Why are you here again? Concordance between consumers and providers about the primary concern in recurring psychiatric visits

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Abstract
Patient-centered care has become increasingly important over the last decade, both in physical and mental health care. In support of patient-centered care, providers need to understand consumers’ primary concerns during treatment visits. The current study explored what primary concerns were brought to recurring psychiatric visits for a sample of adults with severe mental illness (N = 164), whether these concerns were concordant with those recognized by providers, and which factors predicted concordance. We identified 17 types of primary concerns, most commonly medications and symptoms, with only 50% of visits showing evidence of at least partial agreement between consumers and providers. Contrary to expectations, consumer demographics, activation, trust, and perceptions of patient-centeredness were not predictive, while greater preferences for autonomy predicted poorer agreement. Our findings highlight the need for interventions to promote a shared understanding of primary concerns in recurring psychiatric visits. Further attention is needed to ensure the provision of patient-centered care such that consumer concerns are acknowledged and addressed within recurring psychiatric visits.

Keywords: severe mental illness, communication, patient-centered care, shared decision-making
1. Introduction

Patient-centered care has become increasingly important over the last decade, both in physical and mental health care (Institute of Medicine, 2001; National Research Council, 2006). Patient-centeredness is a multifaceted concept that centers around two components: consumer involvement in care and the individualization of care (Robinson et al., 2008). In line with these components, a key concept is shared decision-making (SDM), where consumers and providers work collaboratively to address treatment needs (Charles et al., 1997). At the most basic level, providers need to understand consumers’ primary concerns during a treatment visit (Makoul and Clayman, 2006). If the main concern is not understood, further SDM may be hindered and rapport may be damaged. The purpose of the current study was to explore the content of primary concerns in psychiatric treatment as reported by consumers and providers, and to examine levels of concordance and the predictors of that concordance.

We found no studies specifically addressing agreement about primary concerns in psychiatry. In general medicine, high levels of agreement between patients and providers are typically found (80-90%) (Boland et al., 1998; Jackson, 2005; Gross et al., 2013), except when comparing patients’ reports of events in the appointment with providers’ reports in the medical chart (DiMatteo et al., 2003). Although agreement has not been directly examined in psychiatry, related research is informative. One study examined concordance in ranking the importance of treatment goals. Results indicated that psychiatrists tended to value traditional treatment goals (e.g., decrease psychotic symptoms) more highly than consumers who valued practical, tangible goals (e.g., improved capacity for work) (Bridges et al., 2011). Another study showed that more than 40% of psychiatrist-consumer pairings were discrepant in their appraisal of medication adherence, with consumers more often identifying themselves as adherent (De las Cuevas et al., 2013). In addition, shared decision-making studies have found 79-87% agreement between consumers and psychiatric providers on a treatment decision as rated by observers from audiotaped sessions (Fukui et al., 2013; Matthias et al., 2013).
Understanding correlates of concordance between consumers and providers is also beneficial. Misunderstanding consumers’ main concerns could damage the therapeutic relationship; alternatively, factors of the relationship may instead lead to poor communication and increased chances of misunderstanding the main concerns. One factor that may impact the consumer-provider relationship, patient-centeredness, has repeatedly been linked to improved consumer outcomes such as self-management and satisfaction with care (Rathert et al., 2012). It is possible higher levels of perceived patient-centeredness reflect higher quality provider-consumer communication which may foster trust and the sharing of information, and in turn, higher levels of agreement on the consumer’s primary concerns. In studies outside of mental health, trust in medical provider has been linked to help-seeking and follow-up, consumer disclosure of information, treatment adherence, and satisfaction with care (Safran et al., 1998; Hall et al., 2002; Bova et al., 2006). Research in psychiatry indicates that consumers consider trust in physician to be central to a positive therapeutic relationship and to receiving quality services (Laugharne and Priebe, 2006). Further, poor quality provider communication has been associated with lower trust (Ommen et al., 2011). Consumers with lower levels of trust may have poorer communication with their provider, and we hypothesize lower rates of concordance on their reported primary concern.

