

FINDING COMMON GROUND: EXPLORING THE EXPERIENCES OF CLIENT
INVOLVEMENT IN MEDICATION DECISIONS USING A SHARED DECISION MAKING
MODEL

BY

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ABSTRACT

While shared decision making has gained more prominence in recent years in the field of general health care, few shared decision making models have been studied in the field of mental health. This constructivist study explores the experiences of twelve persons diagnosed with schizophrenia or other major thought disorder, along with their treatment providers (prescribers, nurses, case managers, and peer support workers), when introduced to a shared decision making model around psychiatric medications. Purposeful sampling, with an emphasis on achieving maximum variation, was used to better understand the interactive processes that contribute to as well as hinder client involvement in shared decision making. Multiple interviews with all participants over a one year period allowed for meaning making to unfold over time. Simultaneous involvement with data collection and data analysis was part of an emergent design that culminated in tentative constructions based on participant's experiences. Findings were subjected to a comprehensive member check for confirmability.

Findings explore the multiple interacting factors that contribute to client's involvement in shared decision making, including agreement on a goal that is meaningful and important to the client to guide decisions, the relationship between the prescriber and the client, the presence of non-pharmaceutical alternatives that expand decision options, and behaviors by auxiliary supports (i.e. case management and peer support) that facilitate involvement. Findings also explore the complexity of thought behind client's decisions to use psychiatric medications and the dynamics that change when a new model of decision making is introduced. The findings became the basis of proposing a new tentative framework for shared decision making as well as a concept called activation points. While the findings are intended to improve the process at a

specific mental health center, readers are invited to join the dialogue in regards to the transferability of the findings to other settings.

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CHAPTER 1: INTRODUCTION AND OVERVIEW

First person accounts of the lived experience of psychiatric disability place self-determination as an important aspect of recovery (Ralph, 2000). While definitions of recovery are varied within the literature, several themes reflecting self-determination are mentioned within these first-person accounts including: (1) owning the power to set one's own goals (Chamberlin, 1999; Lovejoy, 1982; Sayce, 2000); (2) having control to make choices that affect one's life (Blanch & Parrish, 1993; Chamberlin, 1998; Leete, 1989; Reilly, 1992); (3) being able to recognize and use one's inner strength to impact positive change (Chamberlin, 1999; Deegan, 1988; Leete, 1993; Stocks, 1995); (4) having a voice in defining what is distressing or problematic in one's life (Cohan & Caras, 1998; Deegan, 1997; S. Mead & Copeland, 2000; Riffer, 1997; Stocks, 1995; Unzicker, 1989); and (5) having a voice in deciding the type and level of services that are helpful to one's recovery journey (Copeland, 1997; Riffer, 1997; Scheie-Lurie, 1992; Stanley, 1992; Unzicker, Wolters, & Robinson, 2000).

Though it could be argued that many people with psychiatric disabilities have become more active in the decision making process about their treatment than at any other time in the history of mental health services (Linhorst, Hamilton, & Eckert, 2002), the principle of client self-determination "has not yet proliferated in the mental health system, and consumers'/survivors' perspectives on the issue have not been widely acknowledged" (Cook & Jonikas, 2002, p.87). This is particularly true in the area of decision making around psychiatric medications.

Makoul, Arnston and Schofield (1995) suggest that whether and how to use medications are among the most important decisions in which people with psychiatric disabilities can participate. Others note that people with severe psychiatric disabilities who participate in

decision making have a higher level of satisfaction with services and greater self-efficacy, confidence, and hopefulness (Bassman, 1997; Chinman et al., 1999; Holland, Knoick, Buffum, Smith, & Petchers, 1981; McCarthy & Nelson, 1991; Salzer, 1997). Hamann, Cohen, Leucht, Busch and Kissling (2005) found in a study of 122 persons diagnosed with schizophrenia that many wanted to be involved in decisions about their medications. Yet, people with a psychiatric disability typically have had limited influence and control over the mental health care they receive, especially regarding medications (President's New Freedom Commission on Mental Health, 2003).

Shared decision making models have been used in health care to increase the level of client involvement in treatment decisions (Stewart et al., 1995). Shared decision making acknowledges that both the client and the practitioner have important information to contribute to the process. Shared decision making can contribute to client self-determination by placing treatment decisions in the context of the client's goals, values, and preferences. Research on shared decision making in general health care has shown positive results in the areas of client satisfaction (Beaver et al., 2005; Hochlehnert et al., 2006; Keating, Guadagnoli, Landrum, Borbas, & Weeks, 2002; Schattner, Bronstein, & Jellin, 2006), improved follow-through with treatment (N. Mead & Bower, 2002; Roter et al., 1998; Wahl et al., 2005), and improved treatment outcomes (M. K. Goldstein et al., 1994; Kiesler & Auerbach, 2003; N. Mead & Bower, 2000; Stewart, 1995; Stewart et al., 1999).

Background for the Study

In October 2006, a Community Mental Health Center in northeastern Kansas introduced a shared decision making model to invite people with psychiatric disabilities to be more involved

in decisions regarding the use of their psychiatric medications. This model, developed by Patricia Deegan, consists of the following components:

- 1) Prior to the medication consultation, clients work with a case manager to develop a Power Statement that sets the tone for the client's expectations for the consultation, and also list what personal medicine the client is currently using that supports their recovery goals.
- 2) Prior to meeting with the prescriber, clients answer questions on a touchpad screen located at a kiosk in the medication consultation waiting room that includes: the Power Statement, the personal medicine they are currently using, how they are doing in a variety of areas related to their current physical or mental health at the time of the appointment, and any decisional uncertainty they have about the use of medications (See Appendix A for screenshots of all questions asked of clients). Clients have the opportunity to either listen to the questions via a headset and respond, or read the questions on the screen. A peer specialist is employed by the agency to assist clients if needed to navigate through the screens at the kiosk. The peer specialist is someone who has been diagnosed with a psychiatric disability and has received services at the agency. They are able to answer questions about what to expect during the medication consultation and how the information they enter will be used in the medication consultation.
- 3) The information obtained from using the touchpad screen is electronically compiled into what is called the Common Ground Report. The peer specialist is available to help the client understand how to read the Common Ground Report, form any questions they may have for the prescriber during the consultation, and/or look up and print out any

information on the internet they request about their medications, diagnosis or wellness strategies.

- 4) The Common Ground Report is taken into the medication consultation so that it is available for the prescriber and the client to review together.
- 5) The prescriber follows a shared decision making model format that consists of : (a) understanding what is most meaningful and important in the client's life (client's Power Statement); (b) understanding the person's use of personal medicine; (c) allowing the client to voice his/her desires for treatment outcomes; (d) elicit the client's subjective experience of his/her situation; (e) explore any decisional uncertainty regarding the use of medications; (f) explore possible options and strategies; and (g) arrive at a mutually agreed upon decision.
- 6) A Common Ground Report is updated to include the shared decision and shared with other people on the client's treatment team. This is important if there are any follow-up steps that need to be taken by other team members. For example, a shared decision might be that the client will take a lower dosage of a particular medicine and increase use of coping skills related to reducing stress in his or her life. A therapist or case manager might be asked to help teach these skills.
- 7) During subsequent visits the client begins again at the kiosk with the touchpad screen and is able to review information from their last visit (e.g. their Power Statement, personal medicine, current pill medicine, etc.). New information is reported by the client regarding how they are doing at the current visit and any decisional uncertainty they may have. Past and present responses are recorded in the system thereby creating a longitudinal record.

This constructivist inquiry examined the experiences of clients and psychiatric treatment team members using a shared decision making model around the use of psychiatric medications. To date, no shared decision making model has been implemented in the field of mental health around psychiatric medications. This was a unique opportunity to not only understand how both clients and treatment team members experience this type of intervention, but also to shape the intervention as it was being implemented to be more responsive to clients.

Because of the limited research on shared decision making for people with psychiatric disabilities, this study was exploratory in nature. We know little about the preferences for people with psychiatric disabilities around decision making, the skills needed for effective decision making, or the outcomes that can be anticipated from increased client involvement in the decision making process. We also know little about prescribers reactions to clients involvement in decision making, the factors that help or hinder the decision making process, or the potential benefits to prescribers engaging in this type of process.

Since this study was undertaken at a single community mental health center, involving clients and staff who had experience with the medication consultation before and after the introduction of the shared decision making process, the opportunity was propitious for understanding the dynamics that changed for people on a personal, interpersonal, and systemic level. It would be impossible to make sense of individual responses without understanding the context that people currently and previously made decisions.

Application to Social Work

The components of a shared decision making model are consistent with social work values, such as respecting the inherent dignity and worth of the person, promoting self-determination, enhancing client's capacity and opportunity to address their own needs, and engaging clients and

partners in the helping process. Bentley and Walsh (2006) encouraged social workers to understand a person's decision making around psychiatric medications "in light of the client's views of their illness, treatments, experiences, interactions, and expectations" (p.210). Gerhart (1990) stated that social workers should take on the role of medication advocate in mental health centers and that ideally social workers should be involved in all phases of client decision making around psychiatric medications.

Social workers currently account for the largest single profession in the field of mental health (Gambrill, 2002). Yet, social workers have traditionally played a more peripheral role around the medication consultation (Bentley & Walsh, 2006). This study lends itself to social work taking on a more active role around client's use of psychiatric medications by understanding the processes and context in which client's make these decisions, as well as the facilitating factors that contribute to clients being more involved in their care. Weick and Pope (1988) stated, "... the role of social workers is to support the awakening and development of self-determination by creating a climate within which the individual's life force may survive and grow" (p.16). This study provides an opportunity for social work to shape the environment in which clients learn to take a more active role in decisions regarding psychiatric medications.

From a social work perspective, it is important to respect the diversity of the people being served, taking into account their preferences and experiences of various treatments. In many of the studies that support psychiatric medications as a best practice, the focal point has been the symptoms, not the person. Tower (1994) advocated for social workers to adopt a consumer-centered approach to practice, stating that "individuals who have direct experience with a particular life condition...are more knowledgeable about their own needs and interests than are their professional counterparts" (p.192). Hartman (1992) reminds social workers that we must

“enter into a collaborative search for meaning with our clients and listen to their voices, their narratives and their constructions of reality” (p.484). Social work can embrace this call by focusing on ways to bring the client into a central role in the helping relationship when discussing possible strategies for helping people deal with distressing psychiatric symptoms.

Concluding Thoughts

Self-determination has been a core value of social work since the beginning of the profession (McDermott, 1975; Reamer, 1997). It is also highly valued by many people with psychiatric disabilities and is viewed as a key component in a person’s recovery (Ralph, 2000). While people with psychiatric disabilities have become more active in the decision making process than at any other time in the history of mental health services (Linhorst et al., 2002), decisions around psychiatric medications continue to largely follow a paternalistic model of decision making. This occurs despite research showing that many people with psychiatric disabilities wish to be more involved in decisions regarding their medications.

This study aims to assist in a transformation from a paternalistic approach to the psychiatric medication consultation to one based upon a shared decision making model. Shared decision making has gained ground in general medical practice, but has not proliferated into the field of mental health. An opportunity exists for the first time in mental health history for a shared decision making model to be fully implemented in a psychiatric setting for people with severe psychiatric disabilities.

Shared decision making supports the values of social work, such as, respecting the inherent dignity and worth of the person, promoting self-determination, enhancing client’s capacity and opportunity to address their own needs, and engaging clients and partners in the helping process. Lessons learned from this study will enhance the social work knowledge base in terms of what

factors enhance self-determination for people with psychiatric disabilities regarding medication use. While most studies around medication usage in mental health focus primarily on the act of non-compliance, this study will provide more in-depth understanding about the decision making process that clients go through when considering medication usage. This study accentuates the person-in-environment perspective widely held in social work, by starting where the person is and drawing in the contextual factors that enter into a person's process of decision making. Strategies for engaging persons with psychiatric disabilities more fully in the helping process will be better understood by drawing out client's voices regarding their experiences of using a shared decision making model.

This study has major implications for practice and policy in mental health. This study was undertaken during a pilot project in the State of Kansas on shared decision making around medications that is being considered for replication. Since non-compliance with medications is viewed in the literature as a major obstacle to people's recovery from a psychiatric disability, there is interest on both the practice and policy levels in decreasing the incidences of non-compliance. While this is not a study on non-compliance, it has implications for exploring an alternative way to viewing the issue of non-compliance and understanding more about how to better collaborate with people with psychiatric disabilities in their recovery process. The inquirer believes that enhancing people's self-determination in the decision making process will increase the likelihood that people will follow-through with treatment recommendations, leading to better treatment outcomes. This study offers a chance for professionals and clients to learn from each other to shape the way decisions around medications are made. This learning will not only guide improvement for shared decision making at this agency, but also other agencies that choose to undertake this endeavor.

CHAPTER 2: LITERATURE REVIEW

While medications are considered by most professionals and researchers as an evidence-based practice in reducing symptoms of schizophrenia (Chiles et al., 1999; Lehman et al., 2003; Mellman et al., 2001), many people with schizophrenia choose not to take medications as prescribed. Studies on medication compliance have consistently shown that less than 50% of all people with serious psychiatric disabilities are compliant with medications (Byrne, Regan, & Livingston, 2006; Cramer & Rosenheck, 1998; Fenton, Blyler, & Heinssen, 1997; Rettenbacher et al., 2004). This number might even be greater when considering that many people do not report medication noncompliance to their prescribers, and many who drop out of studies are more likely to be noncompliant with medication than those who continue in the study (Gray, Wykes, & Gournay, 2002).

Reasons for non-compliance are varied in the research literature, and research has been gathered predominantly through quantitative methods. Some studies have found the severity of the person's symptoms are associated with non-compliance (Kelly, Maimon, & Scott, 1987; Olfson et al., 2000; Pan & Tantam, 1989; Pristach & Smith, 1990; Van Putten, Crumpton, & Yale, 1976), while other studies have shown no association (Ayers, Liberman, & Wallace, 1984; Bartko, Herczeg, & Zador, 1988; Olfson et al., 2000). Strong correlations have been reported between substance use and medication noncompliance among clients with schizophrenia (Drake, Other, & Wallace, 1989; Kashner et al., 1991; Owen, Fischer, Booth, & Cuffel, 1996), while other studies have shown no correlation (Kovaszny et al., 1997). Cross-sectional studies have reported that clients who deny a mental illness have higher rates of medication noncompliance than clients who are reported to have greater insight into their illness (Marder et al., 1983; McEvoy, 1998; Nageotte, Sullivan, Duan, & Camp, 1997), and improvements in insight have

been linked to improved medication compliance (Kemp, Kirov, Everitt, Hayward, & David, 1998). However, longitudinal research suggests that the relationship between insight and compliance may not be straightforward. In two studies, assessments of insight into illness were not found to predict medication adherence at either six months (Cuffel, Alford, Fischer, & Owen, 1996) or one year (Weiden et al., 1991) after hospital discharge.

