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Shared Decision Making and Serious Mental Illness

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Abstract

This study examined medication decision making by 84 persons with serious mental illness, specifically examining relationships among perceived coercion, decisional capacity, preferences for involvement and actual participation, and the outcomes of medication adherence and QoL. Multiple and logistic regression analysis were used in this cross-sectional, descriptive study, controlling for demographic, socio-economic and utilization variables. Appreciation was positively related to medication adherence behaviors for the past six months. Females, older individuals and those living independently were more likely to have taken all their medications over the past six months. Neither client participation, preference, nor preference-participation agreement was found to be associated with better medication adherence or QoL.

Introduction

Although the medication adherence rates of about 50% (Dolder, et al. 2003) for persons with serious mental illness (SMI) is comparable to other chronic illnesses, the consequences of non-adherence in mental illness can be very devastating, including symptom exacerbation, rehospitalization, major disruption in relationships, loss of housing, involvement in the criminal justice system and eventually very poor quality of life (Azrin & Teichner, 1998; Olfson, et al. 2000; Porter, 1998). Mental illnesses rank first among illnesses that cause disability in the United States, Canada and Western Europe (Freedom Commission, 2003) and they come with a very high financial cost. The United States spent almost \$71 billion in one year alone treating mental illnesses (Freedom Commission, 2003).

One goal of this study was to help move mental health care in the direction of the vision of client-centered care articulated in the President's New Freedom Commission on Mental Health titled *Achieving the Promise: Transforming Mental Health Care in America* (Freedom Commission, 2003). It states that, "when clients and family members have access to timely, accurate information that promotes learning, self-monitoring and accountability, and providers develop individualized plans of care in full partnership with clients and families, hope of recovery will be reinforced for every individual, giving clients real and meaningful choices and focusing on recovery rather than merely symptom management" (Freedom Commission, 2003). The concepts of SDM are also at the heart of the December, 2005 United States-Institute of Medicine report titled *Improving the Quality of Care for Mental and Substance-use Conditions*. It recommends "that individual patient preferences, needs, and values prevail in the face of residual stigma, discrimination, and coercion into treatment" (Institute of Medicine, 2001).

The literature reports many factors significant in medication adherence by persons with SMI such as dissatisfaction and unfulfilled expectations, quality of overall health, polypharmacy, cognitive function, literacy level, visual acuity, social support, caregiver availability, immediate physical environment, emergency assistance, access to transportation, individual behavior, interpersonal relationships, historical ideologies, understanding of the drug's

purpose and symptom relief (Mahone, 2004). This review of the literature guided the design of this study to include the constructs of client participation, perceived coercion and decisional capacity with outcomes of adherence behavior and attitudes and QoL.

The Interaction Model of Client Health Behavior (IMCHB) was used as the conceptual framework of the study (Carter & Kulbok, 1995; Cox, 1982). The model includes many of the variables generated by other health-behavior models, with the addition of an emphasis on the client-provider interaction process. The IMCHB model identifies explanatory relationships between client singularity (such as demographic, socio-economic and utilization variables), previous health care experiences, and cognitive appraisal; client-provider interaction (such as decisional control); and subsequent client outcomes (such as adherence and QoL). Past-experiences were operationalized in this study as perceived coercion and cognitive-appraisal as decisional capacity, measuring understanding, appreciation, reasoning and expressing a choice. Decisional control was measured as preferences for involvement in treatment decisions and also actual participation in the client-provider interaction.

Methods

This study was a cross-sectional, correlational study of persons with SMI living in the community. The sample consisted of eighty-five clients being served at four sites of a Community Mental Health Center in central Virginia and surrounding counties. The data was collected from February to October, 2005. Approval was obtained from the Institutional Review Board at the University of Virginia and each participant signed a consent form prior to being interviewed.

Table 1 and Table 2 present descriptors of dependent and independent variables including the instruments used to measure the major constructs of the study and analysis, sample size, means and standard deviations. The *Perceived Coercion Scale* was developed by the MacArthur Research Network on mental health and the law (Rain, Williams & Robbins, 2003). This instrument measures patient perceptions of coercion in mental health treatment regarding lack of control, choice, influence and freedom. Validity: high correlation shown between the *Perceived Coercion Scale* scores and the admission experience interview. Reliability: internal consistency was robust with respect to variation in site, instrument format, patient population and interview procedure.