Consumer-specific traits may also impact the quality of communication during appointments. Two constructs particularly relevant to the decision-making literature include autonomy preference and patient activation. Autonomy preference is the degree to which individuals wish to be informed about their condition and participate in decisions related to their illness (Ende et al., 1989). Studies in mental health have consistently shown that consumers have a desire to participate in their own care (Hamann et al., 2005; Hamann et al., 2007a; O’Neal et al., 2008), and the broader literature has linked consumer participation in care to a range of positive health outcomes (Guadagnoli and Ward, 1998; Wilson et al., 2010). Additionally, physician support for consumers’ desired level of autonomy has been associated
with improved health outcomes and treatment satisfaction (Williams et al., 1998; Jahng et al., 2005).

While autonomy preference represents the desire to participate, patient activation refers to the skills, knowledge, and confidence needed to participate in managing chronic illness (Hibbard et al., 2004). In mental health, higher patient activation has been linked to improved illness self-management, increased recovery orientation, and retention in outpatient care (Alegría et al., 2008; Salyers et al., 2009; Green et al., 2010; Kukla et al., 2013) in addition to being directly linked to improved communication (Alegría et al., 2009). Consumers who have stronger autonomy preferences and patient activation may have more interests or ability to advocate for themselves during appointments, more clearly describe their concerns, and participate in their own care, resulting in increased agreement about primary concerns.

Consumer demographic characteristics may also impact agreement on the primary concern of a psychiatric visit. For example, there is evidence outside of psychiatry that those who are White (Levinson et al., 2005), female, more educated, and older are more likely to want to engage in shared decision-making with their provider (Say et al., 2006). If consumers’ communication styles vary with certain demographic characteristics, it is possible that agreement about the primary concern will also vary. Finally, agreement may vary based on the severity of symptoms or functional impairment, which could interfere with communication and a shared understanding of primary concerns during a visit. The current study includes consumers who are receiving services from either an Assertive Community Treatment (ACT) team or from an outpatient clinic in a community mental health center. Given that ACT teams provide highly intensive services for those who have histories of difficulty engaging in care (Salyers and Tsemberis, 2007), the type of services being received may predict agreement levels.

The current study explored what primary concerns are brought to recurring psychiatric visits for a sample of adults with severe mental illness, whether these concerns are concordant with those recognized by providers, and which factors predict concordance. We hypothesized
that greater autonomy and activation in treatment as well as indices tapping the consumer-
provider relationship (trust and perceptions of patient-centeredness) would predict higher levels
of agreement about primary concerns. Furthermore, we hypothesized that consumers who
were female, older, more educated, and White would have better levels of agreement with their
providers, but that those receiving services from ACT teams would have lower agreement
(compared to those in outpatient clinics).

2. Methods

2.1. Participants

Data for this study were obtained during baseline interviews of a study on
CommonGround, an intervention designed to increase shared decision-making in psychiatric
treatment (Deegan et al., 2008; Drake et al., 2010; Stein et al., 2013). Participants included four
psychiatric prescribers (two psychiatrists, two nurse practitioners) serving consumers in one of
four clinics within a community mental health center (two outpatient teams and two ACT teams).
Consumers receiving services in this community mental health center typically see psychiatric
providers every one to three months; these visits typically entail medication management and a
psychiatric check-in by providers, as well as discussion of any psychiatric concerns brought by
consumers. Further involvement in services varies widely across individuals and clinics, but
multiple opportunities are available, such as case management, group and individual therapy,
adoption services, and vocational support.

For the primary study, consumers were approached and recruited when they arrived for
a psychiatric visit, unless clinic staff requested we not approach (e.g., a consumer was in crisis).
Consumers were screened for eligibility by trained research assistants before completing an
informed consent process with a brief test of understanding. To be included in the study,
consumers had to be fluent in English, be willing to be interviewed 3 times over the course of 18
months, and agree to be audio recorded in 3 separate psychiatric visits. Consumers were not
eligible to participate in the study if they had imminent plans to leave their treatment team due to the longitudinal nature of the original study.

In total, 307 consumers were approached by the study team. A total of 167 consumers (54.4%) participated in the study. Another 21 (6.8%) consumers agreed to participate but were unable to pass a test of understanding for informed consent. Ninety-three (30.3%) consumers declined to participate, primarily for lack of interest. A further 26 (8.5%) consumers were interested in the study but had conflicts preventing participation (e.g., no time on the day of their psychiatric visit). For this analysis, 3 visits did not have complete data from both consumer and provider, for a final sample size of 164.

