

Preferences for Participation in Decision Making Among Ethnically Diverse Patients with Anxiety and Depression

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Abstract This study explored preferences for treatment decision making using the Control Preferences Scale and Problem Solving Decision Making Scale among a sample of ethnically diverse adults ($N = 60$) seeking treatment for anxiety and depression. Most participants expressed a desire for participation in shared decision making. Being Hispanic was significantly associated with a more passive role in decision making. Participants preferred more involvement in decision making versus problem solving tasks for both mental and general health vignettes, and more involvement in mental health versus general health decision-making. More research is needed to confirm tentative results on the influence of sociodemographic variables on preferences for role and participation in treatment decision making and the variation in these preferences. Treatment seeking individuals with anxiety and depression have identifiable preferences for participation in decision making. Asking about patient preferences and a better understanding of variability in preferences may improve patient-provider communication.

Keywords Shared decision making · Ethnicity · Mental health · Preferences

Introduction

The last decade has seen a shift towards patient-centered approaches to health care delivery (Institute of Medicine 2005). One of the key attributes of patient-centered care is patient-physician communication (Roter and Hall 1993). Patient-physician communication has been associated with patients' perceptions of finding common ground with their physicians (Stewart et al. 2000) and improved health outcomes (Little et al. 2001; Kaplan et al. 1989). Recently, methods to enhance patient-physician communication including patient preferences for participation in treatment decision making have received increased interest (Ottawa Health Research Institute 2008; Deber 1994; Deber 1994; Strull et al. 1984; Vick and Scott 1998; Ende et al. 1989). One method, which advocates a more active, participatory role for patients and a tailored approach to patient education, is known as shared decision making. Shared decision making (SDM) takes place when patient and physician share information about treatment options, take steps in sharing a treatment decision and together arrive at a consensus regarding the preferred treatment option (Charles et al. 1999). There is a growing body of literature that shows that shared decision-making interventions or tools such as decision aids increase patients' knowledge about their illness and reduce decisional conflict during the treatment decision-making process. Information and active participation has been shown to increase satisfaction, facilitates treatment adherence, and in some cases improves clinical outcome (O'Connor et al. 1999; Coulter 1997).

Research evaluating SDM for medical illness, utilizing a variety of methodological approaches, has shown that demographic variables influence preferences for participation including age and education level (Strull et al. 1984; Vick and Scott 1998; Ende et al. 1989; Degner and Sloan

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1992; Blanchard et al. 1988), gender (Vick and Scott 1998; Levinson et al. 2005), health status and severity of health problem (Vick and Scott 1998; Ende et al. 1989; Degner and Sloan 1992). There is a need for research that explores the role of ethnicity in preferences for participation in decision making (Cooper 2006; Charles et al. 2006). Inadequate patient-physician communication has been proposed as a mechanism for health disparities particularly for Asians, African Americans and Hispanics (Smedley et al. 2002). Current research shows that Asians, African Americans and Hispanics are more likely than non-Hispanic whites to feel disenfranchised in the decision-making process, receive less health related information, and perceive a lack of respect for their preferences (Ngo-Metzger et al. 2006). This may be especially important in Hispanics, the largest ethnic group (Ramirez and de la Cruz 2002) comprising 13% of the US population, who frequently underutilize or discontinue treatment for mental health relative to non-Hispanic Whites (Lara et al. 2005; Vega et al. 1999; Grant et al. 2004; Barrio et al. 2003; Padgett et al. 1994; Greenberg and Rosenheck 2003).

