments. At a consultation level, this individualism ignores the patient's wider context (Williamson, 2014). Factors such as culture, relationships and economic circumstances may influence the thoughts and values of the patient, and how they express their voice (Davis and Elwyn, 2008). Furthermore, an individualistic view of autonomy does not sufficiently situate the patient's voice within a bidirectional relationship with a healthcare professional, such as a doctor (Quill and Cassel, 1995). The doctor has a level of knowledge and skill generally not possessed by the patient (Schneider, 1998). The patient also has expertise; that of experience. As stated by Sullivan (2003: 1595): "Facts known only by physicians need to be supplemented by values known only by patients". This clearly situates the patient's voice as part of an interactive relationship with a professional. Focusing solely on the patient's autonomy fails to acknowledge this.

Furthermore, patients who do not want to make medical decisions pose a problem to autonomy-based justifications for the importance of the patient's voice in mental health care. Studies have shown that different patients want to have a say in their mental health care to varying degrees (Elstad and Eide, 2009; Laitila et al, 2018). For those who do not want the responsibility of decision-making, the pressure put on them by the increasing promotion of autonomous choice may cause them to feel abandoned by the healthcare system (Quill and Cassel, 1995). They still have a voice, but may prefer using it in alternative ways – such as to seek reassurance. The focus of autonomy in medicine on independent choices therefore does not account for these patients.

Finally, autonomous choice hinges on the capacity to exercise autonomy – which is not equal between individuals (O'Neill, 1984). Within dominant mental health care understandings of autonomy, rational beliefs are often cited as a prerequisite for autonomous choices (Breeze, 1998; Savulescu and Momeyer, 1997). If someone's

decisions are based on irrational beliefs – such as delusions - it may be argued that they are not autonomous (Breeze, 1998). A right to autonomy therefore offers no account of the importance of these patients' voices. Whether these patients actually have autonomy or not is a separate debate beyond the scope of this essay – however the point stands that when a right to autonomy is used to justify the importance of the patient's voice in mental health care, those patients argued to be non-autonomous are not accounted for, undermining the comprehensiveness of this justification.

Some accounts of autonomy exist that partially address the problematic individualism of medical autonomy. For example, Mackenzie and Stoljar (2000) developed the concept of Relational Autonomy. This perspective situates people's autonomy within the context of their relationships and social determinants, arguing that people fundamentally exist in relation to others. It acknowledges the role of others in helping people to make decisions, and suggests that aims are developed within joint interaction (Walter and Ross, 2013). Despite this, relational understandings of autonomy have not progressed sufficiently in the context of clinical medicine (Williamson, 2014). Perhaps developing a more relational account of autonomy within medicine could more comprehensively support the importance of the patient's voice in mental health care from a rights-based perspective.

In summary, rights-based arguments for the importance of the patient's voice in mental health care centre on ethical imperatives to respect autonomy (Sullivan, 2003). In the broad philosophical literature, autonomy is promoted because it defines people as individuals, facilitates ownership over their lives (Dworkin, 1998), and is necessary for a biographical life (Rachels and Ruddick, 1989). However, within the clinical medical literature, autonomy is poorly justified (Walker, 2009). Dominant understandings of autonomy in the clinical literature focus on promoting unrestricted, independent choice for individuals (Schermer, 2003). This does not account for the social context of the patient, or their relationship with the healthcare professional (Williamson, 2014) and neglects those who do not want to make autonomous decisions (Quill and Cassel, 1995). Furthermore, it does not account for the voice of patients lacking rationality, as these patients are (rightly or wrongly) defined as non-autonomous (Breeze, 1998). Though interpretations of autonomy that address some of these problems exist (Mackenzie and Stoljar, 2000), these have not been sufficiently developed in the

context of healthcare (Williamson, 2014). Thus, further work is needed if rights-based arguments are to provide sufficient justification for the importance of the patient's voice in mental health care.

Outcomes-based arguments

Having considered rights-based arguments for the importance of the patient's voice, I will now evaluate outcomes-based arguments. This approach follows the tradition of evidence-based medicine, which asserts that up-to-date, empirical evidence should guide practice, in order to provide maximally beneficial care (Sackett et al, 1996). Outcomes-based arguments suggest that the importance of the patient's voice rests in positive changes in measurable outcomes that it may facilitate (Rise, 2012).

Individuals have different values, lifestyle factors and personality traits, potentially influencing the most appropriate treatments for them (Coulter, 2002). It is argued that listening to the patient's voice will help clinicians choose optimal treatments, potentially improving adherence to treatment and perhaps health outcomes (as a result of improved adherence or otherwise) (Haywood et al, 2006). Furthermore, as patients are argued to expect involvement in their care (Stickley, 2006), it may be that meeting such expectations will improve satisfaction with care (Coulter, 2002). At a systems level, incorporating suggestions made by patients may help to make service provision more appealing and appropriate (Crawford et al, 2002).