2.2. Procedures

Interested consumers were read the informed consent and asked a series of 10 true-false questions about its content. If an individual passed the screening test and consented, the visit with the prescriber was audio recorded. The providers were given a short survey about the consumer before each visit and asked to fill it out immediately after seeing the consumer. After the visit, consumers were interviewed by trained research assistants. Interviews ranged from 30 minutes to 1 hour, and consumers were paid $20 for their participation; providers were not paid for their time. All procedures for this study were approved by the [university] Institutional Review Board.

2.3. Measures

We collected demographic information from each consumer regarding age, sex, race, and education. Several measures relevant to the CommonGround intervention were included as well as a number of recovery-related indices. Detailed below are the measures used for the current study.

Primary concern for the visit from the consumer’s point of view was obtained in an open-ended question during the interview following the visit with the provider, asking: “What was your primary concern today?” Providers reported the reason for the visit on the survey they
completed after the visit with each consumer, asking “What was the consumer’s primary concern today?” Although no additional instructions were provided with the prompts, consumers and providers were allowed to report multiple primary concerns, or to report that there was no primary concern for the visit.

The Autonomy Preference Index (API) contains 14 items and is designed to assess preferences related to autonomy in medical decision-making (Ende et al., 1989). The API has two subscales, information-seeking and decision-making autonomy, with items rated from 1 = strongly disagree, to 5 = strongly agree. The API has been found to have good internal consistency and test-retest reliability (Ende et al., 1989), and has been used in mental health samples (Hamann et al., 2005; O’Neal et al., 2008). However, data from our sample exhibited poor item-total correlations for three items; thus, items 4 and 6 on the decision-making subscale, and item 5 on the information-seeking subscale were removed and subscale scores were recalculated. Deleting those left four items in the decision making subscale (alpha = 0.68) and seven in the information seeking subscale (alpha = 0.87).

The Health Care Relationship Trust Scale (HCRT) was developed to assess the level of trust patients with chronic medical conditions hold for their health care providers (Bova et al., 2006). The HCRT has 15 items rated from 0 = none of the time, to 4 = all of the time, and assesses three domains: interpersonal communication, respectful communication, and professional partnering skills/collaborative trust. A total score was used in this study. The original study displayed good internal consistency, but lower test-retest reliability after a 2-4 week period (r =0.59) (Bova et al., 2006). In the current sample, the HCRT had strong internal consistency (alpha = 0.91).

The Patient Activation Measure-Mental Health (PAM-MH) has 13 items that assess a consumer’s level of activation in mental health treatment (Green et al., 2010), adapted from a general measure for chronic physical illness (Hibbard et al., 2004). Scores range from 0-100, with 100 indicating the highest level of activation. The PAM-MH has been validated for use in
populations with severe mental illness and has been found to have good internal consistency (Salyers et al., 2009; Green et al., 2010). In the current study, the PAM-MH demonstrated acceptable internal consistency (alpha = 0.78).

The Patient Perception of Patient-Centeredness questionnaire (PPPC) has 14 items with variable response options (Stewart et al., 2004). The PPCP produces a total score and three component scores: exploring disease and illness experience, finding common ground, and understanding the whole person (Stewart et al., 2003). Traditionally the PPCP is coded so that lower scores reflect more positive perceptions; however, for this study we scored it such that higher scores reflected more positive perceptions in order to remain consistent with other utilized measures. The PPCP has shown adequate internal consistency in the past (Stewart et al., 2003) and strong internal consistency in this sample (alpha = 0.89).

2.4. Analyses

Qualitative, content analyses were conducted by a team including a clinical psychologist, master’s level project manager, and two doctoral students in clinical psychology. Using an open-coding process, the team examined a subsample of the primary concerns provided (by both consumers and providers) and labeled them with one or more codes describing the content of the concern. The study team then met to assemble a codebook of each type of concern. This was an iterative process in which the codebook was altered several times to more accurately reflect the data. The primary concerns were then coded by at least two members of the study team using the final version of the codebook. All discrepancies were discussed and agreement was reached for all primary concerns.