Although there have not been a great number of SDM studies in mental health to date, patients are increasingly recognized as key decision makers in the mental healthcare treatment process (Wills and Holmes-Rovner 2006). SDM may be especially important for mental health treatment decision making given general public reliance on the Internet for treatment of mental health conditions which overall yields poor quality information (Griffiths and Christenson 2000; Lissman and Boehnlein 2001), treatment preferences (Dwight-Johnson et al. 2000), and stigma associated with seeking mental health services (Link et al. 2001; Rost et al. 1993; Cooper-Patrick et al. 1997). A recent review of SDM in individuals with schizophrenia and depression (Patel et al. 2008) concluded that although barriers to SDM exist in mental health decision making at the patient and physician-level, patients and physicians found SDM acceptable and engage in SDM which results in improvement in patients' knowledge about their illness, a higher level of perceived involvement in decision-making (Hamann et al. 2006), and in some cases improvement in self-management, rate of treatment dropout, and recovery (Hamann et al. 2006; Adams et al. 2007; Ludman et al. 2003; Clever et al. 2006; Loh et al. 2007). A recent study found that involvement in decision-making for depression was better than usual care for improving patient participation in treatment decision making and satisfaction with care without increasing consultation time (Loh et al. 2007).

In addition to an exploration of patient preferences for participation in treatment decision making, a close examination of the decision making process warrants further study. Degner et al. (1997) underscored the importance of characterizing the preferred role in decision making defined

as, "degree of control an individual wants to assume when decisions are being made about medical treatment." Deber et al. (Vick and Scott 1998; Deber et al. 1996) argued that the decision making process consists of two dimension of choice, problem-solving and decision making. Problem-solving identifies the correct solution(s) to the problem and decision making involves choice between several alternatives. Studies that have found that patients wished to be more involved in decision making tasks as opposed to problem solving tasks (Vick and Scott 1998; Hamann et al. 2006). Understanding preferred role and level of involvement in dimensions of decision making are important factors that might contribute to the potential for shared decision making and possibly improved clinical outcome.

The main purpose of this exploratory study was to determine preferred role and level of involvement in treatment decision making for mental health and general health in a culturally diverse group of people seeking outpatient treatment for anxiety and depression. The study addressed three research questions:

1. What role do patients prefer in mental health (MH) treatment decision making and what are the sociodemographic variables associated with preferred role in MH decision making?
2. What is the preferred level of patient involvement in MH treatment decision making and general health (GH) decision making and what are the sociodemographic variables associated with preferred level of involvement in MH and GH decision making?
3. Do patient preferences for involvement in decision making vary by type of health problem (mental health vs. general health) or type of task (problem solving vs. decision making)?

Methods

We explored preferences for decision-making in a convenience sample of 60 adults with anxiety or depressive disorders seeking treatment between January 1, 2007 and April 30, 2008 at an outpatient research clinic, the Anxiety Disorders Clinic (ADC) of the New York State Psychiatric Institute (NYSPI). The ADC has a specialty program, the Hispanic Treatment Program (HTP), which serves the Hispanic community in Washington Heights by offering culturally sensitive treatment by bicultural and bilingual staff. Participants presented for treatment at the ADC and if they self-identify as Hispanic they are then referred to the HTP for treatment. Participants who presented for treatment to the ADC and HTP were included in this sample. All participants met criteria for an anxiety or depressive disorder according to a clinical interview and confirmed by the Structured Clinical

Interview for DSM-IV Disorders (First et al. 2002). The Institutional Review Board for the NYSPI approved this study and written informed consent was obtained.

Upon checking into the clinic for their appointment, a Master's-level research assistant explained the study and asked patients if they would be willing to participate in a study about preferences for making treatment decisions. With their consent, they were asked to fill out two self-report surveys (Control Preferences Scale (CPS) (Degner et al. 1997) and the Problem-Solving Decision Making Scale (PSDMS) (Deber et al. 1996)) in their preferred language (English or Spanish). Both surveys were forward and back translated into Spanish by the first author (SRP) and two bilingual (Spanish) members of the HTP. Within mental health, no instruments are available to measure decision making and these questionnaires are among the most widely used instruments for the assessment of decision making preferences in medical populations thereby allowing for results to be compared among studies. The CPS characterizes preferred role in decision making on the spectrum between paternalistic (passive role for patient) and being informed (active role for the patient) (Degner et al. 1997). The CPS consists of five cards that each portrays a different role in treatment decision-making using a statement and a cartoon. These roles range from: (1) I prefer to make the decision about which treatment I will receive (active role); (2) I prefer to make the final decision about my treatment after seriously considering my doctor's opinion, (3) I prefer that my doctor and I share the responsibility for deciding which treatment is best for me; (4) I prefer that my doctor make the final decision about which treatment will be used, but seriously considers my opinion; and (5) I prefer to leave all decisions regarding treatment to my doctor (passive role). Higher scores on the CPS indicate preferences for passive role in decision-making. The CPS typically involves subjects in making a series of paired comparisons to provide their total preference order over the five cards. In this study, the CPS was adapted for use in a mental health setting and for ease of administration, the choice experiment approach (choose one) for assessing stated preferences (Janz et al. 2004; Louviere et al. 2000) was used. We used the choice experiment approach because it emulates realistic tasks that people perform everyday, the task of choosing one item among several options and this method has been widely used in various areas including health research, marketing, and public welfare analysis (Louviere et al. 2000; Ryan and Gerard 2003; Ryan 1999). Participants were presented with the following statement, "When deciding on what treatment is best for your emotional/mental health problems, what is your preferred role in treatment decision-making?" Participants were asked to read the 5 different roles and pick one role that fell closest to their preferred role. The