Unpleasant side effects are commonly cited as a primary reason why clients decide not to take medications (Hoge et al., 1990; Ruscher, de Wit, & Mazmanian, 1997). However, some researchers (Fleischhacker, Meise, Gunther, & Kurz, 1994; Pan & Tantam, 1989) have failed to find an association between medication side effects and noncompliance.

The availability of family members who remind patients to take their medications is widely believed to lower the risk of medication noncompliance. Several cross-sectional studies have demonstrated higher rates of medication compliance among clients with schizophrenia who live with family members or with people who supervise their medications (Buchanan, 1992; Owen et al., 1996; Razali & Yahya, 1995). One study found that clients whose families are ambivalent about antipsychotic medications are at increased risk of medication noncompliance (Weiden et al., 1991).

Clients with schizophrenia who form strong alliances with their therapists seem to be more likely to comply with prescribed medications than clients who form weaker alliances (Drake et al., 1989; Frank & Gunderson, 1990; Olfson et al., 2000). Frank and Gunderson (1990) found that 74% of clients diagnosed with schizophrenia with fair or poor therapeutic alliances with their therapist did not fully comply with prescribed medication regimens over a course of eighteen months. In contrast, only 26% of clients with a good alliance with their therapist were noncompliant.

Fenton, Blyler, and Heinssen (1997), noted that through the mid-1990's more than 14,000 articles appeared in the medical literature about medication adherence, but almost none were directed toward the subjective experience of clients or their decision making process. The focus is often on the person's actual act of non-compliance with the medication (Garavan et al., 1997; Lacro, Dunn, Dolder, Leckband, & Jeste, 2002; Olfson et al., 2000; Torrey & Zdanowicz, 2001).

Noncompliance suggests that a person has not done what he or she was told by a mental health professional. Repper and Perkins (1998) have highlighted the importance of language in mental health and suggest that the use of words like "compliance" may imply that clients are passive recipients of health care who should follow the direction of those providing services. In this view, clients are not seen as possessing the right or the ability to engage in self-determination. Bentley (1993) states that "a patient's right to refuse medication is often portrayed as illogical, contradictory, and even unethical" (p.101).

Some of the qualitative studies that have been conducted around psychiatric medication usage may begin to shed more light around the meaning that psychiatric medications hold for people with schizophrenia and therefore also their decisions around usage. In a qualitative study by Mancini, Hardiman, and Lawson (2005) involving 15 clients, the authors found that half of the participants viewed medication as key to their recovery. Some stated that the medications had the greatest effect of helping them diminish symptoms they found distressing. However, almost half also described the debilitating emotional, cognitive, and physical side effects of their medication as barriers to recovery. Several claimed medications "kept them in a state of confusion and prevented them from achieving the stability and clearness of mind needed to achieve their recovery goals" (p.52). Some clients stated they actually did better once they got off medications, instead relying on things like supportive relationships, yoga, exercise, and

involvement in activities that they enjoyed to help decrease the effects of distressing symptoms. Mancini, Hardiman, and Lawson (2005) concluded that “the type of treatment was not as important as having the ability to evaluate a variety of alternatives and having the self-determination to choose the method viewed as most effective” (p.53). In a qualitative study using grounded theory of persons diagnosed with schizophrenia by Gee, Pearce, and Jackson (2003), none of the participants reported any specific positive effects from their medications, but several reported how the medications reduced their level of motivation, impacted social relationships, and left them with side effects that were often worse than the distress they experienced from symptoms of mental illness.

The Well-Being Project (Campbell, 1993), sponsored by the California Department of Mental Health, conducted a multi-method study of 331 clients with serious psychiatric disabilities to define and explore factors promoting or deterring recovery. Through focus group interviews, nearly 60% of clients indicated they could always or most of the time recognize signs or symptoms that they were experiencing psychiatric distress, and almost half reported that they could always or most of the time take care of the problem before it became too serious. The most favored coping and help-seeking strategies were to write down their thoughts or talk with someone about what they were experiencing, spend time with supportive others (including family, friends and/or mental health professionals), relaxation techniques, and engaging in enjoyable activities. While taking medications was an important factor for some of the individuals in the study, it did not emerge as a major theme across participants.

In a qualitative study involving 19 individuals with a serious psychiatric disability, Deegan (2005a) found that participants were more likely to discuss what she called “personal medicine” as compared to psychiatric medication as a key ingredient in helping to deal with distressing

psychiatric symptoms. Deegan (2005a) referred to personal medicine as “self-initiated, non-pharmaceutical self-care activities that served to decrease psychiatric symptoms, avoid undesirable outcomes such as hospitalization, and improve mood, thoughts, behaviors, and overall sense of well-being” (p.31). The main categories of personal medicine that participants identified were: 1) activities that gave meaning and purpose to life (e.g. working, volunteering, going to school, spending time with children, etc.); and 2) specific self-care strategies (i.e. exercising, talking to someone supportive, being in nature, changes in diet, exposure to sunlight, etc.). Deegan (2005a) found that non-adherence with prescribed psychiatric medications was found to occur when pharmaceuticals interfered with personal medicine resulting in a diminished quality of life.

The review above shows that there are differences between studies in terms of what is most effective in helping people with psychiatric disabilities cope with distressing psychiatric symptoms. Current mental health practice has given considerable weight to the quantitative literature pointing to the effectiveness of psychiatric medications (especially the second generation antipsychotic medications) in helping alleviate symptoms. The professional literature is replete with articles recommending psychiatric medications as a primary and essential intervention for people diagnosed with schizophrenia, selectively citing quantitative studies that report positive outcomes (Chiles et al., 1999; Mellman et al., 2001; President's New Freedom Commission on Mental Health, 2003; U.S. Department of Health and Human Services, 1999). Omitted, from many national reports on the effectiveness of medications as a front-line treatment for the symptoms associated with schizophrenia, are the qualitative studies and first person accounts of people experiencing psychiatric distress that often show less than favorable responses to antipsychotic medications currently being prescribed. While medications are

attributed as a beneficial factor for many people with psychiatric disabilities, it also is equally attributed as a factor that deters from people's overall well-being and recovery from a psychiatric disability.

Research on Shared Decision Making

One improvement in the area of best practice around reducing distressing psychiatric symptoms would be to move towards more of a shared decision making model when considering what intervention might be most effective. Shared decision making “denotes an interactive process in which clients and practitioners collaborate to make health care decisions” (Adams & Drake, 2006, p.87). It assumes that both client and practitioner have important information to contribute to the process. While practitioners have information on various interventions, including potential benefits and drawbacks, clients are the experts of their own values, treatment preferences, and treatment goals (Charles, Gafni, & Whelan, 1997).

Studies on shared decision making in the health care field have shown positive results in the areas of client satisfaction (Beaver et al., 2005; Hochlehnert et al., 2006; Keating et al., 2002; Schattner et al., 2006), increased knowledge (Hochlehnert et al., 2006; Holmes-Rovner et al., 2005; O'Conner et al., 1998; Schattner et al., 2006), reduced decisional conflict (O'Conner, Rostrom, & Fiset, 1999), improved follow-through with treatment (N. Mead & Bower, 2002; Roter et al., 1998; Wahl et al., 2005), and improved treatment outcomes (M. K. Goldstein et al., 1994; Kiesler & Auerbach, 2003; N. Mead & Bower, 2000; Stewart, 1995; Stewart et al., 1999). Although the concept of shared decision making is becoming more common in the general health field, it is a relatively novel approach in the mental health field (Forrest, 2004). Hamann, Cohen, Luecht, Busch, and Kissling (2005) found that the majority of persons with schizophrenia wished to be more involved in decisions around their treatment, especially regarding medications.

Elwyn and Edwards (2001) found variation regarding the extent to which clients wish to be involved in decisions affecting their care. While there are clients at both ends of the spectrum, from taking a dominant role in decision making to a more passive role in which responsibility for decision making is given to the practitioner, most clients opt for a more balanced role in which the two parties engage in dialogue around the issue and come to a consensual decision (Elwyn & Edwards, 2001).

There is some controversy about the ability of people diagnosed with schizophrenia to make competent decisions about their treatment (Auerbach, 2000). A recent study revealed that few clients receiving antipsychotic medication have been educated about their medication, or had any active involvement in decisions around medications (Marland & Sharkey, 1999). This is despite two studies that have shown that persons diagnosed with schizophrenia were able to make accurate assessments about the effects of their medications and displayed competence in discussing the reasons they did or did not want to take certain medications (Day, Wood, Dewey, & Bentall, 1995; Van Putten, May, & Marder, 1984).

CHAPTER 3: METHODOLOGY AND THEORETICAL FRAMEWORK

Self-disclosure of the inquirer

I have worked in the field of mental health for over twenty years. I have worked as a case manager, a case management supervisor, and a program director for an agency serving homeless individuals with a psychiatric disability. In my current work at the University of Kansas, I oversee training for front-line staff working with adults in Kansas mental health centers. I also oversee the implementation of high fidelity Strengths Model Case Management practice in Kansas.

In saying this, I am predisposed to favoring a particular model of case management practice called the Strengths Model, developed by Charles Rapp at the University of Kansas. This model is rooted in the strengths perspective of social work (Saleebey, 2002), and holds a set of six principles, which are:

- 1) People with psychiatric disabilities can recover, reclaim, and transform their lives;
- 2) The focus is on individual strengths rather than deficits;
- 3) The community is viewed as an oasis of resources;
- 4) The client is the director of the helping process;
- 5) The helping relationship is primary and essential;
- 6) The primary setting for our work is in the community (Rapp & Goscha, 2006).

Also, having obtained my undergraduate and graduate degrees in social work, I hold to the values as established by the profession. Therefore, going into this study, I started with the belief that recovery for people with psychiatric disabilities was possible and that people receiving services not only have the right to define what recovery means to them, but should be the

director of the helping process to support that journey. I make these disclosures up front so the reader can understand and recognize my positioning in the finding and conclusions of the study.

Rationale for the Research Design

A constructivist or naturalistic inquiry (Lincoln & Guba, 1985) framework was used in this study since the purpose was to explore how a newly introduced model of shared decision making around psychiatric medications was experienced by various stakeholders involved in the process. A “constructivist inquiry highlights perceptions” and “its methods provide mechanisms for looking into another’s world” based on those perceptions (Rodwell, 1998, p. 4). The aim of this research is to understand how meaning is constructed by various participants in response to a new model of decision making. It takes into account that all participants are engaged in a state of mutual, simultaneous process of meaning-making.

It is important for the reader to understand key differences between constructivist and positivist inquiry in order to position this body of work within the proper paradigm. While there are multiple differences between constructivist and positivist inquiry, five key areas are briefly presented here. This includes, the nature of reality, the inquirer/participant relationship, the nature of explanation, and purpose of inquiry.

First, constructivist inquiry operates from a standpoint that there are multiple realities that can only be studied holistically. In comparison, positivist assumptions hold that there is a single, tangible reality that can be fragmented into independent variables and processes that can be studied independently of the others. The positivist inquiry therefore typically uses methods aimed at prediction and control, whereas this is rejected in a constructivist inquiry. The constructivist inquiry rather uses methods to understand the ways individuals actively create, modify, and interpret the world in which they live, or in the case of this study, the social

phenomenon being explored. In this study, the inquirer is interested in the convergence of these multiple realities. It is not the goal to achieve consensus about an objective or “right” understanding of the research topic, but rather to achieve some level of understanding that leaves room for varying interpretations of the phenomenon. In constructivist inquiry realities are not discovered, as in the positivist inquiry, but rather participants are constantly creating and re-creating their own perceptions of reality as they interact with others.

Second, in a constructivist inquiry the inquirer and participants interact to influence one another. The knower and the known are viewed as inseparable. This diverges from positivist inquiry which assumes a dualism between the knower and the known. Objectivity cannot be maintained in a constructivist inquiry though methodological controls as is attempted within a positivist inquiry. In this study it is acknowledged that participants, including the inquirer, are changed as a result of the research process. Objectivity is countered by prolonged engagement in which the inquirer and participants develop trust and mutuality. What is known is developed through collaborative relationships that are time-bound and therefore constantly shifting.

Third, since all participants are mutually and simultaneously shaping one another, it is impossible to distinguish causes from effects in the constructivist inquiry. Whereas identifying causality is central to positivist inquiry, all actions in the constructivist inquiry are understood to be the result of multiple interacting factors, events, and processes that occurred prior to the study and continue to occur as the study unfolds. In this study, the inquirer is interested in establishing plausible inferences about the patterns of shaping that result from the shared decision making process. These inferences are open to interpretation by both the participants and the reader.

Fourth, the purpose of inquiry differs between constructivist and positivist frameworks. The purpose of positivist research is generalization. This is rejected in a constructivist inquiry. The

purpose of a constructivist inquiry, as it is in the study, is to develop a characteristic body of knowledge that is particular to the participants involved in the study. There are no truth statements that exist independently of time and context. Rather the reader is offered a series of tentative suppositions based on participants' constructions at the subjective, experiential level. While this study does not attempt to make generalizations, it does offer the possibility of transferability. As Rodwell (1998) states, "transferability allows for the possibility that information created and lessons learned in one context can have meaning and usefulness in another" (p.101). The decision about usefulness of this body of work to other environments rests with the reader. In the discussion section of this study, the inquirer introduces some new concepts and a proposed framework, based upon the findings, intended to improve the process as it exists at the mental health center involved in the study. While this generated knowledge is localized, readers are encouraged to use this information to engage in the dialogue of improving decision making around psychiatric medications at other mental health centers.

Because a shared decision making model has not been previously studied in the field of mental health around psychiatric medications, it was not only unclear what the outcomes might be from using this model, but it was also unknown to what degree individuals with a severe psychiatric disability wish to be involved in the shared decision making process. Some outcomes, such as client satisfaction with the medication consultation, follow-through with the shared decision related to medications, and well-being were explored based upon the research on shared decision making outside the field of mental health (Beaver et al., 2005; Hochlehnert et al., 2006; Keating et al., 2002; N. Mead & Bower, 2000; Roter et al., 1998; Schattner et al., 2006; Wahl et al., 2005). Initially, it was not clear whether three visits with the prescriber prior to the first interviews and three visits prior to the second interviews (covering a period of nine months)

would be sufficient to indicate evolution or change in client outcomes to the shared decision making model, especially considering how radical a change this is in the way the traditional medication consultation has occurred in mental health. However, nine months of experience using the model was considered sufficient to gather rich qualitative data on how people are experiencing this new intervention. The hope was that the findings of this inquiry would contribute to the discussions of shared decision making models that will increase the self-determination of people with psychiatric disabilities around the use of their medications.

It is possible that this study could have been conducted using quantitative measures. There could be merit in a study that explored whether or not a specific shared decision making model was effective in increasing the involvement of people with psychiatric disabilities and the impact it had on specific outcomes of treatment (i.e. satisfaction with services, level of medication adherence, level of symptoms, functioning, etc.). Studies on shared decision making mentioned in the previous section used quantitative methods and have found encouraging results. These studies were conducted outside the mental health field and therefore did not include persons with severe psychiatric disabilities. Replicating these studies with persons with psychiatric disabilities may achieve similar results, but would fail to understand how the decision making process evolves for individual participants. It would also not capture the lived experiences of the people for whom this model works and for whom it does not work, and what changes can be made to improve this process. Understanding how shared decision making works, for whom it works, and how it affects people with psychiatric disabilities will contribute to improvements in this model.

