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BRIEF REPORT

Consumers' Suggestions for Improving the Mental Healthcare System: Options, Autonomy, and Respect

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Abstract

While the mental healthcare-consumer voice has gained in legitimacy and perceived value, policy initiatives and system improvements still lack input from consumers. This study explores consumers' suggestions for improving the mental healthcare system. Participants (N = 46) were conveniently recruited and responded to an online survey asking: "What are your suggestions for improving the mental healthcare system?" Eight themes were identified using iterative, inductive and deductive coding. Themes included treatment options, autonomy and empowerment, respect and relationships, medication management, peer support, insurance and access, funding and government support, and treatment environment. Theoretically, there is interdependence among themes where five of the themes are foundational for the three main themes (i.e. treatment options, autonomy and empowerment, respect and relationships). Findings suggest that consumers see the need for improvement in patient-centered care. While access is the focus of much mental healthcare policy discussions, the ultimate goal should be provisioning person-centered mental healthcare.

Keywords Quality · System reform · Patient perception · Policy

Introduction

There has been substantial effort to improve the mental healthcare system over the past several decades (Barber 2012; Thornton and Lucas 2010; Ivey et al. 1998). Central features of this push have been increased emphasis on consumers' perspectives and patient-centered care (MacDonald-Wilson et al. 2015; Storm and Edwards 2013; Tomes 2006). Indeed, this pattern of increased research on and incentivizing of consumer engagement (or activation) with their care is broadly increasing throughout the healthcare system, with research studies demonstrating a positive relationship between engagement and outcomes (Hibbard et al. 2013; Hibbard and Greene 2013; Salyers et al. 2009). However, while the consumer voice has been gaining in legitimacy and value, policy initiatives and system improvements continue to lack the input of those served. Such integration at the policy level is especially important for mental healthcare consumers who have a history of organizing to have their voices heard and respected (Ridley et al. 2015; Morrison 2013) and whose engagement with care likely depends on how the larger system is organized and performs.

While there has been notable progression in making space for mental healthcare consumers in local and state polices, regulations, and leadership roles (Tomes 2006; Geller et al. 1998), much work remains to make their voice and expertise central to decision-making. Furthering the meaningful use of consumers' opinions and experience into reform discussions and research might help to shape cost-effective treatment options, improve quality and outcomes, and increase feelings

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of respect and trust (Laugharne and Priebe 2006; Stromwall and Hurdle 2003; Fisher 1994).

Past research demonstrates the importance of examining consumers' experiences of mental healthcare and their suggestions for improvement. Consumers report inpatient experiences marked by perceived safety concerns, feelings of frustration, and the need for self-preservation (Stenhouse et al. 2009). Consumers also report low satisfaction with information provided, privacy, involvement with treatment decisions, and the availability of medical providers (Cleary et al. 2003; Barker et al. 1996). Consumers consistently report the desire for greater autonomy, empowerment in treatment decisions, respect, and peer involvement (Roth and Crane-Ross 2002; Deegan 1997; Roth et al. 1998; Howard et al. 2003; Cleary et al. 2003; Simpson and House 2002). In fact, Roth et al. (1998) found that consumers viewed empowerment and the feeling of being taken seriously as "the most critical aspect of their treatment." Accordingly, we were interested in exploring consumers' suggestions for improving the current mental healthcare system, as opposed to exploring their lived experiences or what they believe constitutes good care.

We used data collected from an exploratory study during the summer of 2015 to analyze suggestions for improving the mental healthcare system from adults who had experienced inpatient psychiatric care at least once. Our primary aim was to illuminate and describe the emergent themes among suggestions. We did not aim to test hypotheses in this study, which would have been inappropriate given the nature of the data.