CPS has proven to be an easily administered, valid, and reliable measure of preferred roles in health-care decision-making in a variety of populations (Chapple et al. 2003; Neufeld et al. 1993) however it has also been criticized as misleading for classifying patients as "active" or "passive" with regard to healthcare decision making since patients have different desires for different dimensions of the decision making process (Flynn et al. 2006).

The PSDMS (Deber et al. 1996) examines two aspects of choice behavior: problem solving (PSDMS-PS) and decision-making (PSDMS-DM). Problem solving tasks can be conceptualized as the information exchange part of the DM process. PS tasks are defined as those that require factual knowledge: diagnosis, treatment options, risks and benefits, and determining probability of risks and benefits. DM tasks are defined as those that incorporate both factual knowledge and individual preferences: acceptability of risks and benefits and selection of treatment option (Deber et al. 1996). The PSDMS was adapted for this study to include two clinical (MH: Mental and GH: General Health) vignettes: (1) "Suppose you are experiencing emotional difficulties like anxiety or depressed mood and have decided that you should visit your doctor about this"; (2) "Suppose you had mild chest pain for 3 days and decided that you should visit your doctor about this." For each vignette, participants were asked to indicate for a set of four PS tasks and two DM tasks, "Who should determine/decide..." using a 5 point scale: (1) Doctor alone; (2) Mostly the doctor; (3) Both equally; (4) Mostly me; and (5) Me alone. Higher scores on the PSDMS indicate preferences for active roles in the decision-making process. Reliabilities of the PSDMS are very good to excellent: full scale— $\alpha = .71-.90$, PS— $\alpha = .79-.90$, and DM—.67-.93 (Kraetschmer 1994).

Statistical analyses included descriptive frequencies, means and standard deviations for sociodemographic characteristics (including age, gender, ethnicity, and education) and survey items. We examined relationships between sociodemographics and overall CPS score, overall PSDMS-MH, overall PSDMS-GH scores using Pearson correlations and *t*-tests. Paired samples *t*-tests were explored within vignette differences in decision making (e.g. problem solving versus decision making) and between vignette differences in decision making (e.g. mental and general health vignettes). Associations between the CPS and PSDMS scores on mental health decision making were tested using Pearson correlations.

Results

All participants who were approached to participate in this study agreed and completed surveys. Fifty-eight

percent of the participants completed the surveys in Spanish; the remainder completed the survey in English. The sample ($n = 60$) was 50% female with a mean age of 42 years and an average of 13 years of education. The sample self-identified as Hispanic (58%), followed by non-Hispanic White (29%), Asian (8%), and African American (5%). Given the distribution of the sample, ethnicity was defined as Hispanic versus non-Hispanic (including non-Hispanic White, Asian, and African American) a method used by the US census and the National Institutes of Health (U.S. Bureau of the Census, Population Division, Special Population Staff 2007; NIH Policy on reporting race and ethnicity data: Subjects in clinical research. Retrieved Feb 11 2010). Ninety-five percent of the participants in this sample had already made a decision about their mental health treatment. Table 1 presents the CPS frequency data and mean scores on the PSDMS for the overall sample.