The MacArthur Competency Assessment Tool

Treatment (MacCAT-T) examines patient's performance on separate abilities rather than a "total" MacCAT-T rating (Grisso & Appelbaum, 1998). It measures *understanding* of treatment-related information, *appreciation* of the significance of the information and its relevance for themselves, *reasoning* in the process of deciding on treatment and ability to draw inferences about the impact of the alternatives, and *expressing a choice* about treatment. Its reliability and validity was tested in a study of 40 psychiatric inpatients and 40 community controls (Grisso, et al. 1997). In comparing *MacCAT-T* scores and *Brief Psychiatric Rating Scale* scores, greater symptom severity tended to correlate with lower capacity ratings, which provides support for validity for this tool (Grisso, et al. 1997).

Medication adherence attitudes were measured using the *Rating of Medication Influences (ROMI)* (Weiden, et al. 1994). This instrument was developed to elucidate underlying attitudes and assesses attitudinal factors influencing client adherence to antipsychotic medicine. Support for criterion validity was established by comparing it to other widely-tested measures currently in use such as *Drug Attitude Inventory* (0.56) and the *Van Putten and May Neuroleptic Dysphoria Scale* (0.57). Reliability was demonstrated in the client-

report section of the *ROMI*, where 95% obtained adequate coefficient scores (0.76 to 1.00) (Weiden, et al. 1994).

Self-reported medication use was measured using the *Schizophrenia Outcomes Module Medication Use Questionnaire (SCHIZOM)* (SCHIZOM, 2005). This instrument was developed at the University of Arkansas to measure the process and type of care, outcomes and patient characteristics. It was designed specifically to measure medication adherence behavior and is administered using interviews versus self-administration. Concurrent validity was demonstrated in a sample of patients with schizophrenia where change and absence of change was able to be detected. Validity for the whole *SCHIZOM* module was demonstrated in comparing it to the *Brief Psychiatric Rating Scale, Personal Profile*, and the *Addiction Severity Index*. Overall, the *SCHIZOM* detected change in the same areas and same directions as the validation instruments. Good reliability was demonstrated when test-retest correlations for 6 of 8 outcomes variables on the *SCHIZOM* were excellent and moderate for the other two.

Participation preferences and actual participation were measured using the *Control Preferences Scale (CPS)*. A modified version of the *Control Preferences Scale* was used in this study, asking participants to pick one of the three main choices to reflect their preferences and experiences rather than rank-ordering the five options, as seen in the original version. This tool has shown high reliability and validity with newly diagnosed cancer clients, the general public, clients with breast cancer and men with prostate cancer (Beaver, Luker, Owens, Glyn, Leinster, & Degner, 1996; Davison & Degner, 1997; Davison, et al. 1999).

QoL was measured using the *Schedule for Evaluation of Individual Quality of Life*

Direct Weighting (SEIQoL-DW) (Hickey, et al. 1996). This instrument was developed specifically to elicit the value system of individual respondents and to quantify QoL. Administering this instrument includes the three steps of cue elicitation, determining current status on each cue and quantification of relative weighting of each cue. This tool has demonstrated feasibility and adequate internal reliability with healthy people, healthy elderly, osteoarthritis clients and GI clients (Broadhead, Robinson, & Atkinson, 1998); high levels of consistency, reliability and validity with cancer clients (Waldron, O'Boyle, Kearney, Moriarty, & Carney, 1999).

Findings

Background variables with operational definitions, sample size, means, standard deviations and percentages are presented in Table 3. Following descriptive analysis of the study variables, the relationships between the independent and dependent variables were established using multiple and logistic regression analysis, controlling for the background variables correlating most highly with the outcome variables.

Results/ Discussion

Background Variables

Background variables included demographic, socio-economic and health-care utilization variables (see Table 3). The sample ranged in age from 20 to 62 years, 58% were male, 93% were single and 56% had some college education or were college graduates. Seventy-six percent lived independently yet only 31% of participants were employed. Seventy-six percent of participants had an income of less than \$10,000 and 17% lived in rural areas. Years of treatment was operationalized by number of years since first beginning mental health treatment and ranged from two to 46 years with a mean of 20, while number of

hospitalizations ranged from zero to 100. Twenty-three percent of participants had their psychotropic medication prescribed by a nurse practitioner. Although housing information captured whether the participant lived with family, independent, in supported housing or residential, the variable was collapsed into living independently or other.

Medication Adherence—Medication adherence behavior was operationalized in this study as taking 100% of their medications, measuring both for the past month and for the past six months. Although 54% reported never missing their medication for the past month, that number dropped to 28.6% for the past six months. The one-month adherence report is consistent with the 50% adherence rate estimated by numerous researchers (Dolder et al, 2003).