Methods

Participants

We recruited a convenience sample via flyers at bus stops, in coffee shops, on college campuses, and in grocery stores (primarily in and around Boston, MA), social media platforms (Facebook, Twitter, and LinkedIn), and through email listserves from June to August 2015. A convenience sample was the only feasible approach to recruiting for the larger study from which this paper originates. Participants had to be 18–65 years old and have been hospitalized within an inpatient psychiatric facility at least once; this enabled a wider range of insights to emerge that included the inpatient context.

Procedure and Measures

The current study is part of a larger exploratory project focused on quality of inpatient psychiatric care, which required participants to take a series of questionnaires for roughly 20-min using the internet platform REDCap (Harris et al. 2009). The questionnaires included topics related to demographics, quality of inpatient psychiatric care, and internalized stigma. Eighteen of these individuals later participated in interviews, although these data are not reported on in this paper. The current study only uses data from the demographics survey and one free-response question asked at the end of the demographics survey. After consenting, participants were asked to report on the following demographics: age, income (< $25,000, $25,000–$49,999, $50,000–$99,999, $100,000+), psychiatric diagnostic history, highest level of education (completed an advanced degree, completed 4 years of college, completed trade schools or 2-years of college, some college or trade school, high school or GED, did not graduate high school or obtain a GED), race/ethnicity (White, Black or African American, American Indian or Alaskan Native, Asian or Other Pacific Islander), and type of insurance coverage (public/private/no insurance). At the end of the survey, participants were asked to share their suggestions for improving the mental healthcare system by typing into a free response box.

Analyses

We performed descriptive analysis on the demographic variables and conducted a content analysis of participants' suggestions for improving the mental healthcare system using an inductive and deductive coding approach. The first and second author each openly coded all responses and then met a total of four times to discuss differences in identified themes. After agreeing on overarching themes, the coders re-coded responses using the updated framework and calculated the Cohen's kappa coefficient for inter-rater reliability using all of the data. This analytic approach has been widely used (Bradley et al. 2007). Once agreement was reached, we averaged codes. All study procedures were approved by the researchers' Institutional Review Boards of Massachusetts General Hospital and Boston Medical Center.

Results

Out of a total of 54 participants, 8 did not respond to the primary question asking for their suggestions to improve the mental healthcare system, leaving an analysis sample of 46. The mean age was 45 (SD = 13.5), 34 (73.9%) were female, 28 (60.9%) had at least a 4-year college degree, 41 (89.1%) were white, and 23 (50.0%) earned less than $25,000 a year. These participants were from several states, with the greatest concentration from Massachusetts at 17 (37.0%). On average, participants reported receiving approximately three different psychiatric diagnoses in their lifetime, with 34.8% of the sample having received four or more (range 1–14).

We identified eight overarching themes among the participants' suggestions for improving the mental healthcare system (κ = .85, considered almost perfect agreement): treatment options; autonomy and empowerment; respect and relationships; medication management; insurance and access; peer support; treatment environment; and funding and government support. The most salient themes were treatment options; autonomy and empowerment; and respect and relationships. While these themes are mutually exclusive, representing distinct phenomena, they are practically related. For example, a consumer who feels like they have adequate treatment options might, as a consequence, feel more autonomous and empowered. Similarly, a consumer's relationship with their clinician and feelings of respect might co-occur with feelings of autonomy and empowerment. We conceptualize the other themes to be systemic elements that would support the operationalization of these more salient themes, rather than sub-themes. Below we describe each theme and provide example quotes. Because we were not always able to distinguish the type of "professional" consumers referenced when discussing clinicians (e.g., nurses, psychiatrists, or social workers), we use the term "provider" as a catchall term.

Treatment Options (Main; N = 21)

Suggestions were coded as "treatment options" if they focused on increasing the diversity of available treatment approaches or the accessibility of certain modalities, such as tailored, innovative, evidence-based, or alternative treatments. Some specific suggestions included greater trauma-informed care, more holistic approaches, alternatives to hospitalization, and increased community supports.