Table 1 Control Preferences Scale and Problem Solving Decision Making Scale results ($N = 60$)

Scale	Overall $N = 60$
<i>Control Preferences Scale</i>	
<i>N (%)</i>	
Preferred role	
Active	–
Semi-active	15 (25%)
Collaborative	32 (53%)
Semi-passive	12 (20%)
Passive	1 (2%)
<i>Problem Solving Decision Making Scale</i>	
<i>M (SD)</i>	
Mental health vignette	2.4 (0.6)
Problem solving tasks:	2.2 (0.7)
Diagnosis	2.2 (0.9)
Treatment options	2.3 (0.8)
Risks/benefits	2.1 (1.0)
Probabilities	2.1 (1.1)
Decision making tasks:	2.9 (1.1)
Utilities	3.0 (1.2)
What is done	3.0 (1.1)
General health vignette	2.1 (0.7)
Problem solving tasks:	1.8 (0.7)
Diagnosis	1.8 (0.8)
Treatment options	1.8 (0.9)
Risks/benefits	1.8 (1.0)
Probabilities	1.8 (0.9)
Decision making tasks:	2.7 (1.1)
Utilities	2.8 (1.3)
What is done	2.7 (1.2)

Control Preferences Scale

According to the CPS, 98% of the overall sample preferred to participate in some level of shared decision-making (semi-passive to semi-active) during the mental health treatment decision-making process. *T*-tests revealed a statistically significant relationship between ethnic groups and scores on the CPS, $t(58) = -2.88$, $P < .05$, that is being Hispanic was associated with higher scores on the CPS, preference for a more passive role in decision making. No other demographic variables were significantly associated with preferred role in decision making for mental health.

Problem Solving Decision Making Scale

Mean scores on the PSDMS revealed that a majority of participants in the overall sample preferred between, ‘mostly the doctor,’ and, ‘doctor and you equally,’ for problem solving and decision making tasks of each clinical vignette with some variation between vignettes. Analyses of demographic data and PSDMS scores reveal that being female was associated with preference for more involvement in mental health decision making compared to males, $t(58) = 2.00$, $P < .05$. No other demographic variables were significantly associated with the PSDMS scores.

Paired sample *t*-tests for within vignette differences revealed that for both mental health, $t(59) = -4.90$, $P < .001$; and general health vignettes, $t(59) = -6.50$, $P < .001$; participants preferred more involvement in decision-making tasks as compared to problem solving tasks. In addition, paired samples *t*-tests for between vignette differences revealed preference for more involvement in mental health decision making compared to general health decision making $t(59) = 5.14$, $P < .001$.

CPS and PSDMS

Scores on the CPS were significantly associated with scores on the PSDMS MH vignette $r = -0.35$, $P < .05$ and the DM task question for the mental health vignette (e.g. Given all the information about risks and benefits of the possible treatments, who should decide which treatment option should be selected?) $r = -0.34$, $P < .05$.

Discussion

This study revealed that people seeking outpatient treatment for anxiety and/or depression have identifiable preferences regarding participation and role in treatment decision making for mental health problems. Most participants indicated a preference for participation in mental health decision making that is amenable to shared decision

making interventions. Consistent with previous studies, participants preferred more involvement in decision making versus problem solving tasks (Deber et al. 1996) and mental health decision making versus general health decision-making (Adams et al. 2007). It is possible that participants preferences were influenced because they were being treated for mental health problems and they all had made a recent decision about mental health treatment. We also found that females preferred more involvement in decision making (Levinson et al. 2005) particularly for mental health problems; however because this was an exploratory study we conducted a large number of significance tests and the gender difference found at the $P < .05$ is not significant based on a Bonferroni correction to keep the family wise error rate below .01.