In the univariate analysis of decisional capacity measures and the dependent variables, appreciation was significantly related to the medication adherence subgroup, compliance (T-Statistic= 4.456; $p=.046$). In the multivariate analysis, appreciation was significantly related to medication adherence behaviors for the past six months ($p = .026$) after controlling for age, gender, rurality, years of treatment and housing (Table 4, Model I). Participants with positive-appreciation scores were more likely to have taken all their medications over the past six months. This finding was similar to another recent trial of compliance therapy by Byerly and colleagues, who found that a higher degree of insight at baseline was associated with greater adherence at five months (Byerly, et al., 2005). Also in multivariate Models I, II and III age, gender and housing were significant individual predictors with older individuals, females and persons living independently being more likely to be 100% adherent for the past six months (see Table 4).

In the univariate analysis it was found that 65% of males had perfect adherence behaviors for the past month compared to 37% of females ($p = .018$). The trend continued for the past six months with a greater percentage of males having perfect adherence behaviors. However, in three different multivariate models, after controlling for significant covariates, females were more likely to have taken all their medications over the past six months ($p = 0.014, 0.018, \text{ and } 0.010$ respectively).

The univariate analysis also revealed that the six-month-adherence mean age was 46 years while the six-month-nonadherence mean age was 41.5 years ($p = .0015$). In two different multivariate models age was found to be a significant individual indicator ($p = .015$ and $.006$) with older individuals more likely to have taken all their medication for the past six months. In the background univariate analysis a positive correlation was found between adherence behavior for the past six months and housing status ($p = .020$) with 58% of those who took all medications for the past six months living independently. In Models I, II and III (Table 4) housing was a significant individual indicator ($p = .010, .013$ and $.018$) of adherence behavior for the past six months with individuals living independently were more likely to have taken all their medications.

In this study neither client participation, SDM preference, nor preference-participation agreement was found to be associated with better rates of medication adherence for the past month or the past six months.

Shared Decision Making—Although 82% of participants preferred a collaborative relationship with the prescriber, only 70% of participants reported experiencing collaborative participation. Preference-participation agreement scores showed that 69% of participants experienced what they preferred in participation in the treatment decision. “Getting what you want” was shown to be important in terms of long-term quality of life in

a recent study of breast cancer treatment in older women (Figueiredo, Cullen, Hwang, Rowland & Mandelblatt, 2004).

That 82% preferred a collaborative relationship reflects the fact that many persons with SMI are ready to participate in the client-provider interaction. This is clinically significant as true SDM requires a willing client. That 70% experienced collaboration in the client-provider interaction also indicates that the SDM concept has already been embraced by many mental health providers in this clinic. That 69% of individuals in this sample were receiving what they preferred in terms of participation in the client-provider interaction demonstrates the degree to which respect for client preferences was valued in this clinic.

Of the background information gathered, there were significant differences found in participation scores by types of prescriber ($p = .023$). A higher percentage of participants reported passive participation with physicians (25%) than with nurse practitioners (5.3%). However, when prescriber was entered as a control in the multivariate analysis, it was not a significant individual indicator.

Quality of life—Given the conceptual foundation for this study was the recovery model, where return to functional productive life is the goal versus mere symptom resolution, it seemed fitting that QoL be one outcome measure. Out of a possible score of 480 the overall mean QoL score was quite low at 67. The four domains chosen most frequently as important to QoL by participants were physical and mental health (90%), living conditions (70%), family (68%) and relationships (59%).

In the univariate analysis it was found that rural mean QoL scores (32) were lower than nonrural (44) ($p = .039$). Also African-American mean QoL score (40) was lower than Caucasian/other mean QoL score (48) ($p = .052$). Another finding was that mean QoL scores for those earning less than \$10,000 a year (45) was higher than for those earning more (33) ($p = .029$). For all three of these univariate findings, significant differences did not persist in the multivariate models when controls were added. A significant positive correlation was also found between number of hospitalizations and quality of life ($p = .023$) and three different multivariate models (Table 5) confirmed this finding ($p = .028, .024$ and $.028$). As number of hospitalizations increase, quality of life goes up. This phenomenon may be explained by the fact that these participants were successfully living in the community at the time of the study. In this study neither client participation, SDM preference, nor preference-participation agreement were found to be associated with better QoL.

Limitations and Future Research

Limitations of this study include small sample size, limited variability in preferences and participation, and a narrow definition of adherence. Also the design of selecting clients from those attending an established clinic prevented inclusion of clients seeking crisis intervention or those receiving services elsewhere and may have excluded sicker clients.

