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Recent Advances in Shared Decision Making for Mental Health

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Abstract

Purpose of review—To advance integration of shared decision making (SDM) into mental health care service delivery, researchers have outlined several priorities for future research [2–3]. These include: 1) SDM and its role in mental health care; 2) Patient and provider perspectives on SDM; 3) The degree to which SDM is practiced in mental health settings; and 4) Outcomes of SDM in mental health populations. This article will review recent advances in these areas.

Recent findings—The current literature shows that 1) SDM can play a role in the mental health treatment process from entry into care to recovery; 2) Patients and providers find SDM acceptable and express a willingness to engage in SDM for reasons that are multifactorial; 3) Barriers to SDM exist in mental health decision making including patient preferences and provider level biases; and 4) Outcomes research provide encouraging preliminary evidence for feasibility and effectiveness of SDM during the mental health encounter.

Summary—Although there have not been a great number of SDM studies in mental health to date, the positive effects of SDM are comparable to those documented in general non-mental health patient groups, suggesting that future research is likely to be helpful for patients with psychiatric disorders.

Keywords

shared decision making; mental health; patient-provider relationship; communication

Introduction

Shared decision making (SDM) has received considerable attention as a communication method to improve the quality of health care delivery. Although a majority of the research evaluating SDM has been conducted in general health populations (e.g. cancer and cardiac patient groups) [1], patient participation in the mental health populations has received increasing interest [2–7]. Along with this interest, questions arise including: What is the role of SDM in mental health? Is SDM acceptable and feasible to mental health patients and providers? To what degree is SDM practiced in mental health settings? Finally, what are the

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outcomes associated with SDM? In this review, the authors summarize recent research findings to answer these questions.

Literature Search Strategy

For this review two systematic searches were performed. An exhaustive review of research on shared decision making for mental health was conducted for the time period 1990- January 2007 (search 1). To update the review for the purpose of this paper with the most recent publications, we performed an additional search (search 2) from January 2007 to April 2008. For both searches the following electronic databases were searched: MEDLINE, PsycINFO, and Cochrane Library. In each database every term was searched in the database thesaurus and as free text/key word. The following terms were the central search terms used, further synonyms were added: ('mental health decision making' OR 'patient participation' OR shared decision making' AND psychiatr* OR schizophr* OR depress* OR patient decision aids AND psychiatry OR mental health.)

Inclusion criteria were publications restricted to the topic of decision making for treatment psychiatric disorders, English language articles, conceptual and theoretical articles, studies on patient, provider and mental health system perspectives of SDM, all types of research designs and qualitative research. Exclusion criteria included editorials and articles that examined the effect of SDM on psychological parameters such as anxiety in general health (e.g. cancer and cardiac) patient groups. In search 2 the search strategy, the inclusion and exclusion criteria from the first search remained unchanged, however restricted to only research articles including all types of research designs, perspectives articles and qualitative research with at least 10 subjects.

The search in the online databases and cross referencing yielded 115 titles for search 1 and additional 11 for search 2. From the two searches combined, 102 were excluded after the abstract had been read, as they did not meet criteria. Twenty-four articles were retained for both searches 1 and 2 and will form the basis for discussion in this review.

Shared Decision Making

SDM is built upon the notion that there are two experts in the consultation room: the patient and the provider. Providers have expertise in the science-informed processes of medical diagnosis and treatment. Patients have the expertise by virtue of the lived experience of their disorder, and their intimate knowledge of what gives their life value, meaning, purpose and quality. Ideally both knowledge domains are bridged through the process of SDM, as both parties strive for agreement on what the problem is and what the outcomes of treatment should be [8]. SDM is seen as an intermediate stage between a traditional paternalistic model and an informed choice model. For the patient SDM offers some say without total responsibility, and for the provider an opportunity to go beyond a role of transferring information to also participate in, but not dominate, the decision-making process. Charles *et al.* [9] outline a three-stage model of decision-making consisting of: 1) bidirectional information exchange; 2) deliberation (e.g. expressing and discussing preferences and treatment options); and 3) selection of treatment to implement that is consistent with patients' values and preferences.