> We need a lot more crisis alternatives to hospitalization, less reliance on heavy-duty psych meds and more about wellness and recovery and an emphasis on what we do well, not our disabilities. (65, white, female, diagnosed with depression, income 25–49,999k)

> More providers with eclectic-type therapies may need to become available. As all therapies do not work for all persons. Each person is an individual human being with specialized needs. (32, white, female, 14 diagnoses, income < 24,999k)

> There needs to be alternatives to the traditional medical model. There needs to be a focus on overall health, so a focus on nutrition, building community and social networks, making meaning out of crisis… (37, white, female, 3 diagnoses, income 50–99,999k)

Autonomy and Empowerment (Main; N = 20)

We coded suggestions as "autonomy and empowerment" if they related to the agency and self-advocacy of consumers and their families. Some individuals mentioned that they wanted individualized and less hierarchical care that they played an active role in shaping. They also stressed that treatment providers should have some training *by* individuals with lived experience. Others mentioned the need to have explicit training for consumers and family on individual self-advocacy and larger systems-level change.

> Our judgment should be respected; too often providers think they 'know best' when they have only just met us! I just wish we could be seen as people just like everyone else. (55, white, female, 4 diagnoses, income < 24,999k)

> Service users must articulate what we need and want, and advocate that those are the services we will use. (64, white, female, diagnosed with schizophrenia and depression, income 100 k+)

> More advocacy training for families and persons with mental illness so laws will change (55, white, female, 3 diagnoses, income < 24,999k)

Respect and Relationships (Main; N = 15)

We coded suggestions as "respect and relationships" if they had to do with provider interactions, perceived provider attitude, treatment that recognizes patients' inherent value and rights. Specific suggestions included the need to care for consumers' property, to measure provider qualifications by outcomes and not only credentials, to have greater compassion from providers, to have better sensitivity training for providers, and to feel understood and seen as having value instead of being reduced to a diagnosis.

> I feel that these places need to be a lot more humane and a nicer environment … and less infantilizing attitudes. (33, American Indian or Alaskan Native, female, diagnosed with schizophrenia, income 50–99,999k)

> Patients need to be seen as real, struggling, suffering people who have value and are trying our best. We need to be treated with respect and have our dignity left intact. (55, white, female, 4 diagnoses, income < 24,999k)

Medication Management (Supportive; N = 11)

We coded suggestions as "medication management" whenever participants referenced psychiatric medications and their use. Specific suggestions were that providers should use medications minimally and in conjunction with cognitive therapy, rigorously investigate consumers' medication history, more seriously consider the implications of certain medicines given individual differences (i.e., what works for one person might not work for another), and furnish detailed information about medications' side effects. In addition, some participants suggested addressing the laws governing the operation of pharmaceutical companies.

> Minimal use of chemicals for treatment is imperative and the willingness of providers to accept and support alternative models of treatment for some (not all), will I believe 'open doors' for those who hesitate because of chemical side effects and of course sadly the stigma. (22, white, female, diagnosed with Bipolar, income N/A)

> Information about the side effects should be given to the consumers ahead of time and appropriate alternatives to the medication should be given to the patients because of this. (35, Black or African American, male, diagnosed with schizoaffective disorder and depression, income < 24,999k)

Peer Support (Supportive; N = 10)

Suggestions were coded as "peer support" whenever participants mentioned the need or desire for professional services from peers and individuals with lived experiences. Given the salience of "peer support," we decided to keep this theme distinct from the general theme of "treatment options" and characterize it as a supportive element. Participants suggested that peers should have a meaningful voice in leadership of federal agencies, research, program development, and direct support at every point in the care continuum. Participants also suggested the expansion of peer respites for crisis response and prevention, peer "warmlines" (i.e., emotional and psychological telephone support services), and community peer visits at home or in care settings. Finally, they also stressed the importance of having certified peer specialists in hospitals, police departments, and prisons.