The most popular quantitative measure involving medications in the field of mental health is compliance. It is usually defined as a simple concept measured in terms of whether or not the

person took the medication as prescribed (Axelrod & Wetzler, 1989; Buchanan, 1992; Duncan & Rogers, 1998; Garavan et al., 1997). Some studies have also measured partial compliance (Howard & Reveley, 2000; Weiden & Zygmunt, 1997). In this study, the focus was on the decision making process itself, not just whether or not a person takes a particular medication. It was also the intent of this inquiry to explore how this decision making process unfolds from multiple perspectives (i.e. the client, the prescriber, the case manager and the peer specialist). Shared decision making was not viewed as a specific intervention that is done to people, but rather as a process where each of the participants is jointly engaged. Using a shared decision making model was a new experience for all participants. Individual experiences with this model were a rich source of data, over and beyond specific outcomes that might have emerged.

A constructivist qualitative design was chosen for this inquiry because the results were intended to be formative in improving a shared decision making model for people with psychiatric disabilities. Research supports that people with psychiatric disabilities wish to be more involved in decisions regarding their medications (Hamann et al., 2005), but there is no research exploring people's decision whether or not to be involved and the inter-related factors that facilitate or hinder this involvement. The literature in mental health has also revealed that psychiatrists and social workers have traditionally been resistant to involving clients with psychiatric disabilities in decisions regarding their medications (Bentley, 1993; Bentley & Walsh, 2006; Rogers et al., 1998). It was important to understand the experiences of each of these groups throughout the decision making process. The purpose of this inquiry was to understand the process of shared decision making so that people with a psychiatric disability can increase their level of self-determination related to psychiatric medications. As this shared decision making model was being experienced by both clients and professionals, a hermeneutic

circle was developed that allowed for constructions of the experience to be shared among participants through a comprehensive member check and used to generate useful information for improving practice (Rodwell, 1998).

Research Questions

The research questions explored through this inquiry included the following:

- 1) What are clients' experiences with shared decision making around medications? How do these experiences evolve over time (at least six visits with the prescriber over approximately a nine month period)?
- 2) What are team members' (i.e. psychiatrist, nurses, case managers, and peer specialist) experiences with the shared decision making process? How do these experiences evolve over time (at least six visits with the client over approximately a nine month period)?
- 3) What contributes to clients' involvement in the shared decision process?
- 4) How does a client's level of involvement in the shared decision making process impact various outcomes related to treatment, such as client satisfaction with the medication consultation, follow-through with treatment decisions, and level of well-being?

Definition of Key Concepts

1. Shared decision making

Generally, shared decision making refers to a process in which treatment team members and clients mutually participate in the decision making process (Edwards & Elwyn, 2001). There are differences in the literature in how it is operationalized in practice (Charles, Whelan, Gafni, Willan, & Farrell, 2003; Eddy, 1990; Woolf, 1997). For this study, the definition given by Charles et al.(2003) was used, defining shared decision making as “an interactive process in which physicians and patients simultaneously participate in all phases of the decision-making

process and together negotiate a treatment to implement” (p.932). For the purposes of this study, this definition was modified to reflect prescriber/client rather than physician/patient.

The framework used by Charles et al. (2003) divides treatment making decisions into three approaches: paternalistic, informed, and shared. The paternalistic approach is characterized by physician control. Information exchange is one-way and there is no client input except for informed consent. The informed approach allows for some client autonomy. The role of the physician is to provide information on available treatments and corresponding benefits and risks. The client’s role is to evaluate this information based upon their own values and preferences and make a decision based upon available options. The shared approach is characterized by simultaneous interaction by both the client and physician in all stages of the process. Information exchange is two-way. Clients bring personal information about their experiences of illness, values, lifestyle and goals for treatment. The physician shares information on available treatment options based upon the information that the client presents. Both discuss treatment options and negotiate an agreement on the treatment to implement.

Within the shared decision making model used in this study, the following concepts deserve definition as well: a) the client’s power statement; b) personal medicine; c) the How I Am Doing Scale (HIAD); d) the Decisional Uncertainty Profile; and e) the Common Ground Report.

a. The Power Statement

The client’s power statement reflects something important in the client’s life that must be taken into account regarding any treatment decisions (Deegan, 2005a). An example of a power statement might be, “Being a good mom is the most important thing in my life. I am not willing to sacrifice being a good mom to hearing voices or to medication side effects. You and I must work together to find a treatment option that does not interfere with my ability to be a good

mom.” This power statement was completed by the client, with the assistance of a case manager, prior to the medication consultation and entered on the touchpad screen. It was then shared with the prescriber during the medication consultation. The power statement can be considered the goal the client has for considering the use of medications in treatment.

b. Personal Medicine

Also entered on the touchpad screen was the client’s personal medicine. This was also done with the assistance of the case manager prior to the client’s visit to the Decision Support Center. Deegan (2005a) defines personal medicine as “self-initiated, non-pharmaceutical self-care activities that serve to decrease symptoms, avoid undesirable outcomes such as hospitalization, and improve mood, thoughts, behaviors, and overall sense of well-being” (p.31). This could include such activities as talking to a trusted friend, exercising, reading, playing with a pet, watching a movie, etc. This information coupled with the power statement is intended to reflect the client’s values, lifestyle, and existing strengths.

c. The How I Am Doing (HIAD) Scale (See Appendix B)

The HIAD Scale is a set of 17 questions that measures client’s subjective well-being. Schwartz and Strack (1999) define subjective well-being as “an individual’s current evaluation of his or her happiness” (p.62). Clients rated how they are doing on a scale of one to five in areas related to their mental health, physical health, and overall recovery. For example, under mental health clients were asked about the occurrence of things like racing thoughts, voices, anxiety, etc. since their last appointment and the frequency with which these occurred (i.e. none of the time, a little of the time, some of the time, most of the time, and all of the time). For physical health, clients were asked to rate their physical health since their last appointment (i.e. excellent, good, fair, not so good, and poor). For overall recovery, clients were asked to rate

their perception of things like their living situation, ability to keep up with responsibilities, etc. since their last appointment (i.e. excellent, good, fair, not so good, and poor). The higher the number on this scale, the greater concern the client has in a specific area. Responses of a four or five are flagged in red on the Common Ground report.

The items on the HIAD Scale can be added to or modified by the prescriber to make it applicable to individual clients. For example, if a client was feeling distress when around other people, a question could be added that specifically asks them about this during each visit. The information could be explored and followed-up on in subsequent visits.

d. The Decisional Uncertainty Profile (see Appendix C)

The Decisional Uncertainty Profile is constructed through a set of 11 questions that explore specific areas where clients might have ambivalence around using medications. It aims to remove the issue of non-compliance with medications from being a one-dimensional item; that is, either taking or not taking the medication. The literature has shown there are multiple reasons why people decide not to take psychiatric medications (Bentley & Walsh, 2006; Deegan, 2005a; Finn, Bailey, Scultz, & Faber, 1990; Morris & Schultz, 1993). The Decisional Uncertainty Profile is based upon responses to questions clients answered on the touchpad screen prior to the medication consultation. Decisional uncertainty could be based on logistical barriers (e.g. financial, transportation, etc.), drug and/or alcohol use, medication side effects, ineffective medications, interference with personal medicine, relationship with prescriber, medication fatigue, motivation, or still exploring the benefits and/or consequences to using medications.

e. The Common Ground Report (See Appendix D)

The Common Ground report is the sheet that the prescriber and client review together during the medication consultation to begin the decision making process. The Common Ground Report

includes: i) the client's power statement and personal medicine; ii) an indicator of whether or not they have used their personal medicine since last visit; iii) an indicator of whether or not they followed through with the shared decision from the previous visit; iv) current and previous ratings on the HIAD Scale; v) the client's goal for the current visit; vi) the client's current medication and the degree to which they are using them; vii) the client's Decisional Uncertainty Profile; viii) interventions to consider; and ix) the actual shared decision arrived at during the medication consultation.

2. Client involvement

Client involvement was defined as the client's level of participation in three distinct areas of the shared decision making model: a) entering information for the Common Ground report on the touch pad screen prior to the medication consultation; b) actively exchanging information with the prescriber based on the Common Ground report during the medication consultation; and c) actively participating in the final decision reached at the end of the medication consultation. Clients who participated in all three of these areas were considered to have a high degree of involvement. Clients who participated in one or two areas were considered to have medium involvement. Clients who only participated in entering information on the touchpad screen were considered to have low involvement.

3. Client satisfaction

Client Satisfaction was defined as the degree to which clients are satisfied with the medication consultation. This included not only satisfaction with the decisions reached at the end of the medication consultation, but also their relationship with the prescriber and other treatment team members. This information was obtained through interviews with clients.

4. Client follow-through

Client follow-through was defined as whether or not the client followed through with the shared decision reached from the previous medication consultation. At the beginning of each medication consultation, clients were asked to respond either yes or no to whether or not they followed through with the shared decision from the previous medication consultation.

5. Well-being

Well-being was defined as the degree to which clients think they are doing better from one medication consultation to the next. This was measured by client's responses on the 17-item How Am I Doing Scale. The numerical score for each item will appear on the Common Ground Report. The report shows responses from the client's first visit, last visit, and current visit.

Cautionary Notes to the Study

There are cautionary notes to using the above definitions in the study. The scales and reports used in this study were developed specifically for this project and have not been validated through previous research. Information from previous qualitative research was used in their development (Deegan, 2005a) along with a review of the literature on shared decision making and recovery for people with psychiatric disabilities. These concepts, scales, and reports should be considered working tools and therefore open to evaluation throughout the study in terms of their usefulness in helping people engage in the shared decision making process.

Methodology for Data Collection

Prior to beginning the study, approval for conducting this inquiry was obtained from the Human Subjects Committee-Lawrence (HSCL approval #16247). Study participation was voluntary and informed. Anonymity and confidentiality were maintained by not including actual names in any of the reports, and allowing participants to edit any information that might

compromise their confidentiality. All field notes and transcribed interviews were kept in a locked file cabinet in the inquirer's office.

This study did not begin at the time the new intervention of shared decision making was implemented at the selected mental health center. Since 2005, the prescribers at the mental health center, nursing staff, and one case management team participated in training to learn how to engage clients in shared decision making. In October of 2006, clients first experienced a formalized mechanism of shared decision making as described above. The collection of data for this particular study did not begin until January 2007. This allowed clients to experience this model for three months before the study began.

Client Participants

Purposeful sampling with an eye towards maximum variation was used to select client participants for the study (Patton, 2002). The targeted sample size for this study was ten to twelve clients. To reduce the effects of diagnosis, only individuals diagnosed with schizophrenia were chosen to participate in the study. A printout of all the clients meeting this criterion was generated producing a list of 59 potential clients. From this list, twenty-one (36%) clients were female and thirty-eight (64%) were male. This is consistent with research showing a higher prevalence of males diagnosed with schizophrenia versus females (J. M. Goldstein, 1995). Eleven (19%) clients were Caucasian, two (3%) were Hispanic, and forty-six (78%) were African-American. This is consistent with research showing a disproportionate number of African Americans diagnosed with schizophrenia over other ethnic groups (Coleman & Baker, 1994; Snowden & Cheung, 1990).

Prior to the beginning of the inquiry, the above mentioned list was presented to prescribers and nurses involved in the study. The same list was also presented to the case management

team. Since the intent of the study is to draw from multiple experiences of the shared decision making process, clients who have varying levels of involvement in the process were selected to participate. Clients also needed to have seen the prescriber at least once during the months of October 2006 and January 2007 so they could report on their experience. Variation in the sample was achieved by first interviewing psychiatric treatment team members and having them describe the level of involvement of each of the clients in the above mentioned list. The same was done with the case management team and responses were compared. The goal was to produce a final client list that had equal variation in terms of clients that were perceived to be actively involved to those who were not involved. Variation in race and gender were then determined to approximate the overall population from which the sample was drawn.

For the study, six (50%) clients were chosen that treatment team members agreed were highly involved with the process between October 2006 and January 2007, and six (50%) clients who did not appear to be involved in the process. Of these clients, seven (58%) were male and five (42%) were female. Seven (58%) clients were African American, four (33%) Caucasian, and one (8%) was Hispanic. While age was not a factor in choosing the sample, it should be noted that the mean age for the study sample was 45 years of age, approximating the mean age (43 years) of the entire caseload being served by the case management from which the sample was chosen. Table 1 below shows the demographics of the clients chosen as study participants.

Table 1
Demographics of Client Participants

| Client | Gender | Race | Age | Perceived involvement level with Common Ground prior to the study |
|---------|--------|------------------|-----|---|
| Bernice | Female | African-American | 49 | High |
| Roberta | Female | African-American | 47 | High |
| Mary | Female | Caucasian | 42 | High |
| Samuel | Male | African-American | 44 | High |
| Marcus | Male | African-American | 28 | High |
| William | Male | African-American | 43 | High |
| Maria | Female | Hispanic | 48 | Low |
| Helen | Female | Caucasian | 57 | Low |
| Albert | Male | African-American | 49 | Low |
| David | Male | Caucasian | 46 | Low |
| Andreas | Male | African-American | 52 | Low |
| Jason | Male | Caucasian | 38 | Low |

There are limitations to using this method of sampling. First, by not including individuals with other diagnoses than schizophrenia, there are limitations in applying the results of the study to people with other diagnoses. Most of the studies on noncompliance with psychiatric medication have been conducted with people diagnosed with schizophrenia (Lacro et al., 2002). By focusing on people diagnosed with schizophrenia for this study, an in-depth understanding of the decision making process regarding medications was made available to contribute to the research knowledge base. The small sample size was needed to achieve a thick description of

the phenomenon being studied. Obtaining variation in the sample allowed for comparisons to be made between those for whom shared decision making is working for and those for whom it is not. Second, there are some limitations in having professionals determine the extent to which people are involved in the shared decision making process. While professionals created the original list of potential client participants, informal discussions with clients prior to their selection helped in determining actual participation level in the study. Through these informal discussions, consistency was established between providers' perceptions of client involvement in Table 1 and each clients' description of their involvement.

Treatment Team Participants

The treatment team consisted of all the professionals that worked with the above client participants. This included prescribers (3), nurses (3), peer specialists (2), peer support supervisor (1), case managers (5), and a case management supervisor (1). Some overlap does appear in the above counts. One nurse at the beginning of the study was studying to become an Advanced Registered Nurse Practitioner (ARNP) and became one of the prescribers by the end of the study. Also, one case manager at the beginning of the study was promoted to the role of case management supervisor for the team.