The long-term goal of this study is to design and test a SDM intervention aimed at increasing medication adherence. Because a medication management intervention based on the concepts of SDM has already been successfully demonstrated in the United Kingdom (Gray, et al., 2004), this model could be replicated in a future study. Also, designing and testing a patient decision aid (O'Connor, Graham & Visser, 2005) for persons with SMI would be another goal in promoting SDM in mental health and could be the focus of future studies.

Conclusion

This study was another step in understanding the associations among key factors in medication decision making by persons with SMI. Potential barriers to SDM in the psychiatric population were identified. Because much of healthcare today has already successfully embraced illness self-management and SDM (Barlow, Sturt & Hearnshaw, 2002; Walker, Swerissen & Belfrage, 2003), demonstrating the relationships among these variables in persons with SMI contributes to understanding the responses and attitudes of clients and to developing a conceptual foundation for ongoing inquiry into the importance and potential impact of SDM in mental health (Thorne, Paterson & Russell, 2003). The ultimate goal of SDM models is to provide providers with relevant data and necessary skills to empower chronically-ill clients with the information and confidence to manage their health wisely (Deutsch & Gergely, 2003).

In an exploratory study into the role of community mental health nurses, Jordan, Hardy and Coleman (1999) found that nurses are expected to manage and monitor medications accurately and adequately, are responsible for assessing any contra-indications, recognizing and assessing side effects, and recognizing and assessing treatment responses. These nursing tasks juxtaposed against the backdrop of patient self-management makes the present-day nursing role quite complex requiring a fine balance between expert nursing assessments and empowering clients to self-manage their own illness. This study on medication decision making contributes significantly to a greater understanding of the important variables and dynamics in fulfilling the nursing role.

Since recovery for persons with SMI has been acknowledged as a reachable goal in mental health, illness self-management has been accepted as an evidence-based practice. However, discussion of SDM in mental health is still a relatively new concept (Hamann, et al., 2005) and further research in this field could help move mental health in the direction of recovery.

Although overall self-management strategies appear to be embraced in mental health treatment, there is considerable reluctance to move forward on self management in relation to medication for persons with SMI. The information generated by this study is valuable in understanding the concept of SDM in relation to medication decision making in the SMI population. It offers a basis for development of future research studies that could lead to effective clinical interventions related to medication management and ultimately to help effect changes in mental health practice and policy that will improve adherence and QoL for persons with SMI.

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Quality of Life	Analysis	N	Range	Mean	Median	SD
Vectors created with "collaborative" as the referent group.						
<i>Control Preference Scale/Preference - Participation Agreement</i> : Difference between preference scores and participation scores: Recoded as 1= agreement; 2= disagreement	Collaborative	83			58 (70%)	
	Passive				17 (20%)	
<hr/>						
<i>Control Preference Scale/Preference - Participation Agreement</i> : Difference between preference scores and participation scores: Recoded as 1= agreement; 2= disagreement	Disagreement	83			26 (31%)	
	Agreement				57 (68%)	

Table 2

Descriptors of Independent Variables including analysis, sample size, ranges, means, medians and standard deviations.

Perceived Coercion	N	Range	Mean	Median	SD	Percentages
<p><i>Perceived Coercion Scale</i> Sum of 5 coercion scores = Perceived Coercion Index</p> <p><i>Perceived Coercion Index:</i> Continuous score where: lower sum = less coercion higher sum = greater coercion. (Possible range = 0 – 25) <i>Perceived Coercion Dichotomized:</i> split by below the median = low coercion equal to or above median = high coercion.</p>	84	0 – 14 0 – 1	6.5	6.0	0.61	Low: 47 (56%) High: 37 (44%)
Decisional Capacity	N	Range	Mean	Median	SD	Percentages
<p><i>MacArthur Competency Assessment Tool – Treatment (MacCAT-T)</i></p> <p>Measures: 1) Understanding 2) Appreciation 3) Reasoning 4) Expressing a choice. low numbers = less cognitive ability high numbers = greater cognitive ability.</p>	84	2.8 – 6.0 0 – .53 2 – 4 2 – 8 0 – 2	5.31 0.192 3.93 7.65 1.83	5.5 0.186 4.0 8.0 2.0	0.71 0.17 0.34 1.0 0.53	Yes 80 (95.2%) No 4 (4.8%) Yes 71 (84.5%) No 13 (15.5%) Yes 76 (90.5%) No 8 (9.5%)
<p>Analysis</p> <p><i>Understanding (Original):</i> Possible range: 0–6 Two outliers truncated up to a minimum score of 3.6 and transformed by Reflect & Log. <i>Appreciation (Original):</i> Possible range: 0–4 As only 4 participants did not get a perfect score of 4, created a categorical variable: <i>Appreciation:</i> Yes = 1; No = 0 <i>Reasoning (Original):</i> Possible range: 0–8 Majority of participants had a perfect score. Also created a dichotomous categorical variable of: <i>Reasoning:</i> Yes = 1; No = 0 <i>Express a Choice (Original):</i> Possible range: 0–2 Majority of participants had a perfect score. Also created a dichotomous categorical variable of: <i>Express a choice:</i> Yes = 1; No = 0</p>						