> We need peer-run respites to be available throughout the country and throughout each state. If one had been available to me, I don't think I would have ever been hospitalized… Hire peer specialist in every area of mental health services; fund more peer-run & peer-controlled services; establish peer-run respites in every area. (44, white, female, diagnosed with bipolar disorder and PTSD, income < 24,999k)

> Peers need to have a voice, to be meaningfully involved and their outcomes and priorities need to be centered; not just in rhetoric, but in reality. (34, white, female, diagnosed with schizophrenia, income 25–49,999k)

Insurance and Access (Supportive; N = 9)

Participants suggested the need for more consistent and equitable insurance coverage, greater access to care for the uninsured, health insurance reform, and requirements that insurance companies cover additional non-pharmacological treatments. However, while participants largely provided suggestions concerning insurance coverage and access, they also stated that providers should be less bound to insurance requirements when providing treatment.

> Everyone should have access to mental health care, if they want it and it is medically necessary. (65, white, female, 5 diagnoses, income 25–49,999k)

> Universal health care/Medicare for all. (25, white, female, 4 diagnoses, income 25–49,999k)

Funding and Government Support (Supportive; N = 6)

Some participants mentioned "funding and government support." These participants suggested that additional funding from local, state, and federal governments is imperative to better understand the causes of and treatments for mental illness. They also stated their desire for legislation to bridge the disconnect between what consumers want and need and what is currently provided.

> More funding for mental illness research. (40, white, female, 3 diagnoses, income < 24,999k)

Treatment Environment (Supportive; N = 5)

We coded for "treatment environment" whenever participants discussed an inpatient service facility's milieu or infrastructure. Participants suggested that inpatient care needs to be less frightening, prison-like, and regimented. They also cited the need for an updated therapeutic environment, specifically noting that the décor of many inpatient facilities needs improvement.

> I think most hospitals are really frightening places. I don't think they should be hospitals, but instead more like rehab facilities where people are less restricted. (33, American Indian or Alaskan Native, female, diagnosed with schizophrenia, income 50–99,999k)

> Make psychiatric wards feel less like a prison. (43, white, male, diagnosed with bipolar disorder, income < 24,999k)

Discussion

We identified eight overall themes: treatment options, autonomy and empowerment, respect and relationships, medication management, insurance and access, peer support, treatment environment, and funding and government support. Despite the dominant focus on access (e.g., parity) and funding of mental healthcare among reform discussions (Beronio et al. 2014; Bishop et al. 2014), the domains in need of improvement according to the majority of consumers had to do with consumer agency and treatment within the mental healthcare system, at the interpersonal and treatment modality levels.

While we distinguished emergent themes for the purposes of understanding the landscape of consumer suggestions, our analysis suggests that these domains interrelate in dynamic ways not entirely captured within the scope of this study. We theorize medication management, peer support, insurance and access, treatment environment, and funding and government support to be supportive, or consequential, of the three main themes of expanded treatment options, autonomy and empowerment, and relationships and respect. For example, in order to have expanded treatment options there needs to be the structural support of insurance coverage and access to these options. Further, the themes of medication management and peer support are both types of specific treatment options and likely play a role in consumers' feelings of agency, empowerment, and respect (Chinman et al. 2014; Mead et al. 2001). Finally, both peer support methods and the treatment environment might influence provider-consumer relationships and feelings of respect (Chinman et al. 2014; Curtis et al. 2007).