Phase I – Orientation and Overview

Initially, data were gathered through observations of the physical setting in which the research occurred (Spradley, 1979). This consisted of visits to the agency and observations of the Decision Support Center in which the kiosk with the touchpad screen was located. The inquirer used the touchpad screen to familiarize himself with the protocol and process, as well as observed others using it. General conversations with people who were using the touchpad screen contributed to understanding how the new technology was perceived by people.

The inquirer talked with the peer specialists who were assigned to provide assistance to people using the touchpad screen. At this point, peer specialists had three months of experience helping people use the screen. They were able to give feedback on what has been helpful as well as common challenges encountered through the process. Informal discussions with members of the case management team, the prescribers, and nurses helped to gauge how this process was experienced from the perspective of professionals.

Two clients were also selected to follow through all elements of the process. This consisted of sitting down with the client as they entered information on the touchpad screen, observing their interactions with the peer specialist, and observing the medication consultation where they used the Common Ground report to arrive at a shared decision. Also during this phase, the methodological log was started (Lincoln & Guba, 1985). This log was designed to “record all the methodological decisions made as the design emerges” (Rodwell, 1998, p. 62). Coinciding with the start of the methodological log, a reflexive journal was started as well (Lincoln & Guba, 1985). This journal recorded subjective reflections on the part of the inquirer in relation to the emerging development of the research process. The journal was used to help the inquirer become more conscious of the use of self, bound emotions, values and reactions in the research process (Lincoln & Guba, 1985). Both the methodological log and the reflexive journal were shared regularly with the committee chair.

Phase II – Focused Exploration

The data that emerged from Phase I of the inquiry helped to guide the second phase. Phase II lasted approximately nine months. During this phase, most of the treatment team members and clients involved in the inquiry were interviewed twice. The exceptions were one nurse who no longer saw any of the clients in the study midway through the study. Another nurse became ill

during the study and was not available for a significant portion of the study period. One case manager was not interviewed a second time as the person left the case management team. Two clients were not interviewed a second time. Both of these clients refused a second interview. The first set of interviews took place during the months of February and March 2007 and the second set of interviews took place between October and December 2007.

Each of the twelve clients selected to participate in the inquiry were interviewed for approximately 60 minutes. In addition, prescribers, nurses, case managers, and peer specialists were interviewed for approximately 60 minutes.

The questions asked in the initial interviews were “open-ended and tentative in order to protect and expand the emergent nature of the inquiry” (Rodwell, 1998, p.62). The goal was to allow participants to guide the inquiry in terms of what was important to be known about the shared decision making process. The responses shaped the interview questions in the second round of interviews.

All interviews were tape recorded and transcribed. As part of the individual member check, following each interview, the information collected was summarized back to the participant and he or she had the opportunity to validate or clarify anything that was recorded. This phase of the study was completed once all participants had been interviewed twice and in-depth information with maximum variation in the participant viewpoints has been achieved.

Phase III – Comprehensive Member Check

At the completion of Phase II of the inquiry, a preliminary case report was written and distributed to all participants in the study for their review. Participants had the opportunity to comment on anything written in the report and offer suggested revisions. Two comprehensive member checks were held: 1) one group consisting entirely of all the professionals that were

interviewed (prescribers, nurses, case managers, and peer specialists); 2) one group consisting entirely of clients that were interviewed. The decision to hold separate comprehensive member checks for clients and professionals was to allow for more candid responses from all participants involved. There was a fear that clients would be less inclined to speak with professionals in the room, especially clients for whom the shared decision making process did not work well. Of the twelve clients that were interviewed, ten attended the Comprehensive Member Check. The fact that six of out seven clients from the group for whom the shared decision worked well and four out of five clients for whom the shared decision making process did not work well attended, added credence to the feedback on the overall report. As far as prescribers, all three were able to offer feedback on the final written report, though only one prescriber was able to attend the Comprehensive Member Check. The other two were contacted for a phone interview to obtain their feedback. Each of the nurses attended the Comprehensive Member Check. Four out the six case managers in the study attended the Comprehensive Member Check. The remaining two case managers were no longer on the team at the time of the Comprehensive Member Check and were unavailable to attend.

Methodology for Data Analysis

For this study, data analysis was an on-going process that began with the initial observations of the setting (Phase I) and continued until the final comprehensive member check (Phase III) (Rodwell, 1998). Throughout the study there was simultaneous involvement in both data collection and data analysis. This allowed for an emergent research design to play itself out as well as inductive analysis, following the rules of grounded theory building (Charmaz, 2000), to come up with lessons learned and recommendations for improving the shared decision making model.

The data collected during Phase I and Phase II of the study through transcribed interviews were entered into Atlas ti. and unitized into chunks of data that were relevant and applicable to the focus of inquiry (Rodwell, 1998). Once all data was unitized and coded, each unit of data was compared using the constant-comparative method to identify relevant categories, subcategories, and themes (Lincoln & Guba, 1985). Similar units of data were gathered together creating large provisional categories. When a unit of data did not fit within a large provisional category, then a new one was created. Once all data units were placed in categories, these were reviewed again to ensure that each category was distinct. Compiled categories were further refined to create sub-categories.

The goal was to construct overarching categories that have a relationship with one another. The categories were related in such a way that tentative constructions began to unfold. These constructions were evaluated by participants during the comprehensive member check to see if they successfully captured their experiences of the shared decision making process.

There are some cautions to be noted in regards to the above methodology. From a positivist research paradigm, it could be argued that the research affected the actions of some of the participants. For example, staff and clients may behave differently knowing that they were being observed. There could have been some social desirability bias in that participants may have responded in a way that is perceived to be favorable by the inquirer. Moreover, it was not possible to observe all appointments where clients and professionals interacted. Thus, only selected activities could be observed and analyzed. The inquirer was aware of these limitations throughout the study. Prolonged engagement, persistent observation and triangulation were strategies used to address these concerns.

Trustworthiness

Being a constructivist study, it is fully acknowledged that I, as the inquirer, was involved in shaping this inquiry. My interest in this study stemmed from my years of experience in working with people with psychiatric disabilities, and my passion for the empowerment of this client group. The way this inquiry was designed and data were collected, analyzed, and reported reflected the high degree of interactivity I had with participants. My values and goals for this study were not hidden from participants, but rather made clear and explicit throughout the course of the study. It was important therefore to balance this with maintaining rigor that safeguards the trustworthiness of the data. In constructivist research, trustworthiness relates to the reliability, validity, objectivity, and internal and external validity of the study being conducted (Lincoln & Guba, 1985, 2000; Rodwell, 1998). The standards for evaluating trustworthiness are credibility, transferability, dependability, and confirmability, (Lincoln & Guba, 1985).

Credibility was established through multiple means. One was through the process of prolonged engagement. The inquirer spent a minimum of two days per week during the initial phase of the study at the setting of inquiry, not only conducting interviews and attending medication consultations, but also getting to know staff and clients at the agency and learning more about the workings of the overall agency. Building trust with each of the stakeholders in the study was believed to encourage more honest communication during the study which assisted in overcoming social desirability bias-linked responses from participants.

The other means of establishing credibility is through persistent observation. Data that emerged from Phase I of the study was explored in-depth in Phase II with each of the stakeholders and gave focus to questions and observations during each of the medication consultations. Triangulation was also used to compare one data source to the other and see if

information held up from one participant to the other. This was done not only by checking out information across participants being interviewed, but also through comparing responses from interviews with the written materials involved in the shared decision making process that includes the Common Ground Report, the How I Am Doing Scale, and the Decisional Uncertainty Profile. It should be noted that although qualitative methods are emphasized in naturalistic inquiry, the use of quantitative measures as found in the above reports and scales, are not prohibited when trying to gain an in-depth understanding about a particular phenomenon (Lincoln & Guba, 1985). In fact, the authors encourage the use of these measures to triangulate data sources.

Peer debriefing was used to assist in bounding the subjectivity of the inquirer. Both the committee chair and other staff of the Office of Mental Health Research and Training who were familiar with the project served in this role. Member checks after each interview and a final comprehensive member check were final means of establishing credibility.

Dependability or reliability of the research was established through a methodological log kept throughout the study. All methodological decisions made throughout the study and their justifications were maintained. This included decision rules explaining how each client was included in the study, questions asked, changes in focus of questions, and how data were categorized. All transcripts from interviews and coded data within Atlas ti. were made available for a dependability audit to the methodologist on the dissertation committee.

Confirmability or objectivity was established to “assert the reasonableness of the inferences and the logic of the theory that evolved from the data” (Rodwell, 1998, p.100). The use of triangulation and member checking used to establish credibility was also a source of confirmability. Also, the methodological log and all records of data collected were used for

confirmability. The committee methodologist checked consistency between transcripts and categories, sub-categories, and themes.

A final element of establishing trustworthiness is transferability of tentative ideographic findings or external validity of this study. This “allows for the possibility that information created and lessons learned in one context can have meaning and usefulness in another” (Rodwell, 1998, p. 101). It should be noted that while external validity is not a focus of constructivist or naturalistic inquiry, sufficient thick descriptions are available so that others can decide what about this study can be applied to improving the shared decision making process at the agency of inquiry and other mental health programs to enhance the self-determination of clients around medications.

Chapter 4: Findings

Introduction

The mental health center that served as the setting for this study had long been recognized in Kansas as being innovative in terms of adopting new practices that seemed promising to improving the outcomes for people with psychiatric disabilities. They were among the first in the State to adopt national evidence-based practices such as Supported Employment and Integrated Dual Diagnosis Treatment. They were also among the first in Kansas to embrace the concept of recovery for people with psychiatric disabilities having started one of the first Consumer-Run Organizations, which continues to have one of the largest and active memberships.

When approached with the idea of piloting a new practice within mental health called shared decision making, the agency's administration and medical staff readily agreed to participate. Many of the key decision makers for the pilot, which included prescribers and nurses involved in the study viewed shared decision making as a natural extension of how they already interacted with clients. Many held beliefs of clients having the right to make choices and the importance of clients being involved in their care.

The start-up of the shared decision making pilot coincided with the move to a brand new building that replaced the previous center where many clients in the study had received services for years. Upon entering the new building, just beyond the main reception waiting area, visitors found the Decision Support Center. The Decision Support Center was the new name given to the medication clinic, which included its own waiting area with four cubicles, each containing a computer kiosk station.

The dynamics had now changed for people wishing to see their prescriber. Upon checking in with the receptionist for their scheduled appointment, they now needed to proceed to one of the kiosks where a peer specialist logged them on to their individualized account. They would spend the next twenty to thirty minutes answering questions about themselves, from which a report would be created that they would take in with them to see their prescriber.

This is the setting that awaited twelve clients chosen to participate in this study. These twelve clients were not part of a select group that volunteered to try shared decision making. These clients just happened to be served on one case management team out of five at the mental health center that was selected as the pilot team before the agency opened the Decision Support Center to all clients.

Some clients quickly embraced the new process for coming to medication clinic, while others had reservations. While the overall response from clients to the initial start-up of the Decision Support Center was highly positive, the twelve clients chosen for the study represented not only the voices of the majority who were excited about the new process, but also the minority who struggled to find relevance in the new process or who found the departure from the old way of doing things disconcerting.

Each of the clients was on a journey through life, with their own unique stories of trials and tribulations, hopes and dreams, when this journey intersected with the start-up of the Decision Support Center. First there was Samuel, an African-American male, who had a lust for life. Any negative experience that Samuel ever experienced he had reframed into a positive learning experience that helped him to get to where he was today. Samuel could find the positive in anything, which he hailed as his *modus operandi* for life. The Decision Support Center was viewed as another opportunity for him to take the next step in his own recovery.

Next there was Bernice, an African American female, who was quiet and introverted. Bernice was living with many regrets from her past, including the grief that she was never available to raise her children during her many years of illness and hospitalizations. Now with her children grown, she longed to reconcile her role as a parent and find ways to take care of herself so she could offer them the support she was not able to provide in their younger years. The Decision Support Center came at a time when Bernice was contemplating changes for her life.

Then there was Roberta, an African-American female, who like Bernice also grieved past experiences of parenthood. During the years when Roberta was most ill, she had lost custody of two of her children. Now with a small child at home, she greatly desired not to repeat the same fate again. Up until the time of the start-up of the Decision Support Center, Roberta had continued to go into the hospital at least once a year. She struggled with the medications she was taking and accompanying side effects. Roberta also struggled to find a voice to express what she was experiencing, and was fearful to say much since she was unsure how that would affect her being able to keep her child.

Marcus, the youngest respondent in the study, was an African-American male who was still being accompanied to his medication appointments by his mother. Marcus did not typically talk much during the visits, allowing his mother and prescriber to make most of the decisions. Marcus was a carefree individual who was still trying to find his place in life. He seemed satisfied living in the moment and enjoying the few simple pleasures he was involved in, like listening to his music and shopping for clothes.

Also, there was William, an African-American male, who had been on injections for most of his life. William had an outpatient court order because of his history of violence when he was

not taking his medications. William wanted more from his life though, including getting his own place, enjoying activities like basketball and weightlifting, and most importantly getting off the injections. William had reached a point in his life where he was tired of feeling drugged out and not in control of the decisions that affected him. The Decision Support Center came at a time when William was once again struggling with the decision of whether to take medications or not.

Mary was a Caucasian female who had recently taken on a position as a peer specialist. She had finally reached a point of stability in her life after years of medication changes, hospitalizations, and unbearable side effects. Mary had a lot of pent up frustrations with a system she felt never heard what she was trying to tell them. Like Bernice, Roberta and William, she grieved lost time that she felt had been taken away because of illness and unhelpful medications.

These six individuals all found aspects of the shared decision making process helpful to them. Although each of their stories was unique, they each found relevance within the process to something they were trying to attain in life. Their experiences are contrasted with six individuals who did not share their positive experiences. The one exception is Maria, whose experience slowly changed from being peripherally involved to one of high involvement.

There is Albert, an African-American male, who had long struggled to find benefits to the medications he was prescribed. Albert had a goal to work, but he found the effects of the medications as interfering with his ability to do this. Albert, like William, was on a court order to take medications because of past history. Because of Albert's decisional uncertainty with taking medications he would frequently stop taking them only to find himself back in the hospital. The Decision Support Center came at a time when Albert was struggling with the decision of whether to take medications or not.

Next there was David, a Caucasian male who also struggled to find benefits to the medications he was taking. David was a quiet, introverted person who desired to be left alone, but like Albert and William, was on an outpatient court order to receive services and take medications. David was conflicted between a view that he needed some type of help, but not satisfied with the type of help he was receiving. David would frequently try to discontinue services, only to find himself re-hospitalized and back on medications.

Then there was Andreas, an African-American male who had difficulty communicating with members of his treatment team. Andreas's speech was fragmented and his thoughts appeared disorganized. Andreas experienced significant paranoia about the medications he was prescribed. Though he regularly came in to see the prescriber, he vocalized beliefs about his medications as being poisonous and harmful.