After coding the concerns, each set of consumer and provider concerns were rated for agreement by at least two members of the study team. We looked at pairs of responses and rated them as reflecting no agreement, partial agreement, or full agreement. Sets of consumer-provider concerns could receive a rating of partial agreement in two ways. First, if similar concerns were reported but not clearly the same (e.g., “overall mental health” and “auditory
hallucinations”), a rating of partial was given. Second, if multiple concerns were reported by either member of the pair, and at least one (but not all) concerns were identified by the other in the pair, a rating of partial was given. In this way, agreement may have been present for one of multiple reported concerns, but not others. Inter-rater consensus was reached for all sets of concerns, with discrepant ratings discussed among the study team. Coders were able to reliably discern no agreement, partial agreement, and full agreement (κ = 0.81).

For the series of predictive analyses, bivariate relationships were first examined between level of agreement and consumer demographics (i.e., age, sex, race, education), autonomy preference (decision-making and information-seeking), activation, and consumer-provider relationship (trust and perceptions of patient-centeredness). Ordered logistic regression (i.e., cumulative logit model) (Allison, 2001) analysis was then conducted to examine how consumer demographics, autonomy preference, activation, consumer-provider relationship, and service types (i.e., ACT & outpatient) predicted our ratings of provider-consumer agreement. In this study, consumers were nested within clinics (ACT & outpatient). A mixed effects logistic regression model is an ideal strategy accounting for the nested data structure. However, given small cluster size, we created a dummy code for clinic memberships and included it in the logistic regression model to account for the effect. Because we hypothesized that ACT consumers would have less concordance, the clinic effect was considered. Analyses were conducted in SAS version 9.3.

3. Results

The sample was predominantly male (N=93, 56.7%) and Black (N=91, 55.8%). Most had less than a high school education (N=68, 41.5%), but a large proportion had completed high school (N=60, 36.6%) or had some college or more education (N=36, 22.0%). Participants’ mean age was 44.1 (SD = 10.4). Coder ratings of agreement about primary concerns for the visit indicated that for 50% of encounters, consumers and providers had no agreement, for 30% of encounters they had partial agreement, and for 20% of encounters they had full agreement.
Qualitative analyses revealed 17 types of primary concerns identified by either consumers or providers. See Table 1 for descriptions and frequencies of each code. For consumers, medication was the most often mentioned category, followed by symptoms and reference to a follow-up visit. For providers, the most common category was symptoms, followed by medication and employment or education.

Bivariate analyses showed decision-making autonomy was associated with lower levels of agreement (See Table 2). Demographic variables were not significantly related to level of agreement. Multivariate regression results (Table 3) revealed that autonomy preferences were predictive of agreement, but in the opposite direction of hypotheses. For a one unit increase in preference about autonomous decision-making, odds of being in a lower agreement category increased by about 1.7 times. A trend in the same direction was observed for autonomy in information-seeking. Further, as hypothesized, outpatient provider-consumer pairs tended to have higher agreement compared to ACT provider-consumer pairs (OR = 2.5). Nagelkerke $R^2$ (max rescaled $R^2$) was .14 ($\chi^2 (11) = 20.7, p<0.05$).  

4. Discussion

This is the first study we are aware of that examined primary concerns brought to recurring psychiatric visits, agreement levels of concerns between consumers and providers, and predictive factors of agreement. We identified 17 types of primary concerns, most commonly medications and symptoms, with only 50% of visits showing evidence of at least partial agreement between consumers and providers. Our predictive analyses revealed that consumers who had greater preferences for autonomy and were ACT service users (compared to outpatient service) had poorer agreement. Consumer demographic variables, relationship variables (trust, perceptions of patient-centeredness), and consumer activation in treatment did not predict agreement levels.