Table 3
Background variables with operational definitions, sample size, means, standard deviations and percentages

Variable	Operational Definitions	N	Mean	SD
Age	A continuous variable of chronological years.	84	43	10
Hospitalizations	Continuous variable measuring lifetime number of hospitalizations	84	8.8	12.3
	Truncated & Transformed	2.53	0.7	
Duration/Years of treatment	Continuous variable measuring years since first receiving mental health treatment	84	20	11
	Transformed by square root.	8.4	4.3	1.3
		N	Category	%
Employment	Two employment categories including unemployed and other.	84	Unemployed	(69%)
			Other	(31%)
Gender	Two gender categories including male and female.	84	Male	(58%)
			Female	(42%)
Race	Two race categories including African-American and other.	84	Af-Am	(25%)
	African-Am = 1		Other	(75%)
	Other = 0			
Marital status	Two marital status categories including: single and other.	84	Single	(93%)
	Single = 1		Other	(7%)
	Other = 0			
Housing	Two housing categories including	84	Independent	(76%)
	Independent = 1		Other	(24%)
	Other = 0			
Household income level	Two Income categories:	84	<\$10,000:	(76%)
	1 = <\$10,000		> or = \$10,000	(24%)
	0 = > or = \$10,000			
Education	Four education categories including: some high-school, graduated high school, some college and graduated college.	84	Some high school:	(14%)
			High school grad:	(30%)

Variable	Operational Definitions	Analysis	N	Mean	SD
Rurality:				Some college:	(35%)
Rural = 1				College grad:	(21%)
Nonrural = 0	Two rurality categories including: major cities zip codes and others.		84	Rural:	(17%)
				Non-rural:	(83%)
Prescriber	Two categories including 1 = Nurse practitioner 0 = Physician		84	Physician	(77%)
				Nurse	
				Practitioner	(23%)

Table 5

Quality-of-Life Models

MODEL I	Dep Variable Quality of life	MODEL II	MODEL III	Dep Variable Quality of life
Independent Variable Decisional Capacity Individual Scores	Standardized Beta Coefficients	Independent Variable Perceived Coercion	Independent Variable Control Preferences Scale	Standardized Beta Coefficients
Understanding	T-Statistic	Perceived Coercion Sum	Active Participation	T-Statistic
.123	1.035	0.199	Active Participation	-0.157
Appreciation 1=Yes; 0=No	1.261		Passive Participation	-0.071
Reasoning 1=Yes; 0=No	1.605			-0.641
Express a Choice 1=Yes; 0=No	- .689			
Control: Rurality 1=Rural; 0=Nonrural	-1.771	Control: Rurality 1=Rural; 0=Nonrural	Control: Rurality 1=Rural; 0=Nonrural	-0.219
Control: Race 1=AF-Am; 0=Other	.418	Control: Race 1=AF-Am; 0=Other	Control: Race 1=AF-Am; 0=Other	0.128
Control: Marital Status 1=Single; 0=Other	-.839	Control: Marital Status 1=Single; 0=Other	Control: Marital Status 1=Single; 0=Other	-0.128
Control: Income 1=<\$10,000; 0=>or=\$10,000	-1.533	Control: Income 1=<\$10,000; 0=>or=\$10,000	Control: Income 1=<\$10,000; 0=>or=\$10,000	-0.181
Control: Hospitalizations	2.244*	Control: Hospitalizations	Control: Hospitalizations	0.242
				2.303*
				2.243*

* Significant at the .05 level.

MODEL I: Adjusted R² = .103; F = 2.048*; p=.046.

MODEL II: Adjusted R² = .114; F = 2.757*; p = .018

MODEL III: Adjusted R² = .090, F 2.144*, p=.049