Helen was a Caucasian female who was in conflict with her treatment team members about what she was experiencing. Helen vocalized her experience of seeing ghosts, which she described as both comforting and at times distressing. The ghosts were a part of Helen's reality. Her prescribers viewed the ghosts as part of Helen's mental illness and prescribed medications to get rid of them. Helen did not want this and while she would accept the prescription she would not take the medication. She continued to take an anti-depressant which she found helpful and which served as the reason for continuing to come into medication clinic regularly. Helen struggled with not remembering much about her past and was quite distressed about it. She did not have much hope for getting better and determined that no medication would ever help her recover her life. Helen did find enjoyment in seeing her grandchildren, which is what seemed to keep her going, but this was often blocked by her sons who were disconcerted about Helen talking about ghosts. The Decision Support Center came at a time when Helen yearned to spend

more time with her grandchildren, but feeling hopeless that anything was going to improve for her.

Jason was a Caucasian male who had some extreme social phobias. Coming into medication clinic took considerable effort for him because he did not like being around people for long periods of time. He would come in to get his medications and then would immediately want to leave. Jason had the desire to go back to work, which he found to be an important part of his identity. Because of Jason's illness he had difficulty keeping a job for any length of time. The Decision Support Center came at a time when Jason was frustrated with not finding work and not feeling he was getting the help he needed to get better.

Lastly there was Maria, a Hispanic female who recently had experienced the death of her father, with whom she was very close. Maria came in regularly to medication clinic to get the same medication that she had been prescribed over ten years ago by a previous prescriber. Maria believed that too much medication in her system was a negative thing. Her current prescriber did not feel that the older medication she was taking was helping her much and thought some of the newer medication available would be more helpful. Maria continuously resisted any change in her medication regimen. The Decision Support Center came at a time of considerable upheaval in Maria's life, due to death of her father. It also came at a time when Maria was beginning to explore alternatives in her life besides medication to help her feel better.

Before discussing the findings of the study, some notes should be mentioned about the treatment team members as the Decision Support Center was being implemented. While treatment team members embraced the concept of shared decision making, the actual application of a shared decision making model proved to be more of a departure from the traditional way of doing things than initially anticipated. From October 2006 to the beginning of this study in

February 2007, treatment team members participated in on-going training with the software developer of Common Ground. For prescribers, this consisted of observations of medication consultation visits, getting feedback on shared decisions made in clinic, and discussion of strategies based on client's Common Ground reports. For case managers, this consisted of reviewing Power Statements and personal medicine they had helped clients develop, as well as reviewing Common Ground reports and discussing strategies to support clients based on the shared decisions made in clinic.

All treatment team members met weekly to discuss mutual clients using Common Ground, with the Decision Support Center supervisor in attendance and often the developer of the software. The learning curve of incorporating Common Ground into practice for treatment team members proceeded slowly and was still being navigated at the time the study began. While treatment team members were still genuinely excited about the shared decision making process as the study began, there were still unresolved questions about how to work with clients at different stages of preferred involvement, skill levels for decision making, or even enthusiasm for the new process. It is in the midst of this setting that this study took place.

Themes

Six themes emerged from the data. These themes are as follows:

Theme 1: Common Ground redefines the expectations, roles, and rules of engagement in medication clinic. (p 48-66)

In this theme initial reactions to the Common Ground software are explored. This includes interactive processes that contribute to clients' decisions to use Common Ground, decisions related to what they share, as well as their decision to continue using Common Ground. Readers

are introduced to dynamics that begin to change with the advent of a “new way of doing things” in medication clinic.

Theme 2: The invisible becomes visible: staff and clients view Common Ground as helping to raise things that were never discussed prior to Common Ground. (p.67-88)

In this theme the information that is generated through the use of Common Ground is explored. This includes not only the processes that facilitate the generation of new knowledge between client and prescriber, but also processes that hinder information from being made available. Readers are introduced to dynamics that either begins to set the stage for shared decision making to occur or stifle shared decision making from even occurring.

Theme 3: The centrality of the goal: When goals that are meaningful and important to the client are made the focal point of medication clinic, clients feel heard and are more engaged in shared decision making. (p. 89-120)

In this theme the primary components to effective shared decision making are explored. This includes an exploration of common elements shared between those for whom shared decision making worked well, and contrasting that with the absence of these elements among those for whom the process did not work well. Readers are introduced to dynamics that either facilitate or hinder the client’s goals from becoming the focal point of medication clinic.

Theme 4: The concept of personal medicine shines a new light on ordinary activities and causes a transformation in philosophy and practice that empowers clients in a new way. (p.121-156)

In this theme, a particular component of Common Ground that was found to be common among participants for whom the shared decision making process worked well is explored. This includes the meaning that personal medicine holds for various participants and its role in

enhancing the shared decision making process. Readers will be introduced to the processes involved in bringing this concept into an integral part of the shared decision making process.

Theme 5: Peer Support enhances and in some cases is essential to the shared decision making process. (p.157-183)

In this theme peer support as an auxiliary support to the shared decision making process is explored. This includes participants' reactions to the presence of peer support and their role with Common Ground. Readers will be introduced to the dynamics that shape the functions of peer support as it relates to the share decision making process.

Theme 6: Case Managers vary in the extent to which they support client's use of Common Ground, but can serve as important auxiliary supports in the shared decision making process. (p.184-219)

In this theme another auxiliary support to the shared decision making process, case managers, is explored. This includes the processes that influence the role of case managers around Common Ground and the shared decision process. Readers will be introduced to the dynamics that impact variation in how case managers support client's use of Common Ground and their contributions to the shared decision making process.

Note on Participant Quotes

Throughout the findings section, participant quotes used to support each of the above themes. Participant quotes identified by their participant interview number and the line number(s) where the quote can be found in the transcript. Therefore, a quote ending with (P25:154) would indicate that the quote came from participant interview number 25, line 154. For a full listing of participants and their interview number, refer to Appendix E.

Theme 1: Common Ground redefines the expectations, roles and rules of engagement in medication clinic.

The introduction of the Decision Support Center was a significant departure from the traditional way of doing things for both medication clinic staff and clients at the mental health center. In the past, clients would check in at the receptionist's desk for their appointment with their prescriber. Then, within thirty minutes of being called inside the medication clinic for their appointment, they would have seen the nurse, had their vital signs checked, asked about any concerns they had since their last visit, seen the prescriber, discussed any concerns they shared with the nurse, received a prescription if warranted, then returned to the receptionists desk to schedule a follow-up appointment.

While this is an oversimplification of the traditional medication consultation, many of the client participants in the study described a similar typical flow. The focus was typically on the prescribing of medications with limited discussion of client's goal for actually coming to medication clinic, any uncertainty around medications, or options beyond medications to help clients deal with problems they were facing. The role of the client could be termed as being a "passive recipient" in regards to the medication clinic, with several clients reporting that they never said much in medication clinic and rarely would they question decisions made by their prescriber.

With the advent of the Decision Support Center, the dynamics of medication clinic drastically changed. Clients were now asked to begin preparing for the medication consultation even before walking into the clinic. Case managers started working with clients to develop power statements intended to guide discussions regarding any decisions made during the medication consultation. Case managers also worked with clients to develop a list of personal

medicine they were currently using or could use to help them stay well. Clients were asked to come thirty minutes prior to their actual medication clinic appointment to answer questions on a computer related to how they were currently doing (How I Am Doing Scale), and regarding any uncertainty they had around the use of medications (Decisional Uncertainty Profile). They were also asked to confirm their power statement, use of personal medicine, and use of psychiatric medication since their last visit.

These additional requests for information were met with varied reactions among the client participants, ranging from excitement about being more involved in medication clinic to invoking suspicion about how the information was to be used, to disinterest and feelings that the information brought nothing new to the table that would be of benefit to them. Likewise, the added information had varied reactions among staff, ranging from excitement about getting a better picture of what clients were actually experiencing and wanting from medication clinic, to feelings of being overwhelmed with how to use this information, and how it fit within the current structure and process of the medication consultation.

Whatever the reaction to the new process, the Decision Support Center caused all participants (clients and staff) to re-evaluate the expectations, roles, and rules of engagement surrounding interactions at medication clinic. A look at the positive reactions point to the opportunities and potential of the Common Ground process to increase the self-determination of clients regarding decisions made at medication clinic. Included in these positive reactions are indications that some people move from passive to active roles in terms of communicating information about themselves. The negative reactions and those invoking suspicion and skepticism help us to view the potential challenges of engaging people at medication clinic using this process.

There seem to be three crucial decision points that clients are faced with: 1) the decision of whether or not to use Common Ground; 2) the decision of what to share with prescribers through Common Ground; 3) the decision of whether or not Common Ground provides enough of a benefit to continue using the software.

The Decision to use Common Ground

The decision to use Common Ground seems to be based on two factors: 1) The relationship between prescriber and client prior to Common Ground, and 2) A curiosity regarding whether or not Common Ground can help them achieve a specific goal.

When the relationship is positive then clients have no hesitation in trying out the new system. If there is not a strong relationship between the prescriber and client, then clients will still use it if they see it as the new expectation and perceive they have no choice if they want to see the prescriber or they defer to the second factor. Samuel, Bernice, Marcus, and Maria easily made the decision to use Common Ground because of their strong relationships with their prescriber. Helen had a strained relationship with her prescriber, and Mary, Roberta, David, William, Albert, Andreas, and Jason had reasons to be distrustful of prescribers because of past experiences prior to Common Ground. Mary, Roberta, and William engaged more quickly with Common Ground because they saw potential in helping them to meet specific goals. David, Albert, Andreas, and Jason were not actively seeking specific help through Common Ground but initially agreed to try it because of the expectation for them to try the new process.

For Mary, the Common Ground process completely changed the way she interacted with prescribers at medication clinic. Mary views herself as someone who has suffered through a lot because of the symptoms of mental illness, but found it difficult to speak up for herself and question the decisions that were being made about her treatment. Mary described years of

medication clinic visits where her medications were constantly being readjusted without any positive impact. She told stories of repeated hospitalizations and instances of over-medication to the point that she had started to lose faith in the mental health system. Common Ground gave Mary new hope that things could be different. Mary states:

I support doctors, and I'm not out to get doctors... there's other people that have been through more, even more than I have, and there's people who have committed suicide, I suppose, over as much or less than I've been through, but, honestly, I still have a certain amount of faith in doctors, but...I have more faith, now, in the Lord Jesus, and I thank God for the Common Ground report, so I've got my own ability to advocate for myself and the support of the Common Ground report. (P44:257)

The view that Common Ground created an opportunity for people to advocate for themselves was common among client participants who found the new process helpful. This was a new role for many clients who were traditionally used to taking a passive role in medication clinic. Prior to Common Ground, there was not a specific mechanism to actively bring clients into the discussions. If clients were actively involved, this said more about the personal communication styles of the client and the prescriber. Mary was a client who did not say much in medication clinic, and from her perspective her prescribers did not seek to probe beyond the traditional questions asked during medication clinic. The Common Ground report provided a mechanism for Mary to communicate what she was experiencing and indicated specific areas for her prescriber to seek further understanding. Mary states:

Before, when there wasn't the Common Ground Report, you go in the office, they ask me how I'm doing. Do I have delusions and this and that, and that's all that was said in there. And they'd say, "Well, okay. We'll see you later." But now, now they have that sheet for him and he goes over and says, "Well, what did you say this for?" And goes on through that. So I see a drastic difference. (P15:16)

And also:

To me it was a more of a hit and miss situation in the doctor's office, because when you're having symptoms it's hard to relate to the doctor and tell exactly what's going on and the doctor doesn't know, doesn't necessarily know what's going on, what kind of trouble I'm

having. Because I'm not much of a speaker, but when I hand him that report, they go into detail about it. They check every little thing (P15:16).

Bernice also confirms the detail that prescribers now pay attention to with the Common Ground Report saying, "he discusses everything with us that we put down" (P1:18). Bernice, like Mary, was a person who didn't say much in medication clinic prior to Common Ground. Now with Common Ground she is able to bring out the information she wants to discuss with the prescriber, knowing that it will be discussed in detail. She says:

I wouldn't talk as much or say as much. They wouldn't get as much information out of me. Because once I tell the computer what my situation is and they discuss it with me and that has helped. (P1:32-34)

The change has been a positive experience for Bernice because she now feels like she is directing what is being discussed during the medication consultation, which is a dramatic departure from her more passive role prior to the Decision Support Center. Bernice talks about the empowering effect of using the Common Ground Report to help her direct discussion:

One thing, I'm giving all the answers and I'm seeking the help when they get the paper. This is what I have said that's wrong and I'm concerned about. (P1:208)

Several of the clients for whom the process has worked well for refer to the Common Ground Report as "the paper". The Common Ground Report seems to serve as a mechanism for opening up communication for both the client and the prescriber that is more focused on what the client wants. One case manager talks about how the Common Ground Report has helped a client take an active role in communicating with his prescriber:

One individual wants to have his medication switched from a shot to an oral medication. And so through using the program, he's been able to answer the questions and get a sheet of paper in his hand to have the process of how he wants to talk to his doctor to be able to do this. And so they are systematically working with him titrating back his shot and replacing it with the oral medication. (P4:6)

Prescribers also note the value of the Common Ground Report for helping to bring a focus to the medication consultation. While in the past, a good portion of the medication clinic visits would consist of asking multiple questions to find out what was going on with the client, the work done on the Common Ground Report prior to the visit allows for more in-depth discussion regarding what the client is concerned about to begin right away. One prescriber says:

When we look at the paper, it gives us an automatic focus about what are you concerned about, and we just go right to it. We don't have to ask ten questions to get to that. So I think it really helps the client for me to be able to delve right into their decisional conflict without asking 20 questions and losing them somewhere along the way. (P8:79)

William confirms that his prescriber looks at the Common Ground Report with him during each visit:

Yeah. They look at it. I get one and they get one and she reads it off before she starts her procedure or how I feel and the paper shows that and it'll tell you or they ask you something on the paper that might think that you ain't doing so good or they might ask you one questions if one part of the paper say one thing and the next part saying another thing, they ask you what was the reason for the other thing, you go by steps. (P11:48)

Several of the client participants reported feeling more engaged in medication clinic with the introduction of the Common Ground report. Roberta used to feel that she went through the motions of medication clinic, but now with the report she has felt more engaged in medication clinic. She says:

It used to be you just go into the doctor, the system wasn't there, and I don't...you just go into your med clinic and see the nurse and that was it. You wouldn't always see the doctor. But now, the doctor comes in with your sheet and they go over it. And he's all, well how you doing? It's better. (P9:60-63)

Marcus also feels more engaged in medication clinic. He talks about how medication clinic visits used to be prior to Common Ground:

Just go in and take (the medicines), answer the questions that my doctor ask and just take my medicine and get ready to go home and get my appointment sheet and gone. It's different. It's something new but I think it's good. (P10:21)

While Bernice, William, Roberta, Marcus and Mary were individuals who did not say much in medication clinic prior to Common Ground, Samuel was a person who had already started opening up more to his prescribers. Samuel was taking an active role in medication clinic prior to Common Ground by writing down information he wanted to communicate. While Samuel was already taking an active role, he found that the Common Ground process enhanced his ability to communicate with his prescriber because it established the sharing of information as part of the regular routine. Here Samuel compares the old way of doing things to the new:

And what would happen there is no one would brief you prior to seeing the doctor. No one would brief you. And what I used to have to do with my doctor there, I would have to, the day prior to seeing my doctor I would write down things that I think he or her needs to know when I go on my next appointment, but they did not have, their system, if this one is compared to that one, I'd give that one about an 8 and I'd give this one about a 9½ or a 10. (P2:37)

The Decision to Share

The decision of what information to share through Common Ground seems to be based on:

1) The relationship between the prescriber and the client; 2) how information has been used in the past; and 3) what information is needed to attain a particular goal.