In our sample, both consumers and providers most frequently identified medication and symptoms as top reasons for the visit. However, it is interesting to note that providers
mentioned non-psychiatric topics such as employment/education, finances, interpersonal concerns, and physical health as the next most common topics. In contrast, consumers more frequently mentioned issues related to follow-up, side effects, and “none”. These findings are inconsistent with findings from Bridges et al. (2011) that psychiatrists tended to value traditional treatment goals (e.g., symptoms, medication), while consumers valued tangible goals (e.g., work). Whereas providers acknowledged broader (non-psychiatric) topics brought by consumers in our study, consumers seemed to narrowly identify primary concerns within more traditional psychiatric topics. Although we did not examine the content of the actual session in the current study, prior work suggests that in sessions, providers tend to initiate more scientific-based discussions (e.g., pros and cons, uncertainties around treatment) than preference-based discussions (e.g., consumer preferences, alternative possibilities) (Fukui et al., 2014). Discussions about medication led by providers frequently occur around symptom reduction, rather than how the medication or non-medication options can help consumers work toward recovery (Deegan, 2005, 2007). It is possible that the medication and symptom discussions are more salient for consumers after the visit when we asked about primary concerns. Alternatively, consumers may perceive that these are supposed to be primary topics in recurring psychiatric visits, and thus report them as a result of social desirability bias.

While both consumers and providers frequently identified medication and symptoms as main concerns in recurring psychiatric visits, these similarities did not translate to high levels of concordance at the individual level. Our rates of concordance were considerably lower than concordance rates reported in medicine of 80-90% (Boland et al., 1998; Gross et al., 2013), and were more in line with studies comparing concordance between patient report and chart review for events occurring during visits (DiMatteo et al., 2003). There are several possible reasons for the low level of agreement in our study.

First, the nature of the visits we were studying may explain lower concordance. Visits were frequently recurring (typically every 1-3 months and potentially more often for the ACT...
teams where consumers could drop-in to see the provider). Frequent visits may not facilitate
new concerns from consumers, but rather encourage discussion of ongoing, maintenance-
related items, such as tweaking a medication or addressing recurrent symptoms, which may not
be viewed as a “primary” concern by consumers or providers. This might also result in relatively
higher frequencies of “follow-up” or “none” as primary concerns.

Second, the low level of agreement in our study may stem from an absence of agenda
setting (whereby the consumer and/or provider set out a list of items to discuss during their time
together). As prior research shows, agenda setting is often omitted in recurring psychiatric visits
(Frankel et al., 2013). Agenda setting has been identified as critical when establishing the
partnership between providers and consumers (Fortin et al., 2012). However, attempts to set
the agenda or revisit agenda items may get buried in routine and recurrent visits. Research in
primary care has shown that when physicians do not solicit patient concerns at the beginning of
the visit (as is done with proper agenda setting), late-arising concerns occur more often
(Beckman et al., 1985; Marvel et al., 1999). Late-arising concerns occur toward the end of a
visit, making them difficult to fully address, and sometimes these concerns may not be
addressed at all. Agenda-setting with a full solicitation of consumer concerns acts to reduce the
occurrence of late-arising concerns and ensure that all concerns are prioritized at the beginning
of a visit (Marvel et al., 1999).

Third, while agenda-setting refers to a shared understanding of goals for a particular
visit, shared understanding of broader goals may also be important for concordance. Goal-
setting has been shown to increase involvement in treatment and enhance ownership of the
recovery process in consumers with severe mental illness (Levack et al., 2006). It may be that
more frequent and explicit goal-setting processes in recurring psychiatric visits could improve
concordance about the main concerns. Alternatively, checking with the consumer about the
importance of the goal may clarify its status as a main concern in the visit.
In examining predictors of agreement, greater autonomy preferences predicted poorer agreement. Though our findings countered hypotheses, there is some research to suggest that greater autonomy preferences may not necessarily facilitate agreement. For example, Hamann, Cohen, and colleagues (2007b) argued that greater preference for autonomy may be a result of dissatisfaction with care, leading consumers to feel an increased need to advocate for themselves and/or seek information independently from their provider. Our data also supports this trend -- greater decision-making autonomy was associated with lower levels of trust and perceptions of patient-centeredness (see Table 2). In addition, some research in primary care indicates that those with the strongest relationships with their providers preferred a more passive role in decision-making (i.e., less autonomy; Kraetschmer et al., 2004). Our research infers that stronger autonomy preferences could facilitate consumers’ own acknowledgement and advocacy about their concerns, but if providers misperceive them, it may lead to poorer concordance.

Our regression analysis also showed that the type of clinic in which consumers received services (ACT vs. outpatient care) predicted agreement level. Consistent with expectations, those attending the ACT clinics had poorer agreement than those receiving outpatient services. This may reflect the severity of symptoms of consumers, as ACT services are typically only provided to consumers with high rates of hospital use and/or inpatient stays. It may also be that providers on ACT teams differed from those on outpatient teams, but with the small number of providers, we could not adequately sort out provider from clinic effects. Further exploration in other samples is needed to parse out factors that may contribute to this finding.