Differences between Hispanics' and non-Hispanics' preferred role in decision making emerged in our sample. Hispanics preferred a more passive role in mental health decision making while non-Hispanics in this sample preferred more active roles. A recent population based study of public preferences for participation in decision making among English speaking adults also found that Hispanics were more likely than non-Hispanic Whites to prefer leaving decisions about medical care up to their doctors (Levinson et al. 2005). Several patient-level reasons are hypothesized for these findings. First, Hispanic patients' health worldview including health belief model or attribution of symptoms, expectations for the visit, acceptability of treatments, treatment preferences, and involvement of family or social network may vary and influence their preferences for participation in decision making (Cabassa et al. 2007; Cooper et al. 2003; Dwight-Johnson et al. 2004). Second, participants' preferences for passivity may be the result of a perceived lack of knowledge (Dwight-Johnson et al. 2006), low health literacy, lack of self-efficacy or a learned response influenced by cultural attitudes (Alegría et al. 2008). In the only intervention targeting patient-physician communication in Hispanics retrieved in our review of the literature, the Right-Question Project-Mental Health, Alegria and colleagues (Cortes et al. 2008) found that patient self-reported activation, attendance to scheduled visits and retention in treatment improved for Hispanics seeking treatment in community mental health clinics. Qualitative findings on the process of activation/empowerment suggest that cultural (i.e. concerns about hurting physician's feelings or offending by asking questions considering their views as of physicians as figures of authority) and contextual (i.e. degree of familiarity with the US health care system and the potential to be perceived as intimidating) factors can influence the experience for Hispanics regarding participation in health care interactions (Alegría et al. 2008). Third, stigma towards mental health treatment may exist in Hispanic cultures (Interian et al.

2007). It is important to also recognize that physician-level reasons may contribute to variation in preferences for participation and role in decision making. Physician gender and ethnicity, beliefs about patient expectations, interpretations of symptoms, and engagement in decision making, and bias towards different racial/ethnic groups may influence patient preferences (Cooper-Patrick et al. 1999; Jahng et al. 2005; Roter et al. 2002; Robinson and Thomson 2001).

Charles and colleagues (2006) challenge the assumptions of a "one size fits all contexts" model of shared decision making and the assumption of a common meaning and application across different cultural groups. Findings from this study underscore the need for further research to explore the influence of culture in mental healthcare decision making and other important variables, such as knowledge and stigma. Attitudes and experiences of some cultures may represent facilitators or barriers to participation in decision-making, and research needs to determine whether this is the case. The incorporation of such data into the development of decision aids is important so that a balance can be struck between assisting diverse groups to play an active role in the treatment decision-making process, without disregarding genuine preferences for participation.

Several study limitations must be acknowledged. First, the generalizability of the findings is limited to a small convenience sample in an outpatient specialty research clinic for people whose decision about treatment had already been made. It is likely that individuals who have not made a decision or are not yet in the position to make a decision about treatment may have different preferences. Additionally, receiving treatment in a specialty treatment program for Hispanics may have influenced decision making preferences in this sample and these may vary if this sample was seen in a different setting that caters to White non-Hispanic individuals or African Americans. Second, we examined preferences using an adapted chronic mental health vignette versus an acute general health vignette for which the decision-making preferences are likely to vary. Third, we limited our analysis to Hispanics versus non-Hispanics and cannot make generalizations regarding other groups (i.e. non-Hispanic whites, Asians and African Americans) and did not include measures of acculturation. Lastly, although both measures were significantly correlated and provided some evidence of reliability, we are limited by quantitative measurement of preferences. Future research will need to assess a larger more representative sample to examine whether the findings of this study extend to other minority groups in diverse mental health settings using several health vignettes and qualitative or market research methods (Ryan and Farrar 2000; Kennelly and Bowling 2001) to allow for comparisons of preference patterns. In addition, it will be important to capture individuals at different stages of their

help seeking to better understand how these preferences vary and determine appropriate timing for a shared decision making intervention.

To our knowledge this is the first quantitative study of preferences for role and participation in treatment decision among adults seeking treatment for anxiety and depression in an outpatient clinic setting. The results bring to light the variation in preferences for participation and role in decision making that exist: the variation in preferred role in treatment decision making among ethnically diverse populations; and in preferences for involvement in decision making by gender, tasks involved in decision making process, and clinical vignette. If physicians ask their patients about their preferences for decision making during the consultation it may improve communication, congruence and expectations between patient and physician.

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