For clients with strong relationships with their prescriber prior to Common Ground such as Samuel, Marcus, Bernice, and Maria, there seemed to be full disclosure and honesty to questions posed in Common Ground from the onset. William and Mary also developed strong relationships with their prescribers because the information they were sharing was being responded to and was being used to assist them with the achievement of specific goals. Therefore they quickly entered into full disclosure and honesty through Common Ground. Roberta and Helen were both guarded about sharing information because of past experience and only partially disclosed information because of this. Roberta though found that she could share particular information that helped her achieve a specific goal (changes in medications that helped

her do things that were important to her). David, Albert, Andreas, and Jason were not specifically dishonest in their answers to questions on the Common Ground Report, but they had not yet found that sharing information on Common Ground was helpful for achieving particular goals.

Deciding what to share

Samuel, Bernice and Marcus stand apart from the other client participants who found Common Ground helpful to them because prior to Common Ground, they already had full trust in their prescribers. Neither of these individuals had any misgivings about starting the new process. What each of these three individuals found was that the Common Ground process allowed their discussions with their prescriber to go into more detail about what concerned them. As Bernice says, “There’s not too much different, but when I get to the doctor it’s more in depth” (P1:78). It seems that with a solid working relationship in place, the new way of doing things does not seem to be perceived as much as a drastic departure as it is an enhanced mechanism to build from that solid relationship. Samuel talks about a time when his relationship with his prescribers was not strong and this led to his decision to refrain from giving information:

Yes, there was a time when my symptoms was existing. I’d refrain. I’d repress those thoughts and feelings. I’d tell my doctor I’m doing very well and I wasn’t doing very well. Or I might tell my doctor that I’ve been taking my medicine as prescribed and maybe at that time I wasn’t taking it at that time. So there have been some times that I haven’t been honest with my doctor. (P2:211)

Now Samuel is completely comfortable sharing information with his prescribers. He says:

But I can honestly say that I’ve been frank with my doctor now approaching 14 years. I’ve told him exactly my symptoms, what am I experiencing, when I’m lethargic or tired or suicidal, paranoid to symptoms resurfacing, flashbacks, night terror, ominous dreams. All these things. And what I’ve learned is that my doctor and me is like I don’t really see him or her as a doctor. I see them as a doctor and a friend. I feel comfortable that when I confide in them in something, I feel comfortable confiding in them. I don’t feel any distance between, a bridge between me and my doctor. (P2:211)

The relationship between the client and prescriber prior to beginning Common Ground seems to play a key role in how clients respond to the new way of doing things. Clients who were previously engaged in medication clinic prior to Common Ground and had a strong relationship with their prescriber did not seem to be hesitant about sharing information on the computer. It seemed to be information that they would have shared with their prescriber even if a mechanism or process was not available that encouraged them to share this information.

For other clients though, that strong relationship with their prescriber was not present when Common Ground was introduced. For these clients, the Common Ground process challenged previously held expectations, roles and the rules of engagement within medication clinic. It confronted clients with crucial decisions about how to respond to this new way of doing things and what information would be shared.

For some clients, like Roberta, it took time to adjust to the new way of doing things. Roberta had become comfortable with the traditional process of going through medication clinic though she wasn't always happy with the results. The advent of the Decision Support Center confronted Roberta with a decision about how she would respond to the new questions that were being asked of her. Since Roberta was a person who previously did not say much at medication clinic, she would hurry through the questions at the kiosk without giving them much thought, hoping that once she was in the actual medication consultation things would return to the way they had always been. But Roberta found that her prescribers read through all of the answers on her Common Ground Report and talked with her to make sense of the responses she was giving. This was pivotal in terms of how Roberta began to rethink how she responded on future Common Ground Reports. Roberta talks about her transition to thinking more carefully about her responses:

Usually I would want to get through it real quick and then I really took a minute to sit there...it takes some people awhile to catch on to what you're doing. And I sit there and I answer the question and I thought about the question before I answered instead of just reading and push yes or no always, you know. I thought about the question...I used to rush through it just to get off of it real quick, you know, get this out of the way. (P9:236)

Roberta's transition to taking more time in thinking through her responses on the Common Ground Report seemed to be aided by two factors: 1) she began to view the Common Ground Report as a means to helping her communicate with her prescribers about something that was previously a concern to her (effects from the medications she was being prescribed), and 2) her prescriber's willingness to pay attention to the information on the report and engage her in discussions around the responses. Roberta viewed this new way of interacting in medication clinic as giving her more control and placing her in an active role during the medication consultation:

Yeah. I feel more control with my medicines and different options that I have with my medicines. Either I'm taking it less or I'm taking it more or I'm not taking it at all. Now, I be truthful on that and that's what they need to know about. (P9:108)

What Roberta alludes to here is that she is now honest with her prescribers about information that concerns her medications. But Roberta is not always up front concerning other aspects of her life. The changed dynamics of medication clinic create a crucial decision point for clients in terms of what to share and not share about themselves.

Clients were faced with these decision points even before the Decision Support Center started, such as when they were asked questions like "Have you been taking your medicine?," "Have you felt like harming yourself or others?," or general questions regarding how they were feeling at the time of the visit. But now clients are confronted with reading or listening to specific questions on a computer screen that ask for personal information that will not only be

put into writing but printed out and looked over by others. The fundamental question that seems to be considered by clients is “How will this information be used?”

A few of the clients perceived that information had been used against them in the past to either be involuntarily admitted to the hospital or have a child removed from the home. Therefore they are careful with the information that they share on the Common Ground Report. While Roberta answers questions honestly about her medication and chooses to disclose some information about the side effects and symptoms she is experiencing, she sees a limit to disclosing other aspects of her life to the computer. She always puts down a response to all the questions, but some of these responses might not accurately reflect what she is thinking:

But not always true. Because I don't want to be judged. I have depression, too. So sometimes I do feel like I need something done to me. I get so low and they're not there when you're feeling this low. And you call around to different people, they tell you to talk to your case manager or you need to talk to a therapist. But like the system, this place is like anything that you tell them that is not right, like I have a child in my home and I can't be open with them with the problems in my home because I did that once and they called child protection agency on me. So that, and they want me to see a therapist but anything you tell them, you know, like if your child is all whammy, they can use that against me with the therapist and child protection agency. So there's a limit to everything. (P9:70)

Roberta also states:

But I don't drink or do drugs and I want to emphasize this. That's one of the questions that's on there, and I don't think they should put that on there because I don't think everybody will answer that question fairly because I had, I have problems with believing people and I think in the long run eventually this data process we're going through, it can be used against you in court or something. Like if you think about suicide and stuff like that. I have paranoid schizophrenia, so I'm always thinking, you know, it's a catch to it. I just put the best answer. (P9:30-34)

Helen has figured out that her prescribers will gravitate towards the responses she has marked with either a four or five (indicates a concern reported by the client in a specific area), which will show up in red on her Common Ground Report. Because of her past history with being put in the hospital when she has stated that she felt like harming herself or others, she is

careful in how she responds to this question and does not always put down the answer that truly reflects how she might be feeling:

Well, they tend to go towards the bad numbers and...ask you questions. Just because the patient isn't answering them truthfully is not their fault. Well, like 'do you feel like hurting somebody?' Well, yeah, but you're not going to sit there and say all the time because then they are going to want to put you in the hospital so you're not going to say that. (P22:93-101)

Helen, like Roberta, is faced with a difficult decision when answering questions at the computer kiosk. Neither want to communicate that they are feeling completely fine, because each of them recognize that they need some help with distressing symptoms, but at the same time they worry about being completely honest in disclosing their thoughts because of perceived consequences of doing this. Helen says:

Well, I don't say it's okay, but I don't put the worst answer down either when I'm feeling the worst. Yeah, because...they need to talk to you about it instead of thinking you need a hospital. (P22:105)

And also:

And sometimes you're not going to tell them the truth because they'll want to put you in the hospital. That's just between you and me (P22:101).

Helen related that she has been in hospitals most of her life and has a fear of returning. She says, "Yeah, I don't like it" (P22:109). While Helen states that a few of those times she thought she needed to be in the hospital, she doesn't want to give them information to be put into the hospital when she doesn't think she needs it. She states:

A couple times I did. But not when you're going to try to kill yourself because, do they think you're stupid and going to tell them? No. No. You're not. Maybe when you're killing yourself, you might think oh, God, I wish I wouldn't have done that. Help me. But that's not how it works. It's just not how it works. (P22:117)

Helen seems to be in a dilemma of wanting help, but not knowing how to communicate this information to her prescribers. She vacillates between times of feeling good and times of feeling extreme distress. She says:

It's the same questions...I don't understand it sometimes. Well, like they'll say oh, they always ask do you want to hurt yourself? Well, maybe not at that moment you don't, but you can go home and then in an hour you can cut yourself up with a razor blade. (P22:29)

And also:

Like I left here once. I was feeling pretty good. When I got home, everything like exploded. And I wasn't feeling so good then. But when I was here, I was okay. But then when you go home, there's always some kind of turmoil. (P22:41,45)

Even though Helen is having difficulty communicating all that she is experiencing to her prescribers through the Common Ground Report, she does see herself as doing a little better than she has in the past. While she still doesn't see the overall value to using Common Ground, she has been able to communicate on the How I Am Doing Scale that she has low energy and that her mental health is a concern. For her this is enough to keep communication open with her prescriber that she wants help and continue to receive the anti-depressant that she finds helpful.

She says:

Yeah. I don't cry all the time. I've been getting, there was times I haven't looked out of the house for years, you know. And, but I'm starting to go out a little bit now and yeah. I see a little difference. I don't know if it's the medication or maybe I'm just getting better. I really don't know. And since I started the medications, I am doing a little bit more, yeah. (P22:173)

But Helen does not want to communicate about the distressing voices she is experiencing and therefore chooses to keep information about this to herself and refuses any anti-psychotic medication.

A similarity between Roberta and Helen is that they both recognize they need help and find some of their needs being met through using the Common Ground Report. Both of them also

have had experiences with professionals in the past that have caused distrust. The relationship the person has with their prescriber seems to be an important factor in the degree to which clients choose to reveal themselves through Common Ground. For clients like Roberta and Helen, the door seems to remain open to further collaboration around Common Ground with the development of a trusting relationship with their prescriber.

The Decision to Continue

The decision for a client to continue using Common Ground seems based on either: 1) the benefit the client receives from continuing to interact with the prescriber around the Common Ground report; or 2) the presence of the expectation that they use it to achieve a desired end. By the end of the study, Samuel, Bernice, Marcus, Maria, Mary, Roberta, and William continued to use the Common Ground process regularly and viewed it as a positive means of impacting something that was important to them. David, Andreas, and Jason did not use the Common Ground process regularly because they did not see specific benefits to using the process. Helen and Albert continued to use the process, but mostly out of it being perceived as being an expectation for them to see the prescriber. Neither would have continued using it if they didn't view it as something they needed to do.

For clients like David, the door seems to be shut at the moment and he refuses to engage in Common Ground. David's case manager says:

Yeah, he tried it two or three times and he won't do it anymore. Ever since then he's come in, and even those two or three times, they talked with him and had to work with him for a half hour to even get him to do the program on those occasions he did do it. But then he flat out said he wasn't doing it. (P4:8)

David's case manager talks about David having reservations of putting anything down on paper:

He's not putting anything on paper because too many people are trying to get in his business. So it has more to do with the paranoia because he won't sign paperwork of any type. (P4:10)

David's case manager talks further about David:

He puts up walls to try to prevent people from getting information. And I think that stems from his dad trying to assist him in getting his disability claims taken care of. Because his dad pushes him to respond and answer the letters and fill out the paperwork to get stuff taken care of. I think that's where it initially came from and that's bled over into that he feels like anything, The Man is going to get the information so he doesn't want The Man to have information so he won't provide anything. (P4:12)

David started to use Common Ground and was able to communicate during those initial visits that he didn't want to take Lexapro anymore and also wanted off Risperdal injections, neither of which he found to be very helpful to him. His prescribers responded to this request by taking him off Lexapro and switching his prescription of Risperdal from injections to pill form. A few months later, David was put into the State hospital and Lexapro was re-prescribed. David states:

Yeah. I told them I didn't want to take the Lexapro anymore and they got me off of that, which was a good thing. I also didn't think I needed the Risperdal shots anymore and so they are going to try me on pills now and see how that goes....it (the Lexapro) wasn't helping me any, didn't seem to improve my mental state any or help with my daily living situation, you know...they wanted me to give it a while longer, but I just didn't see any need to take it. But they went ahead and took me off it. Back in February I think, yeah February, but then they put me back on it again since I've been in here. Guess they thought that it had been out of my system long enough and that I needed it again to function better. I dunno. (P21:12-16)

David didn't see a reason for the re-hospitalization. He says:

Nah, but whatever. Guess they didn't think I was doing well, so they put me in here...it was an involuntary hospitalization. My case manager came out to see me cause I missed a few appointments and he thought I wasn't doing well. He asked me if I thought I needed to go to Rainbow or Osawatomie and I said I didn't think I needed to go. Then he left and I knew it was just a matter of time. Didn't know when it was going to happen, but a few days later the police came to pick me up, so I guess he had already made his decision. Probably went back and talked with his supervisor and made the decision that I need to be in here. (P21:18-20)

And also:

Not really. I mean I wasn't causing any problems, you know like I wasn't trying to hurt myself or anyone else, no one that I know of had been complaining about me or anything, but I guess they thought that since I wasn't seeing my case manager that I wasn't doing well.