The most substantial bodies of literature on outcomes-based arguments centre on 'patient involvement' (also referred to as user involvement, or patient/user participation) (Simpson and House, 2002; Storm et al, 2011) and 'Shared Decision Making' (SDM) (Duncan et al, 2010). Both conceptualisations refer to the role of the patient in healthcare decisions. SDM operates at an individual level, focusing on a partnership between a healthcare professional and patient wherein both parties share information and the patient expresses their views and preferences (Barry and Edgman-Levitan, 2012). Patient involvement spans a range of definitions, but generally focuses on increased patient input into decisions, and collaboration with professionals (Tambuyzer et al, 2011). Craig's (2012) aforementioned definition of voice encompasses both of these understandings; therefore, studies implementing

patient involvement or SDM are examined to assess the importance of the patient's voice in terms of outcomes.

Despite promising outcomes-based arguments for the importance of the patient's voice in mental health care, the evidence is lacking (Rise, 2012). For example, while it may be intuitive that the patient's voice would facilitate provision of treatments that patients are more likely to adhere to, current evidence contradicts this. In a systematic review of interventions designed to implement SDM in mental health care consultations, Duncan and colleagues (2010) identified two sufficiently robust studies, finding no improvements in treatment adherence in the intervention groups compared to controls. This finding is reflected in the wider healthcare literature. For example, in a review of studies aimed at improving the patient-provider relationship, Auerbach (2009) found that though interventions often successfully improved patient involvement in decision-making within consultations, this did not translate into improvements in medication or appointment adherence.

There is also limited empirical evidence for the importance of the patient's voice regarding health outcomes. In mental health care, these tend to be measured via symptom scores (e.g. Chinman et al, 2000; Hamann et al, 2006 ; Loh et al 2007 Solomon and Draine, 1995). Reviews by Duncan and colleagues (2010) and Simpson and House (2002) found no improvements in symptom scores when SDM or patient involvement interventions were implemented in mental health contexts. In the wider healthcare literature, there is a similar paucity of empirical evidence regarding health outcomes (Auerbach, 2009).

It may be that meeting patients' expectations for involvement improves satisfaction with care (Coulter, 2002). Though in wider healthcare some limited findings have implied that satisfaction may be improved by listening to the patient's voice (e.g. Crawford et al, 2002), within mental health the findings are less clear. Storm and colleagues (2011) studied the effects of a patient involvement intervention on both a system and individual level. Though professionals reported a greater focus on patient involvement within the organisation, patient-reported satisfaction with care did not increase. In Duncan and colleagues' (2010) aforementioned review, one study found a significant improvement in patient satisfaction in the SDM intervention group

compared to a control group, the other did not. This supports the idea that while it may be feasible for organisations to listen to the patient's voice more, this does not necessarily improve satisfaction.

Some positive outcomes have been associated with incorporating the patient's voice into care. For example, in a systematic review of studies involving patients in mental health services, Simpson and House (2002) found studies showing that when previous mental health patients were employed in case management services, patients of those services had less frequent hospital admissions than patients of standard services. They also found that when current or previous mental health patients were involved in staff training, trainees developed a more positive attitude towards those with mental illness. However, Rise and colleagues (2011) investigated the effect of several initiatives to enhance patient involvement in one mental health hospital compared to two control hospitals, and found no improvements in knowledge, practice, or attitudes of staff.

Some authors have also noted negative effects of patient involvement. Trivedi (2001) reported that patient involvement in the development of the National Service Framework for Mental Health (Department of Health, 1999) was disempowering, due to poor support and accusations of non-representativeness. Omeni and colleagues (2014) obtained qualitative data from patients and service providers across three mental health trusts about the perceived impact of involving the patient's voice in mental health care. While perceived benefits included feeling listened to and improved access to information, disadvantages included involvement being detrimental to mental health and tokenistic involvement without resulting change. It is also important to consider publication bias. It is possible that further studies finding no effects of patient involvement or SDM interventions remain unpublished (Easterbrook et al, 1991).

Overall, there is little empirical evidence supporting outcomes-based arguments. Most research on patient involvement and SDM is not focused on mental health, and of the studies that do exist, few are methodologically robust enough to offer clear conclusions (Duncan et al, 2010; Rise, 2012). This does not mean that the patient's voice is not important for improving outcomes, but importance should not be assumed. The

patient's voice could be important for improving outcomes in some contexts or decisions - but only further empirical research, with rigorous methodologies and measurable outcomes, can clarify this. For now, outcomes-based arguments are insufficiently evidence-based.

Conclusion

Insufficient scrutiny has led to policies and recommendations seemingly based on assumptions that involving the patient's voice in mental health care is inherently positive. In 1993, Charles and DeMaio (1993: 882) noted that recommendations for involving patients in their care seemed to be based on "simplistic assumptions about the inherent merits of a cherished but poorly articulated notion of lay participation", and commented on the lack of empirical evidence for its benefits. Almost twenty years later, Rise (2012: 75) reached similar conclusions, noting that "legislation on user participation in health care has come before and despite any conclusive evidence that participation is effective". This essay concurs, and adds that insufficient empirical evidence from an outcomes-based approach is matched by a paucity of robust justification from a rights-based perspective. This does not necessarily mean that the patient's voice is not important, but does suggest that arguments from both approaches are currently insufficiently developed to offer firm conclusions as to the importance of the patient's voice in mental health care.

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