Autonomy and empowerment was the second most suggested theme and further highlights the importance of patient engagement research and incentive structures. What patient engagement looks like to mental healthcare consumers, however, is perhaps distinct compared to other areas of healthcare (Salyers et al. 2009; Alegría et al. 2008). The financing of mental healthcare might play a role in determining the extent to which a consumer can have agency (Salkever et al. 2014), as well as incentivize organizations and providers to modify their standards of care (Horgan et al. 2016; Bao et al. 2013). Moreover, insurance coverage is tightly aligned with the current reliance on pharmaceutical treatment approaches, which was its own distinct theme to have emerged (medication management). Pharmacologic treatment methods might be the most cost-effective for insurers and providers compared to other methods. However, while psychotropic and antipsychotic medication might be effective for some consumers in the short term, there is evidence for concern when it comes to the long-term efficacy and consequences born by the consumer (Wunderink et al. 2013; Harrow and Jobe 2007). It is critical, then, that mental healthcare consumers are able to partake in shared-decision making, where costs and benefits can be weighed in a collaborative fashion, and that providers' have the capacity to deliver such person-centered care.

The findings from this study provide an important extension of past work exploring consumers' perspectives and experiences of the system. The consumers/survivors/ex-patient movement highlighted the importance of consumer engagement in the recovery process—one that moves beyond a narrow focus on symptom reduction to encompass a holistic view of consumers and their needs (Drake et al. 2010; Anthony 1993; Deegan 1988). Recovery is conceptualized as non-linear and deeply individual, suggesting the centrality of consumer engagement and shared decision-making, including decisions regarding medication (Schön et al. 2018; Deegan and Drake 2006; Onken et al. 2007; Matthias et al. 2012). Slade et al. (2014) propose a ten-pronged pro-recovery framework involving peer support workers, psychiatric advance directives, wellness recovery action planning, illness management and recovery, the REFOCUS intervention for community mental health providers, a strengths model of case management, recovery colleges or recovery education programs, individual placement and support, supported housing, and mental health "trialogues." Additionally, recovery-based systems should offer engaging, personalized programming that is free of stigma and that recognizes the importance of non-professional supports (Anthony 1993).

All three of our main themes (expanded treatment options, autonomy and empowerment, and relationships and respect) and three of our five supportive themes (medication management, peer support, and treatment environment) are discussed at length in the recovery-oriented literature. However, the fact that consumers cited them as areas needing improvement in 2015 suggests that there remains an ongoing and urgent need to further alter the scope and focus of the mental healthcare system. For example, Gumber and Stein (2013) found that the first-person reports of consumers diagnosed with schizophrenia did not differ significantly from 1979 to 2010, with the frequency of negative themes (30%) regarding inpatient hospitalization far exceeding positive ones (12%).

It is important to note that the participants in this study had received an average of three different psychiatric diagnoses in their lifetime, with over a third of the sample having received four or more diagnoses. This phenomenon is common for mental healthcare and is directly linked to insurance providers' reliance on diagnoses to determine coverage; both public payers and private payers typically require mental health to align with the taxonomic approaches of physical health (Lowe et al. 2007; Braun and Cox 2005). However, it has been demonstrated numerous times that mental distress does not fit the treatment and classification methods of physical illness and that accumulating labels and misdiagnoses can have iatrogenic effects on consumers by way of their self-perception, providers' perception of the consumer, and access to certain treatments (Sanders 2011; McHugh et al. 2004). Therefore, addressing the financing structure and role and validity of psychiatric diagnoses might be an apt mechanism for reform. Focusing on these factors could support expanding treatment options, which was the one domain the majority of consumers suggested needs improvement, along with other components of care such as medication management, relationships and respect.

Limitations

This study is limited by its exploratory design and convenience sampling. In addition, the aims explored in this paper use data from a larger study; therefore, the design of the study was not tailored towards addressing the aims of the study presented here. In particular, our sample was comprised of people who had experienced inpatient psychiatric care at least once in their life, which was an intentional inclusion criterion for the larger study but not necessarily as useful for this sub-analysis. While there was great variation in the number of times individuals had been hospitalized, the suggestions might not represent the suggestions of those who have only ever experienced outpatient mental healthcare or individuals who do not even have access to the mental healthcare system. However, it could be argued that our sampling approach allowed for richer lived experience with the system that includes the inpatient context and from individuals who might have more chronic mental health conditions and utilize services at higher rates relative to outpatient-only consumers. Further, participants for this study were primarily white women, though there was diversity in age, diagnoses, and income. However, it is important to note that the goal of qualitative research is not to make quantitative inferences or generalizable conclusions. Future research should consider building upon this work to develop a survey that could be used to assess consumers' suggestions for improving the mental healthcare system, for which more representative sampling techniques could be appropriately applied.