Decision support interventions and decision aids can help facilitate the process of SDM [10]. In order to facilitate and standardize the shared decision-making process, decision aids have been developed for defined medical situations. Decision aids are evidence-based tools intended to assist the process of making informed values-based choices about screening, treatment options and disease management. They are designed to supplement rather than replace patient-provider interaction. A variety of media is used to present the information in an accessible form to patients, including pamphlets, audiotapes, interactive programs, websites, and decision

boards [10]. In a Cochrane review, O'Connor *et al.* [11**] concluded that decision aids increased patient involvement in decision-making, knowledge, and the proportion of patients with realistic expectations of the chances of benefits and harms, and reduced decisional conflict.

What is the Role of SDM in Mental Health?

In recent years, mental health practice has become increasingly complex in terms of the available treatment options, use of new technologies, and consumer driven health care. SDM has received interest in mental health for reasons of empowerment, autonomy, and quality of life. With this interest, ethical concerns have also been cited in the literature with respect to patient participation in SDM for psychiatric disorders. Hamann *et al.* [12] conducted the first review of SDM in mental health and discussed the feasibility of SDM raising important concerns about competency to participate and reduced decisional capacity [13] among illness groups such as the acutely ill, those with dementia, and schizophrenia. The authors cite evidence of capacity to give informed consent in pharmaceutical studies to participation in therapeutic/educational interventions and conclude that successful inclusion of psychiatric patients in the therapeutic process could counteract existent prejudice about capacity to participate and may even lead to increased empowerment and quality of life.

In the psychiatric literature thus far, SDM has been cited as a method to enhance the patient-provider relationship that can be used throughout the evolving treatment process from facilitating entry into care to recovery and psychiatric rehabilitation [8,10]. Deegan and colleagues assert that people with psychiatric disabilities need support to resolve decisional conflict regarding the use of psychiatric medications. Much like other groups with long-term disorders such as hypertension, epilepsy and AIDS, people with psychiatric disabilities experience decisional conflict for reasons of stigma, symptom suppression, and delayed onset of consequences due to discontinuation of medicine. Furthermore decisional conflict may arise when patients are faced with decisions about treatment that have high risks (e.g. side effects such as tardive dyskinesia) and for which there are two or more alternatives to address the health problem, or low certainty [14]. SDM is appropriate for such types of decisions.

Is SDM Acceptable and Feasible to Patients and Providers?

For SDM to take place there is an assumption of two active participants willing to engage in SDM and find it acceptable and feasible within the constraints of a clinical encounter. To date there has been mounting evidence that those with severe mental illness and depression endorse positive attitudes towards SDM, desire to be involved in decisions, and are able to participate in decision making [15,16 17**,18]. Four studies conducted in the past year (3 qualitative; 1 quantitative) reveal that patients' motivations to participate are multifactorial and often explained by their past experiences in treatment (e.g. involuntary treatment) [19], types of treatment-related decisions to be made, and their desire for recovery.

In a pilot study of 30 patients with severe mental illness Adams *et al.* [20**] found that patients generally preferred greater participation than they are offered, and their preferences vary in relation to the type of decision being made with particular preference for involvement about decisions regarding medications.

Using qualitative focus group data, Tannenbaum *et al.* [21*] examined consumer perspectives on information and decision making with the severely mentally ill. Their qualitative data revealed that consumers very much want information about their illness, welcome scientific evidence and like to be kept up-to-date about illness and treatment related information as well

as broader supports within the mental health system. Trust in one's provider and recovery from illness was cited as especially important.

Hamann *et al.* [22**] examined the extent to which psychiatrists and patients agree on which events are considered to be decisions in treatment for schizophrenia, particularly decisions about medications, nonpharmacological treatments, hospital discharge or change in treatment setting.