Lastly, consumer demographics, patient activation, trust, and patient-centeredness were not significant predictors of agreement. While activation, trust, and perceptions of patient-centeredness are correlated with each other (see Table 2) and are considered to be important factors in shared decision-making practices, they did not predict higher concordance about primary concerns in our sample. Although concordance was generally poor, our participants
rated high levels of trust and patient-centeredness about their providers. It could be that frequently recurring visits lend themselves to this pattern of findings; with established consumer-provider relationships, rapport may be strong, and consumers may not feel compelled to clarify the main concerns in each visit, regardless of activation levels. Alternatively, the lack of associations may in part be due to a statistical artifact of restricted range, as trust and perceptions of patient-centeredness (HCRT and PPPC) exhibited high mean scores and a number of participants reported the maximum possible score. Our high scores are similar to the findings in the initial validation study of the HCRT (Bova et al., 2006), but the PPPC did not exhibit a ceiling effect in its initial validation (Stewart et al., 2004). It is possible the scale operates differently in this population, or at least our sample. Further research is needed to examine trust and perceptions of patient-centeredness in this population and how these constructs relate to consumer-provider communication.

As an initial study of consumer-provider concordance, our study opens the way into a new area of research in mental health. However, we are limited in making generalizations by a smaller sample in a single service setting, and although we did include different types of services (ACT and outpatient), we had only four providers. In addition, consumers were being recruited for a larger study, and needed to pass a cognitive screener to be enrolled. It is possible that we excluded people who may have more difficulty in describing primary concerns due to greater cognitive difficulties, which could further lower the rates of agreement we found. Further, given the recurring nature of the visits used in this study, consumers may not have a specific primary concern for their visit, but may have reported such “standard” concerns as medication or symptoms. In this vein, consumers may have answered in a socially desirable manner, indicating results may not accurately represent true concerns or may over-represent “standard” concerns. Future work may ask consumers whether they had any primary concerns for their visit before asking what it was. Further, use of the word “primary” may have been interpreted by some participants as a request for just one concern, perhaps imposing an
artificial ranking of concerns in the visit upon the consumer or provider. Agreement level may have been different if participants had just been asked what concerns they had in the visit, as opposed to what was their primary concern. Finally, a general limitation which could be applied to any shared decision-making study includes a lack of good measurement tools (e.g., see Geiger and Kasper, 2012). Our study is not an exception, including the ceiling effects for the HCRT and PPPC as well as lower reliability for the API in our sample.

4.1. Conclusions and Implications for Practice

In conclusion, our results suggest that levels of agreement about primary concerns in a psychiatric visit are variable, with a large percentage of visits indicating no agreement. Low agreement may be particularly problematic for those with high levels of preferences for decision-making autonomy and for those on ACT teams. The low level of agreement found in our study has implications for clinical work. In our sample, primary concerns were only agreed upon (at least partially) in half of the sample; this indicates that for half of our sample, providers and consumers were not on the same page regarding concerns of most importance during the psychiatric visit. This could have negative implications for consumers’ treatment outcomes, and should be targeted for improvement in mental health services. Our Table 1 could easily be used to create a checklist for consumers to fill out and share with the provider in each visit. Other tools are also available to increase understanding between consumers and providers. For example, CommonGround includes peer support and computerized tools to assist in shared decision-making (Deegan et al., 2008). Other interventions train consumers to ask questions and get information about treatment from providers, which can increase attendance, retention in treatment, and patient activation (Alegría et al., 2008). An intervention such as this may be modified to also train consumers on how to communicate their primary concerns clearly at the beginning of each visit. Furthermore, use of patient-centered practices such as purposefully setting an agenda at the beginning of psychiatric visits (Frankel et al., 2013) may serve to solicit primary concerns early in the visit, perhaps increasing rates of agreement. Given the
fundamental role of having a shared understanding of primary concerns to facilitate collaboration, further attention is needed to ensure the provision of patient-centered care such that consumer concerns are acknowledged and addressed within recurring psychiatric visits.
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