Conclusion

This study lays important groundwork for survey design and more rigorous follow up studies and has also identified very specific calls to action for policy makers. Moreover, given the lack of research into consumer engagement when it comes to systems improvement more generally, this study also helps to prepare the foundation for such research outside of the mental healthcare context. Future work should attempt more far-reaching and targeted sampling techniques. The findings of this study suggest that improvement in mental healthcare practice and policy should focus on expanding treatment options, autonomy, empowerment, and respect at least equally, if not more, than the current focus on access and funding. However, given the complexity and interdependence between these main themes and the supportive themes, it would be more apt to suggest that the primary goal for policy makers should be to support the person-centered transformation of the mental healthcare system, with the understanding that parity and financial support are critical starting points and potentially powerful foundations for achieving this goal.

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

References

Alegría, M., Polo, A., Gao, S., Santana, L., Rothstein, D., Jimenez, A., … Normand, S.-L. (2008). Evaluation of a patient activation and empowerment intervention in mental health care. *Medical Care, 46*(3), 247.

Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal, 16*(4), 11–23.

Bao, Y., Casalino, L. P., & Pincus, H. A. (2013). Behavioral health and health care reform models: Patient-centered medical home, health home, and accountable care organization. *The Journal of Behavioral Health Services & Research, 40*(1), 121–132.

Barber, M. E. (2012). Recovery as the new medical model for psychiatry. *Psychiatric Services, 63*(3), 277–279. https://doi.org/10.1176/appi.ps.201100248.

Barker, D. A., Shergill, S. S., Higginson, I., & Orrell, M. W. (1996). Patients' views towards care received from psychiatrists. *The British Journal of Psychiatry, 168*(5), 641–646.

Beronio, K., Glied, S., & Frank, R. (2014). How the affordable care act and mental health parity and addiction equity act greatly expand coverage of behavioral health care. *The Journal of Behavioral Health Services & Research, 41*(4), 410–428.

Bishop, T. F., Press, M. J., Keyhani, S., & Pincus, H. A. (2014). Acceptance of insurance by psychiatrists and the implications for access to mental health care. *JAMA Psychiatry, 71*(2), 176–181.

Bradley, E. H., Curry, L. A., & Devers, K. J. (2007). Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health Services Research, 42*(4), 1758–1772.

Braun, S. A., & Cox, J. A. (2005). Managed mental health care: Intentional misdiagnosis of mental disorders. *Journal of Counseling and Development: JCD, 83*(4), 425.

Chinman, M., George, P., Dougherty, R. H., Daniels, A. S., Ghose, S. S., Swift, A., et al. (2014). Peer support services for individuals with serious mental illnesses: Assessing the evidence. *Psychiatric Services, 65*(4), 429–441.

Cleary, M., Horsfall, J., & Hunt, G. E. (2003). Consumer feedback on nursing care and discharge planning. *Journal of Advanced Nursing, 42*(3), 269–277. https://doi.org/10.1046/j.1365-2648.2003.02616.x.

Curtis, S., Gesler, W., Fabian, K., Francis, S., & Priebe, S. (2007). Therapeutic landscapes in hospital design: A qualitative assessment by staff and service users of the design of a new mental health inpatient unit. *Environment and Planning C: Government and Policy, 25*(4), 591–610.

Deegan, P. E. (1988). Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal, 11*(4), 11–19.

Deegan, P. E. (1997). Recovery and empowerment for people with psychiatric disabilities. In U. Aviram (Ed.), *Social work in mental health: Trends and issues*. Binghamton, NY: The Haworth Press.