In addition to illness and diagnosis-specific characteristics and contextual characteristics (i.e. setting) there are other factors such as culture that may also influence preferences for decision making regarding mental health treatment. Charles and colleagues [23] discuss the influence of culture on the treatment decision-making process and challenge cultural assumptions underlying the development of decision-making interventions.

In the first study examining cultural variations, Cortes *et al.* [24*] examined qualitative data on Latino perspectives of a patient activation and empowerment program in community mental health care settings and found that some participants were reluctant to use some of the participation skills learned due to concerns about offending their providers because they view them as friends or family members valuing the 'personalismo' (personalism) aspect of care, or their attitudes towards the provider as an all-knowing authority figure. Attitudes and customs of some cultures may represent facilitators or barriers to patient participation in decision making.

Provider perspectives on participation in SDM are characterized by a cautious willingness. In general most psychiatrists report advocacy of a cooperative therapeutic relationship yet particular obstacles exist. These include patient competence, the impact of unwanted side effects on motivation to participate in treatment, and honesty about adherence to medication [25].

Goossensen *et al.* [26**] measured the extent to which clinicians in a psychiatry department involve patients in decision making by using the Observing Patient Involvement in Treatment Choices instrument (OPTION). Results show that clinicians in the study are willing to engage in SDM with their patients however are not willing to ask their patients about preference for involvement in decision making and patients did not express great concern about this. Clinicians explained that they intuitively feel if a patient is capable and interested in participating in SDM.

To What Degree is SDM Practiced in Mental Health Settings?

Preferences for participation in SDM are multifactorial and it is important for providers to engage their patients prior to decision making and inquire about their preferences for participation. To what extent SDM is being practiced in settings where mental health needs are identified and treated has generated interest yet little research has been done in this area. Research has shown that SDM for mental health problems is being practiced at a low level in both psychiatric and primary care settings [26,27]. To date, research has shown that SDM for psychiatric disorders is being practiced at the level of information exchange (e.g. defining mental illness) and has not advanced beyond this first stage in the 3-stage model proposed by Charles *et al.* Several patient (i.e. culture), provider (i.e. biases) and system-level (i.e. time constraints) factors may be responsible for the low level of practice [27].

What Are the Outcomes Associated with SDM in Psychiatry?

Several researchers have taken initial steps towards understanding the effect of SDM by developing and testing SDM interventions. The focus of outcome research for SDM in mental

health has ranged from feasibility of SDM in various settings, decision process outcomes (i.e. knowledge, perceived involvement in decision making), and satisfaction with care. Clinical outcome data are inconclusive to date and merit further research.

In a prospective, national cohort study of depressed primary care patients, the Quality Improvement for Depression (QID) Project, researchers found that higher involvement in decision-making was associated with a higher probability of reporting guideline-concordant care and recovering from depression over an 18-month period [28]. Using the same QID data Swanson and colleagues [29**] performed cross-sectional analyses to understand if SDM and/or receipt of mental health care was associated with satisfaction with overall and mental health care. Given these encouraging findings about interpersonal care, authors discuss policy implications including benefit of health plans to train existing and future providers in SDM and including SDM in practice guidelines for depression care.

Randomized controlled trial research on the feasibility and effectiveness of shared decision making interventions both in severely mentally ill and depression show that compared to usual care the SDM interventions do not result in longer consultation time and are associated with positive decision process outcomes. Hamann *et al.* [14] conducted the first controlled trial of SDM in a sample of acutely ill patients with schizophrenia and found that it was feasible for most patients to be involved in decisions about their care, patients had better knowledge about their illness and a higher level of perceived involvement in decision-making. In an RCT of a primary care-based intervention for prevention of depression relapse, Ludman and colleagues [30] tested a SDM approach for treatment of depression and found improvement in self-efficacy, tracking of depression symptoms, and planning for coping with high-risk situations.

Loh *et al.* [31**] conducted a cluster randomized controlled trial of a SDM intervention in primary care of depression and found that the intervention was better than usual care for improving patient participation in treatment decision making and satisfaction with care without increasing consultation time.

In an pre/post test comparison group evaluation of a patient self-reported activation and empowerment intervention, the Right-Question Project-Mental Health, Alegría *et al.* [32**] found that self-reported activation, attendance to scheduled visits and retention in treatment improved for minority patients seeking treatment in community mental health clinics.

Conclusion

Since the review by Hamman *et al.* [12] five years ago, there has been considerable advancement in research on SDM and its applications in mental health. Recent evidence points favorably towards the inclusion of SDM in mental health decision making given that majority of patients with mental illness prefer to be involved in the process and desire information about their illness. It is important to remain mindful that preferences for participation can vary by demographics and treatment experiences. Studies examining the degree of SDM being practiced in mental health decision making indicate low levels of SDM practice. Providers express a willingness to engage patients however several barriers are noted in the literature including: competence to participate, preference to rely on intuition regarding patient interest in SDM, and concerns about patient medication use. Shared decision making intervention data provide good preliminary evidence for SDM as a method to improve mental health services including receipt of guideline-concordant care, attendance and retention in treatment, and satisfaction with health care. There is evidence that SDM is feasible and time comparable to usual care in psychiatric and primary care settings. Patients perceive greater involvement in the treatment process and increased knowledge about illness.

In summary, although there have not been a great number of SDM studies in mental health to date, the positive effects of SDM are comparable to those documented in general non-mental health patient groups, suggesting that future research is likely to be helpful for patients with psychiatric disorders. Future directions for SDM research in mental health include: assessment of preferences for participation, what participation means and how acceptable it is among diverse psychiatric and cultural populations, research on clinical outcomes of SDM, the development of decision aids and interventions that are in accordance with quality criteria [33], the development of multimedia decision support interventions [34**,35**], and a better understanding of barriers and facilitators for integrating SDM in mental health decision making at the provider and system level.

Abbreviations

SDM

Shared decision making

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Table 1
Studies of SDM for mental health from January 2007 to April 2008

Authors	Participants and clinical scenario	N	Study question and brief description	Outcome measures	Results
Adams <i>et al.</i> [8••], USA	Adults with severe mental illness in community mental health center	30	Pilot study of perceived role and preferences for shared decision making	Autonomy, Preference Index-Decision Making Scale (API-D), Control Preferences Scale (CPS)	Participants preferred greater participation than they experienced. Participants preferred SDM particularly with respect to their mental health care and medications
Alegria <i>et al.</i> [9••], USA	Latino outpatients from community mental health clinics, mood disorders	231 patients	Evaluation of Right-Question Project-Mental Health (RQP-MH: patient activation/empowerment intervention) using pre/posttest comparison group	Self-reported patient activation/empowerment	Intervention participants were two times more likely to be retained in treatment, three times more likely to have scheduled at least one visit during 6-month follow-up and had 29% more attendance to scheduled visits Significant increase in patient activation for intervention group
Cortes <i>et al.</i> [10•], USA	See Alegria <i>et al.</i> [9••]	141 patients	Qualitative data from RQP-MH to describe patient activation process in intervention group	Treatment attendance Retention in treatment Thematic analysis of open-ended questions from interviews	Patient activation and patient empowerment are interdependent processes Cultural (reluctance to ask questions given values of 'respeto' and 'personalismo') and contextual factors (navigating the mental health system) influence experience of Latinos' participation in care
Goossens <i>et al.</i> [11••], The Netherlands	Clinicians and patients in outpatient psychiatry clinic, mood disorders	61 patients, 8 clinicians	Measurement of SDM in consultations, patient satisfaction with clinician communication behaviors	Observing Patient Involvement in Treatment Choices (OPTION) Scale	Clinicians scored low on overall shared decision making