Deegan, P. E., & Drake, R. E. (2006). Shared decision making and medication management in the recovery process. *Psychiatric Services, 57*(11), 1636–1639. https://doi.org/10.1176/ps.2006.57.11.1636.

Drake, R. E., Deegan, P. E., & Rapp, C. (2010). The promise of shared decision making in mental health. *Psychiatric Rehabilitation Journal, 34*(1), 7–13. https://doi.org/10.2975/34.1.2010.7.13.

Fisher, D. B. (1994). Health care reform based on an empowerment model of recovery by people with psychiatric disabilities. *Psychiatric Services, 45*(9), 913–915.

Geller, J. L., Brown, J.-M., Fisher, W. H., Grudzinskas, A. J., Jr., & Manning, T. D., Jr. (1998). A national survey of "consumer empowerment" at the state level. *Psychiatric Services, 49*(4), 498–503.

Gumber, S., & Stein, C. H. (2013). Consumer perspectives and mental health reform movements in the United States: 30 years of first-person accounts. *Psychiatric Rehabilitation Journal, 36*(3), 187–194.

Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics, 42*(2), 377–381.

Harrow, M., & Jobe, T. H. (2007). Factors involved in outcome and recovery in schizophrenia patients not on antipsychotic medications: A 15-year multifollow-up study. *The Journal of Nervous and Mental Disease, 195*(5), 406–414.

Hibbard, J. H., & Greene, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. *Health Affairs, 32*(2), 207–214.

Hibbard, J. H., Greene, J., & Overton, V. (2013). Patients with lower activation associated with higher costs; delivery systems should know their patients' "scores". *Health Affairs, 32*(2), 216–222.

Horgan, C. M., Stewart, M. T., Reif, S., Garnick, D. W., Hodgkin, D., Merrick, E. L., et al. (2016). Behavioral health services in the changing landscape of private health plans. *Psychiatric Services, 67*(6), 622–629.

Howard, P. B., El-Mallakh, P., Rayens, M. K., & Clark, J. J. (2003). Consumer perspectives on quality of inpatient mental health services. *Archives of Psychiatric Nursing, 17*(5), 205–217.

Ivey, S. L., Scheffler, R., & Zazzali, J. L. (1998). Supply dynamics of the mental health workforce: Implications for health policy. *The Milbank Quarterly, 76*(1), 25–58. https://doi.org/10.1111/1468-0009.00078.

Laugharne, R., & Priebe, S. (2006). Trust, choice and power in mental health. *Social Psychiatry and Psychiatric Epidemiology, 41*(11), 843–852.

Lowe, J., Pomerantz, A. M., & Pettibone, J. C. (2007). The influence of payment method on psychologists' diagnostic decisions: Expanding the range of presenting problems. *Ethics and Behavior, 17*(1), 83–93.

MacDonald-Wilson, K. L., Schuster, J. M., & Wasilchak, D. (2015). In managed behavioral health care, a seat at the table is not enough. *Psychiatric Rehabilitation Journal, 38*(4), 374.

Matthias, M. S., Salyers, M. P., Rollins, A. L., & Frankel, R. M. (2012). Decision-making in recovery-oriented mental health care. *Psychiatric Rehabilitation Journal, 35*(4), 305–314.

McHugh, M., Caplan, P. J., & Cosgrove, L. (2004). *Bias in psychiatric diagnosis*. Lanham: Jason Aronson.

Mead, S., Hilton, D., & Curtis, L. (2001). Peer support: A theoretical perspective. *Psychiatric Rehabilitation Journal, 25*(2), 134.

Morrison, L. J. (2013). *Talking back to psychiatry: The psychiatric consumer/survivor/ex-patient movement*. London: Routledge.