Authors	Participants and clinical scenario	N	Study question and brief description	Outcome measures	Results
Hamann <i>et al.</i> [12••], Germany	Psychiatric state hospitals and university clinic, schizophrenia	60 patients, 30 psychiatrists	Qualitative study of perceptions of clinical decision during treatment for schizophrenia	Semistructured interviews	<p>Clinicians were not willing to ask patients about preferences for participation in decision making and preferred to rely on intuition</p> <p>Patient satisfaction scores of 29 patients did not reflect concern about low scores in SDM</p> <p>Good correspondence between patients and psychiatrists regarding decisional topics</p> <p>Poor correspondence regarding individual decisions such as medications, leave from ward, change in treatment, and nonpharmacological therapies.</p> <p>High rates of noncompliance and rehospitalization</p>
Hamann <i>et al.</i> [13••], Germany	Psychiatric state hospital inpatients, schizophrenia	107 patients	Examination of long-term compliance/rehospitalization rates after a cluster RCT of an SDM program	Symptoms	<p>Intervention showed a positive trend but no clear beneficial effect on long-term outcomes</p>
Jeste <i>et al.</i> [14••]	Literature search of Medline, PsycINFO, and CINAHL, mental and nonmental health populations	37 randomized controlled trials (33 nonmental health RCTs)	Review of studies that compared the effects of multimedia educational aids versus routine procedures	<p>Therapeutic alliance</p> <p>Autonomy Communication/decision-making effectiveness</p> <p>Satisfaction Adherence</p> <p>Scale for Assessing Scientific Quality of Investigations (SASQI)</p>	<p>Two-thirds of studies in diverse patient populations reported that multimedia educational aids produced better understanding of information than routine methods</p>

Authors	Participants and clinical scenario	N	Study question and brief description	Outcome measures	Results
Loh <i>et al.</i> [15••], Germany	Primary care clinics in university setting	405 patients, 23 primary care clinicians	Cluster RCT to examine the effect of an SDM intervention in primary care of depression	Patient involvement and satisfaction	It is likely that multimedia educational aids could become an effective supplement to the clinician–patient interaction in the near future Intervention was better than usual care for improving patient participation in treatment decision making and patient satisfaction without increasing consultation time There was no intervention effect for depression severity
O'Connor <i>et al.</i> [16••]	Literature search of Medline, PsycINFO, EMBASE, Cochrane Review, and CINAHL	55 RCTs of patient decision aids	To describe the extent to which patient decision aids meet effectiveness standards of the International Patient Decision Aid Standards (IPDAS)	Treatment adherence Depression severity/remission IPDAS criteria for establishing a decision aid is effective	Among 55 RCTs, 38 studies used at least one criterion that mapped on to IPDAS effectiveness criteria Patient decision aids improve decision quality (knowledge, accurate risk perception, and values congruence with chosen option) compared with usual care Detailed decision aids were more effective than simpler ones
Swanson <i>et al.</i> [17••], USA	Primary care clinics, quality improvement for depression study	1317 patients	To assess if SDM and or receipt of mental health care was associated with patient satisfaction for patients with depression and if	Satisfaction with overall and mental health care	Mental health care and shared decision making were important independent predictors of patient satisfaction for depressed primary care patients

Authors	Participants and clinical scenario	N	Study question and brief description	Outcome measures	Results
			gender modified this relationship	SDM	Gender was not a moderator of health care or SDM on satisfaction
				Social support	Positive association between SDM and satisfaction
				Health status	
				Depression symptomatology	
				Alcohol use	
Tanenbaum [18•], USA	Mental health consumers within a suburban/rural community, severely mentally ill	38 patients	Qualitative study of mental health consumers' perspectives on information and decision making	Thematic analysis of focus group data	Consumers desire and seek information about their illness and the mental health system
					Consumers identify scientific studies as information with special and welcome properties
					Trust in one's provider and recovery are other important inputs into treatment decision making