Onken, S. J., Craig, C. M., Ridgway, P., Ralph, R. O., & Cook, J. A. (2007). An analysis of the definitions and elements of recovery: A review of the literature. *Psychiatric Rehabilitation Journal, 31*(1), 9–22.

Ridley, J., Newbigging, K., McKeown, M., Sadd, J., Machin, K., Cruse, K., … Poursanidou, K. (2015). *Independent mental health advocacy-the right to be heard: Context, values and good practice*. London: Jessica Kingsley Publishers.

Roth, D., & Crane-Ross, D. (2002). Impact of services, met needs, and service empowerment on consumer outcomes. *Mental Health Services Research, 4*(1), 43–56.

Roth, D., Crane-Ross, D., Hannon, M., Cusick, G., & Doklovic, S. (1998). Longitudinal study of mental health services and consumer outcomes in a changing system. In D. Roth (Ed.), *New research in mental health* (Vol. 13, pp. 104–116). Columbus, OH: Ohio Department of Mental Health.

Salkever, D., Gibbons, B., & Ran, X. (2014). Do comprehensive, coordinated, recovery-oriented services alter the pattern of use of treatment services? Mental health treatment study impacts on SSDI beneficiaries' use of inpatient, emergency, and crisis services. *The Journal of Behavioral Health Services & Research, 41*(4), 434–446.

Salyers, M. P., Matthias, M. S., Spann, C. L., Lydick, J. M., Rollins, A. L., & Frankel, R. M. (2009). The role of patient activation in psychiatric visits. *Psychiatric Services, 60*(11), 1535–1539.

Sanders, J. L. (2011). A distinct language and a historic pendulum: The evolution of the diagnostic and statistical manual of mental disorders. *Archives of Psychiatric Nursing, 25*(6), 394–403.

Schön, U.-K., Grim, K., Wallin, L., Rosenberg, D., & Svedberg, P. (2018). Psychiatric service staff perceptions of implementing a shared decision-making tool: A process evaluation study. *International Journal of Qualitative Studies on Health and Well-being, 13*(1), 1421352. https://doi.org/10.1080/17482631.2017.1421352.

Simpson, E. L., & House, A. O. (2002). Involving users in the delivery and evaluation of mental health services: Systematic review. *British Medical Journal, 325*(7375), 1265–1271.

Slade, M., Amering, M., Farkas, M., Hamilton, B., O'Hagan, M., Panther, G., … Whitley, R. (2014). Uses and abuses of recovery: Implementing recovery-oriented practices in mental health systems. *World Psychiatry, 13*(1), 12–20. https://doi.org/10.1002/wps.20084.

Stenhouse, R. C., Bondi, L., Robertson, A., & Tilley, St. (2009). Unfulfilled expectations: A narrative study of individuals' experiences of being a patient on an acute psychiatric inpatient ward in Scotland. *Doctoral Dissertation*. Retrieved from Edinburgh Research Archive.

Storm, M., & Edwards, A. (2013). Models of user involvement in the mental health context: Intentions and implementation challenges. *Psychiatric Quarterly, 84*(3), 313–327.

Stromwall, L. K., & Hurdle, D. (2003). Psychiatric rehabilitation: An empowerment-based approach to mental health services. *Health and Social Work, 28*(3), 206–213.

Thornton, T., & Lucas, P. (2010). On the very idea of a recovery model for mental health. *Journal of Medical Ethics*. https://doi.org/10.1136/jme.2010.037234.

Tomes, N. (2006). The patient as a policy factor: a historical case study of the consumer/survivor movement in mental health. *Health Affairs, 25*(3), 720–729.

Wunderink, L., Nieboer, R. M., Wiersma, D., Sytema, S., & Nienhuis, F. J. (2013). Recovery in remitted first-episode psychosis at 7 years of follow-up of an early dose reduction/discontinuation or maintenance treatment strategy: Long-term follow-up of a 2-year randomized clinical trial. *JAMA Psychiatry, 70*(9), 913–920.