I just didn't feel like I needed to see him at that time. But I guess they know what they are doing so they made the decision. (P21:22)

And also:

Yeah, I know I need help but I don't necessarily need to be in here. Seems like there could be another way. (P21:40)

David's recent hospitalization sets up a further division between him and his helping professionals. Because of his past experiences with the system, he almost expected it to happen. Embedded in David's responses is acknowledgement similar to Helen that he needs some type of help. Though he is initially reluctant to use the Common Ground process because of his mistrust of the system, he finally agrees to try it. He uses it as an opportunity to communicate that his current medications are not working for him and asks for them to be discontinued. While his prescriber partially agrees to his request (discontinues one and changes the form of the other), communication did not seem to delve deeper into ways David and his support system could work together to help him with the things that were most distressing to him. David reflects on his perception of what could have been done differently:

I dunno, maybe. Seems like, you know, there could be someone to talk to, like a therapist, kinda get things out that you need to talk about. Problems that you are having with regular daily living. I like to watch sports on TV, but there is only so much TV that you can watch. I sometimes will go take a walk and sometimes that helps, but I don't know what could be done differently. (P21:24)

And also:

With my daily living, keeping my place up and getting things done I need to get done. Helping me with my abilities to do things. I sometimes have difficulty getting things done like I need to. (P21:42)

David admits that he did not discuss all these things with his prescriber prior to the hospitalization. He says:

No, I mean I did say the medications weren't working, and I guess they did do something about that, but I'm back on them now, so well. (P21:26)

For the Common Ground process to work according to its intended purpose, it requires all parties involved to arrive at a goal they can work toward together. For clients whom it is working for, a clear goal has been established that guides discussions around the Common Ground Report and decisions that are made (Samuel – increasing personal medicine to help him stay well; Roberta – taking care of her son; Bernice – being able to continue with her art; Maria – spending time with family; Marcus – being able to enjoy his personal medicine [listening to music and shopping]; William – spending time with family; Mary – being able to work). Answering questions for the Common Ground report takes on meaning, because it is for a purpose. For clients like David, Andreas, Helen, and Jason, answering questions at the computer lacks meaning and focus. They become disengaged from the process because what occurs during medication clinic doesn't seem to have relevance for what they experience in real life.

When clients do not see how the “new way of doing things” is making a difference in their life, they perceive that things have really not changed much. As David states:

It hasn't been any different. Except for the computers, it's all the same as it always has been. I go in, they ask about the medications, they say what they think I should be taking and they write out a script. Not really much difference. (P21:88)

Albert was a person like David who finally gave Common Ground a chance even though he had negative experiences in the past with how information has been used. During the first interview with Albert, he was generally positive about the experience. Here he talks about his initial reaction to using Common Ground:

They spend more time with you. They spend more time with you understanding things you're going through. (P16:14)

What can be gathered here is that Albert engaged with Common Ground with an expectation that something might be different; that it might help him communicate something to his prescribers that he wanted to discuss. Like David, Albert wanted to communicate that his

current medications were not working and requested them to be discontinued. Albert was experiencing negative effects from his current medication and wanted his prescribers to discontinue the injections. By Albert's second interview, he already stopped seeing the value of the computers. Albert says, "No. I don't even know what they're here for. But they said it helps them I guess." Albert no longer sees the value of the Common Ground process because it didn't make a difference in something that mattered to him, getting off the injections or being able to go back to work. Albert says, "No, it doesn't change. No, no. I'm still getting a shot" (P30:35-37). Albert's case manager mentions that he wouldn't do Common Ground if he didn't have to:

He wouldn't do it. Because, he's tried to talk me into why he doesn't need to do it. But, our position has been, well, this is how med clinic works, now. It's for your relationship with med clinic. (P34:99)

Rather than viewing Common Ground as a process to help him communicate with his prescriber, the process has become more of a burden for Albert than a benefit. If the expectation of Common Ground is to increase client self-determination by bringing them into a more active role in medication clinic, this ideal falls short for people like Albert and David.

Conclusion

As we see, Common Ground changes the dynamics for clients around medication clinic. It shifts the role for some clients from being a passive participant at medication clinic to playing a more active role. This active role requires them to share more about themselves in medication clinic (which will be explored further in Theme 2). It also requires them to be more involved in the decisions made about their care (which will be explored more in Theme 3).

The transition to this role seems to be facilitated by a few factors to this point:

- 1) The relationship the client has with the prescriber. When the relationship between the prescriber and client is strong and built on mutual trust, the client seems to be more willing to engage in the Common Ground process.
- 2) The comfort level of the client in sharing information about themselves. Clients seem well aware that they have the power to disclose or not disclose information about themselves. Past experiences with how information has been used weigh greatly into their decision to disclose, as well as how they perceive the information they disclose will be used presently.
- 3) The context for sharing information. When clients perceive that there is a benefit to sharing information, they are more likely to engage in the Common Ground process and disclose any information that will move them forward in achieving a specific goal.

In terms of client experience, there is an important bifurcation between the group that is highly involved with Common Ground and the group that is not. The group that is not involved does not view the Common Ground process as substantially different from how medication consultations occurred prior to introducing Common Ground. The group that is highly involved notices substantial differences. While it cannot be ignored that the manner of collecting information through Common Ground and the types of information being solicited are a significant departure from the previous way of doing things in medication clinic, it suggests that the way this information is used during the medication consultation is the factor that signifies that an important change in procedure has occurred. In the next theme, we will look at how the content of information has changed for some people as a result of using Common Ground and in the third theme we will see the difference in application of this information within the actual medication consultation.

Theme 2: The invisible becomes visible: staff and clients view Common Ground as helping to raise things that were never discussed prior to Common Ground

A benefit of the Common Ground process is that it has increased the amount of information available to be discussed at the medication consultation. The intention of Common Ground was that it would facilitate clients being able to communicate information they wanted to reveal to their prescribers to help them make decisions regarding their medications. The prescribers would then review this information with the client, lay out possible options, elicit client feedback, and then together arrive at a shared decision of how to proceed.

For the process to work as intended, the information needs to be reflective of what the client is actually experiencing. Information collected through the Common Ground process includes: 1) the goal the client has that will guide the decision making process (the power statement); 2) the non-pharmaceutical strategies and activities the client is using to promote their own well-being (personal medicine); 3) current usage patterns of prescribed medications; 4) an assessment of how the client perceives they are doing in various areas (How I Am Doing Scale); 5) an assessment of areas where the client has decisional uncertainty around medications (Decisional Uncertainty Profile); and 6) specific goals the client has for the medication consultation that day.

Prior to Common Ground, if any of the above information was communicated during a medication consultation it was not done in any structured way. As noted in the previous section, most clients were “passive recipients” during the medication consultation prior to Common Ground. The traditional role of the prescriber as “expert” in making decisions involving medications seemed to be infused throughout the medication consultation. With Common Ground, clients were now being asked to share their own expertise (the lived experience) and have it enter into the decision making process involving their care. As we will see, the Common

Ground process serves as an assistive technology for revealing what was previously not disclosed in the medication consultation. In essence it helped to make the invisible become visible.

Areas where the invisible become visible:

- 1) Underlying reasons why clients decide not to take medication
- 2) Identification of symptoms that current medications weren't addressing
- 3) Identifying possible unspoken concerns a client has with medications (even if they continue taking them)
- 4) The clients goal for taking medications
- 5) How the client is really doing on the medications
- 6) More honesty around use of drugs/alcohol

What helps the invisible become visible:

- 1) Communicating through Common Ground feels safe
- 2) Facilitates the client remembering what they want to discuss with the prescriber
- 3) The paper becomes proof for people
- 4) Helps client organize thoughts (even those with disorganized thinking)
- 5) The client has a reason to reveal things previously not revealed (relates to goal)
- 6) Finally feeling heard by prescriber
- 7) Areas marked in red are followed up by prescriber
- 8) Provides a lexicon to help clients describe how they are feeling

What gets in the way of the invisible becoming visible:

- 1) Mistrust of how the information might be used
- 2) Prescriber not responding to client's stated concern

3) Not feeling information is making a difference

One thing that was apparent to prescribers and nurses when they first started using the Common Ground process was the amount of new information that became available to them during medication clinic visits. This produced a lot of the enthusiasm about the potential that Common Ground offered. A common perception by prescribers and nurses was viewing Common Ground as having an ability to finally get at what the client was thinking and experiencing. Common Ground served as a doorway into this previously unrevealed information and brought it to the forefront of discussions and decision making during the medication consultation. One nurse talks about this here:

I think it opens more doors to patients' thoughts. Before I think they always didn't share that with you. And you know, their answers bring that to the foreground. So that gives you just more information to make decisions...And to how they're doing and what they're really thinking. (P12:90;92)

This same nurse also says:

I think it's been helpful for a lot of clients to clarify some of their thoughts about their illness, about their medicines, things that they don't normally bring up or discuss. (P12:8)

One prescriber concurs with this. She views the new information being received as a change from what they had been receiving in the past. The perception is that this information is more truthful; a more accurate reflection of what is really going on with the person. Reflected in her statements is that a process of understanding is beginning to develop. Previously, prescribers may have accepted a client's passive response in medication clinic as indicating that the client was doing well and satisfied with the course of treatment. New doorways opened through Common Ground shed new light on the client experience that has the potential to change interactions within medication clinic:

I've seen changes. As far as huge changes, I mean to me I think we know more. We know more truthfully what is really going on, and we know more truthfully from the client what

they're thinking about the medication. Sometimes we kind of think oh everything is going great, so I think as far as having a huge change, it starts the process of understanding if there's miscommunication between us and the client. (P13:42)

Another prescriber also views that the new information being revealed now at medication clinic is very useful. He describes how the information presented on the Common Ground report provides a clearer picture of what is actually going on with the client:

I think at the very minimum we get a good snapshot going into the clinical session of how the person is doing and what's going on with their meds and what kind of concerns they are having with their meds...So I think it's kind of moved us a little further in terms of knowing what is going on in their lives. (P8:9)

The same prescriber says:

And we've had some people who we really just got very little information out of in a clinical visit who will come in with a pretty detailed report, but then be able to talk about it. And now they have been able to engage with us in a clinical session much better than they had in the past. And then I think we've had some people where that's also been the case with hallucinations, where they seem a little bit more willing to tell the computer that they are having more of a struggle than what they've been willing to tell us. (P8:9)

One prescriber views that communication with clients has improved through the use of Common Ground. This is significant in terms of Common Ground having the potential to increase self-determination on the part of the client. An opening is created for clients to reveal something about themselves that previously they have not disclosed. It also creates the opportunity for clients to reveal expectations they have for receiving medications. The prescriber says:

I think we're just at the beginning, and I haven't had enough people to really notice if it's significant, but I think it's opening up pathways of communication for sure....I think it's just more open for the client to give us that information or to make a bold statement about what they want out of their meds. (P13:42)

One of the areas where the pathways of communication have been opened is around discussions of medications. A valuable piece of information that is disclosed is around client's expectations for the medication they are prescribed. One case manager indicates that some of the

clients he works with have unrealistic expectations for how the medications should work. When the medications do not help the client to feel better immediately, they may infer that the medications are not working and stop taking them. Previously, prescribers may not have known the specific reasons why the client stopped taking the medications, but with Common Ground a mechanism is created for this information to be revealed. The case manager states:

A lot of consumers stop taking medication because they think they should be better immediately. And so because there was a lack of communication, that was a constant issue. But now because they are able to explain well, you may still have this and you may still have this, because it's highlighted in red, okay, I'm not sleeping. I'm taking Tegretol but I'm not sleeping. Well, they address that issue. They talk about it. They move the medication around. Whereas before the person would just say it's not working for me. They wouldn't say why it wasn't working. They'd just say it's not working and stop taking it. (P4:36)

The same case manager gives a specific example of where the pathways of communication were opened between the client and the prescriber around medications. What the Common Ground process made visible was the client's perceptions of what he thought should happen once he started taking medications. Knowing the client's expectations allowed for discussions in medication clinic to stay focused on the client's concerns. The case manager says:

Because he would always start out with the same thing, 10 milligrams of blah, blah, blah, and when he'd take it for a week, the voices wouldn't improve so he'd stop taking it. And so that was a cycle with him constantly. Well, when he went through the kiosk system and was talking to them about it and the doctor and I and the nurse explained to him that well, this isn't a given that in a week these symptoms are going to go away. That's why we have to come back for adjustments. And so in doing the program he was able to put that in there as a concern and because he did that they addressed it. So instead of him stopping taking the medicine after a week he came back and reported that the voices weren't any better so we adjusted the medication. Now the voices are manageable. So he finally got over a hump he couldn't get over for many, many years because he just wasn't talking to people. (P4:32)

Another case manager talks about how the pathways of communication were opened between one of the clients she works with and the prescriber. The client struggled with taking medications because of perceptions he held about his prescriber. Some of the perceptions could

have been created because of the client's mistrust of medications and never having any options presented to help him except for medications. Common Ground allowed this client to reveal his concerns and the prescriber was able to respond to this by broadening the options available to him besides medications. The case manager says:

Now another one that I can think of off the top of my head that it has really opened up discussions for him and his providers about his medicine because I was just doing a quarterly with him this Tuesday and he said he really liked common ground because it allowed him to do more discussion...because he was kind of delusional about one of our providers here. And so it has opened up more discussion about not him always taking medication, but what he can do to try to help change those distortions that he has about the provider. So he's wanting to look at doing different activities per se than always taking medicine to help him with his symptoms. So that was a really big breakthrough for him because he was able in doing the common ground questions to put his concerns, and then (his prescriber and nurse) will talk to him about that. (P19:7)

Another case manager views that the Common Ground process is helping clients and their prescribers move beyond the dichotomy of compliance versus non-compliance. What becomes more visible are the intricate reasons clients make the decisions they do in regards to their medications. Some clients may be engaging more in medication clinic now with the Common Ground process because they have always wanted to enter into more in-depth discussions about the medications. There just did not seem to be a mechanism for them to do this. The case manager says:

I think people are engaging more and talking about what's going on and really getting active around going beyond compliance and noncompliance. I mean they'll talk to you about what's really going on with the meds. Whereas before, they were more telling us what they thought we wanted to hear about what was going on. And it started to broaden just beyond, I mean case managers could usually get to that point because they're with them more often, but broadening that to talking to the nurses about, okay really I'm not faking this at all, which the nurse probably knew. I think it's just something that they've realized is just a part of the system now. (P33:99)

Another case manager talks about a client who previously did not communicate much during the medication consultation. As with many clients, he would go through the previously

established routine, get his prescription and then leave. Now with Common Ground, he is faced with looking at the two disparate ways of doing things and deciding which provides the most benefit to him. When starting to use the new program, he comes to realize that revealing more information about himself and what he is experiencing provides a greater benefit. Once he sees the benefit, he begins to reveal more about other symptoms he has been experiencing that the medications were not addressing. His case manager says:

Because before he'd go in and he just would sit there and just yeah, yeah, yeah and get a packet or sample of the pills and walk out. This has actually helped him to realize that that wasn't benefiting him because he wasn't telling them actually what was going on. And by using the program, they have identified he has some other symptoms of other things that are going on that that medication wasn't addressing. (P4:32)

Another case manager views that most of the clients on her caseload have now become accustomed to using the Common Ground process. It has become a means for them to communicate information about themselves and their experiences that they might not share in other settings. While earlier one case manager stated that for some of her clients Common Ground was a means for clients to communicate things that they might have previously shared only with their case manager, this case manager sees that sometimes clients reveal things on Common Ground that they have never even discussed with her. This is important because it shows the potential of Common Ground to elicit new information that can factor into the treatment process. The case manager responds to the idea of not having Common Ground available to clients:

I think it would be a bad thing, because change is difficult for a lot of our clients, and I think this is something, especially for the ones on our case loads...they've gotten accustomed to this. They've gotten accustomed to going to the Decision Support Center and answering these questions about what they've been experiencing since their last med clinic appointment, and sometimes, even though I feel I have pretty good relationships with my clients, they might disclose something on there, on their Common Ground report that they didn't disclose to me or they didn't think about disclosing to me, but it's flagged on their

Common Ground report. Then, their provider's able to address it with them, and I'm able to follow-up. (P35:218)

Common Ground also seems to have the potential to help clients raise previously unspoken concerns they might have about their medication. For example, Bernice was a person who did not previously say much during the medication consultation, but despite her reticence to speak up about her concerns, she continuously held fears about the side effects of her medications. Bernice has diabetes and was unsure if this was something caused by the medications. Common Ground allowed her to voice these concerns to her prescriber so they could be discussed in the medication consultations. Without Common Ground, Bernice might have always kept these concerns to herself, but since she knows that the prescriber is willing to discuss these concerns with her directly, she is more open about revealing them on the report. She says:

Because once I tell the computer what my situation is and they discuss it with me and that has helped. Just like the side effects and just like if I have, I have diabetes, and I always wondered if the medicine was creating some of these problems or was it something else. And that's given me more information for myself to know so I can talk to my doctor and it's given me everything explained better and a better medical profile for me. (P1:34-36)

One nurse talks about how having more information present during the medication consultation is helpful regarding clarifying any previously unspoken concerns clients may have around medications or decisional uncertainty regarding medications. Because Common Ground allows for these discussions to take place now, prescribers and nurses are in a better position to be of assistance to the person. The nurse says:

And that's where it's been so helpful because you clarify what their thoughts are about the meds or ...what is the issue with the medication. Sometimes they do have a question and they need more education about it; I don't really understand this med or why I'm taking it. Then other times, it's just I didn't have the money or there's a lot of dual diagnosis, and that can be real helpful too if we have that. I'd say sometimes you say I spend my money at the beginning and I'm having trouble budgeting or figuring out are the meds worth saving for or not. So that's a really good - was there not transportation; do you need more support; that sort of thing. (P13:40)

Another case manager talks about a client who was never comfortable talking about a specific side effect of the medication he was experiencing. Rather than discussing these concerns with his prescriber, he would just throw the medication away. By using Common Ground, he was finally able to express this concern and the prescriber was able to make the needed changes. The case manager discusses the situation here:

There was a guy on one medication and he never said what it was that was affecting him. He just wouldn't take it. Just constantly they'd give it to him and he wouldn't take it. He'd throw it away. He wouldn't take it. He'd throw it away. He wouldn't take it. So he came in and he started the kiosk program and first of all he was skipping med clinics for a while and then he finally came in. And he went through the kiosk program and through going through the kiosk program, they found out that he was concerned about the side effects of sexual impotence with the medication they had him on. And so he never said anything before so no one ever addressed it before. I mean it was totally with the side effects, but he never said anything. And so finally he said something and so his medicine got changed because he went through and he said he had some uncertainty about his medication or something of that nature. So they finally were able to look at what is your question? And they finally were able to get out of him what his question was. And in doing that they were able to switch his medication, which he then started taking. Just a small way of changing and doing things, which allowed him to be able to express himself. He just felt I think embarrassed and he didn't want to say it right out. (P4:54)

The situation the case manager describes speaks directly to the compliance/non-compliance conundrum that is frequently faced around medications. With the client above, he continues to come to medication clinic in search of some type of help. He is prescribed a medication, but the medication has side effects that the client finds intolerable. Rather than making this a point of discussion at the next medication clinic visit, the client decides not to take medication. The help the client initially sought out during the initial visit goes unresolved and from a prescribers point of view they only see the client as being non-compliant with medications. What Common Ground made visible in this situation is the actual thought process the client is using to base his decision about whether or not to take medication. Once what was previously invisible becomes

visible, it allows for a different path of decision making to occur between the client and the prescriber.

One prescriber talks about similar dynamics with a client he was working with. The client would be prescribed medications during one medication consultation but would then show up at the next appointment either not taking the medications or only taking them sporadically.

Underlying the non-compliance or partial compliance with medications was decisional uncertainty around whether or not the medications were actually helpful and also some logistical concerns about paying for the medications. Once these concerns were made visible through Common Ground, the prescriber and client were able to discuss ways to resolve this. The prescriber says:

We have a lady who had been pretty ambivalent about meds, and she would come in usually off of her meds or not taking them very effectively and having a lot of mood symptoms. And we would typically come up with a plan related to meds and I think there was a lot of difficulty with her following through on that. And then when we started using this software with her, she was able to identify a decisional uncertainty that the reason she sometimes didn't take meds was partly because she didn't know if they were helpful, but also partly because she had trouble covering her co-pays. And so she did a decisional balance worksheet where she looked at the pros and cons of medications versus not using meds and was able to rate the use of medications as, I think 10 was the highest she could rate it, but it was the most important for her recovery that it could be. And then she did a budget worksheet that was something that allowed her to find a way that she could pay for the medication. And as far as I know, she's been able to take her medications now and she is engaged in taking them rather than sort of ambivalent about whether she wants to have them or not. (P8:21)

The prescriber continues talking about the same client:

She is at least now engaging to the point that we'll be able to tell if her medications were helpful. I think before she would come in not feeling too well, and we really didn't know if the meds weren't helpful or if it was just they weren't getting used adequately or what the problem was. And I think it allowed her to really focus her thinking in a way that she hadn't done before. She was able to sit down and assess a number of issues related to med use and decide for herself whether the meds were something that she wanted to try to use or not. She decided she did. (P8:23-25)

This situation also speaks to the potential of Common Ground to help clients reveal information to themselves. While the client was experiencing decisional uncertainty prior to the use of Common Ground, the software allowed her to present her experience in such a way that she could come to a decision for herself about what she wanted to do regarding medications. What she is able to express to herself through Common Ground is that the medications are important to her recovery and she now has a mechanism to evaluate how helpful they are to her.

One peer specialist also speaks to this phenomenon of Common Ground helping clients to reveal things to themselves. He puts it in terms that it “enlightens them” (P37:19). Common Ground serves as a mechanism that helps clients collect their thoughts and offers them a focal point of what they want to discuss with their prescriber. Common Ground also becomes an evaluative mechanism for them to gauge how they are doing from one appointment to the next. This organized self-reflective opportunity is another example of increasing the self-determination of the client to be more active within the medication consultation. The peer specialist says:

I’ve heard that they say it gives them a reference to, when they want to communicate with the doctor or nurse better. And they say it’s a good measure of their mental status at the time. And a lot of people enjoy just simply working with the computer. But a lot of people enjoy inputting the information there and it kind of enlightens them, you know. It makes them aware of what’s been going on during their last appointment. And since they condensed the meeting time with the doctor and the nurse at 15 minutes, the doctor can immediately look at the report and see what applies and discuss that. (P37:19)

Another area that seems to become more visible through Common Ground is clients’ use of drugs and/or alcohol. One prescriber states that some clients are now more likely to reveal the use of drugs and/or alcohol with their prescriber now through Common Ground. The prescriber says:

And then I think on a little bit deeper level we have seen some people admit to certain symptoms such as using recreational substances to the computer that they had never admitted to us. (P8:9)

Another prescriber also views that clients have been willing to discuss use of drugs now with the aid of Common Ground. What she finds is that Common Ground opens a doorway for her to approach this subject with some clients. She says:

The drugs are a lot easier topic to approach. Sometimes they're more honest, or the fact that you can see the past. I found a lot of times when you can bring up last time you said this, it makes it a more friendly topic for them to talk about. Whether you have it from your information or if you have it from a shared decision, it's kind of well you told me you did this in the past so it makes it a little bit more. Definitely you can go to that topic and people tend to open up a little bit more. (P13:6)

One case manager presents a specific example of how Common Ground allows for discussions around drugs and alcohol to be revealed. The case manager says:

He would get on and off of it (the medications). He would be symptomatic. He would drink and he would do illegal drugs and his symptoms would increase. And he would go in the hospital. For some reason, with the Common Ground report, he finally decided to speak up. Maybe he had an instrument to let his feelings go. (P20:88-91)

For this client, Common Ground served as a mechanism for him to reveal what was going on with him when he decided he was ready for a change. Not only was the client able to reveal through Common Ground his usage of drugs and alcohol, but it also allowed him to communicate his preferences regarding the medications he was taking. The case manager says:

It was just a really cycle thing going on. Then I started with him and we had started coming around and started coming here. You know, he had decided that he was due for a change, but I think the fact that when he said I don't want to take this medicine anymore and we said okay, and I want to take this as needed, and we said okay. It's like oh, okay. And he's coming to med clinic. He's making his appointments. He still meets with me. He's going to decide. (P20:84)

The case manager goes on to talk about how well this client is now doing in his life:

He is managing his symptoms. He moved and he's been with his relatives, and he's doing rather well...He has stable housing. He got his driver's license. He's planning on going to trucking school and he's managing symptoms. He's been doing well since February, March, April, May - three months - and he came in and says I don't want to take these meds. I want to take this other one but I want to take it as needed. He has been off of illegal drugs. (P20:78)

Sometimes clients are experiencing concerns in their life not related to medications that can have an impact on what transpires inside medication clinic. One case manager talks about how Common Ground helped a client who found it previously difficult to speak in medication clinic express other concerns besides medications that she was experiencing. The case manager recalls the conversation she had with her client about discussing these concerns with her prescriber through Common Ground:

You know, what areas we could be looking at, or, what is concerning you the most right now. And, it will help the nurses, so this is something not to pry into your private life, but just to help us know how we can help you better and then, sometimes it's hard for you to talk. Because, for her, it's hard for her to talk about her business. (P36:63)

The case manager talks about the resulting Common Ground report that the client used to reveal her concerns:

It talked about, she was concerned for her son that soon was going to be released from jail, and he doesn't know if he's going to be homeless or not. She has talked to me about it, but I don't think she had talked to . . .the med staff about it. So, this kind of thing helps bring, you know, the circle, you know, closes the circle. The client and the practitioner and the CM (case manager), you know. I think they got some information that they would not have gotten otherwise...that they would get from the notes, but not in so much detail, I think. (P36:67-83)

Common Ground clearly has the potential to help clients raise information that is relevant and important to them. Staff speak of this as being a major departure from the way things used to be in the past. As one case manager states:

It's a pretty big change. This stuff would never come up. You know what I mean? I guess it could come up some, but this way it's definitely coming up. It's a more organized structure for doing that. (P42:122)

Or as a nurse describes:

The main thing I guess that I see where it's working is that I feel like there's more information that is on the paper than what the client would have verbalized. So I think in lieu of that, that we have a better handle on what's really going on in their life. That gives us more of a picture of if their symptoms are less or more or how they're really doing I think. Sometimes I think it also helps to kind of see what's not working too. (P12:102)

One prescriber reports that some clients seem to be more activated through Common Ground. Some clients who were not previously engaging in medication clinic are now engaging and sharing things about themselves that they never shared before. The prescriber says:

They've somehow been activated or maybe they haven't shared with us their decisional uncertainty issues before and those are coming out now. So I think it is bringing a lot out for most people that we weren't getting before. (P8:17)

While it seems obvious that Common Ground has the potential to make what was previously invisible during the medication consultation visible, what are the factors that seem to allow for this occur? One of those factors seems to be that it provides a safe means for clients to disclose information about themselves and their experiences. One prescriber was surprised at the amount of new information that is being revealed through Common Ground, especially with those clients who previously would say very little during the medication consultation. The prescriber views Common Ground as providing a safe means for clients to reveal themselves. The prescriber says:

Sometimes it's surprising when you get the most knowledge from people who you haven't been able to talk to before. You might ask them. I think it may be an opener to topics that people don't want to tell you face-to-face, but they will tell you via the shared decision-making. (P13:6)

One case manager talks about her client enjoying Common Ground. It helps him to be more honest with what's going on with him in a safe way:

And he enjoys Common Ground but sometimes he always isn't, at least with me, forthcoming about what's going on with him. But Common Ground has given him a way, to me in a safe way, to really get out...what's going on with him. So I think he really enjoys that. (P19:11)

This same case manager would hate for the new Common Ground process to ever stop. In her view, many clients have become accustomed to now sharing information in this manner and it is able to help the client reveal thoughts, emotions, and experiences they previously did not

feel comfortable sharing with staff. Though she perceives that she has a strong relationship with the clients she works with, there is still some information that people are not comfortable disclosing even to her. It seems that for some clients the computerized format of asking personal questions reduces the client's perception of being judged about what they wish to disclose. The case manager states:

If the Shared Decision Support Center or the Common Ground reports stop...we wouldn't have that tool there to help identify what our clients were going through. Especially if they don't disclose it to us. And, that's what one of my current clients mentioned, talking to her yesterday, and she was talking about her fears and she was, mentioned to me finally some fears that she had, to me, that she had identified on her Common Ground report, but she had never been comfortable in disclosing to me, but she was like, she didn't want people to think different about her, so you go through that consultation, well, we're not going to think different of you if that's part of your mental illness. But, you can say things to clients all day, but at the end, it falls back on how comfortable or how they feel about disclosing that, and the Common Ground report is an excellent tool in being able to help them, because they will be able to say, what they feel. (P35:218)

One client (Roberta) talks about often being nervous around people. Because of feeling nervous during the face-to-face interaction of the medication consultation, she would often forget what she wanted to convey to her prescriber. The computer becomes a safe option for disclosing information because she does not have the added stress of having to interact with another person. She says:

It's a good experience because it helps, it reminds me of the problems I've been having and I forgot about it when I got here because I get kind of nervous around people. And the computer helps me open up to my doctor about my concerns with my medicine. (P9:18)

One prescriber recognizes that some clients might be a little intimidated during the face-to-face interactions with the prescriber. While the prescriber views that most clients are now engaging with the Common Ground process on some level, the prescriber views that there has been a substantial change with those clients who previously did not feel comfortable sharing information nor had difficulty communicating information in person. The prescriber says:

I think there have only been a few people who haven't engaged with it. I think the vast majority of our people it really is working for. I think maybe we're seeing a little more dramatic results with some people who have been maybe a little intimidated to engage with us or maybe kind of seem disorganized in their thinking when they came into clinic and so we maybe didn't get the full picture that we're getting now. But I think almost everybody has engaged at some level with it. (P8:7)

Bernice is another client that did not do well during face-to-face interactions with her prescriber. As with Roberta, important information would be lost during the actual medication consultation because of difficulties communicating information in person. This introduces another factor that seems to help the invisible become visible. Common Ground seems to serve as an organizational apparatus that allows some clients to think through their experiences and present it in a consolidated manner to enhance and focus discussions with their prescriber. Bernice talks about how the Common Ground experience has been helpful to her being able to finally get out information that she wants to discuss with her prescriber:

Uh-huh. It has been. Because I wouldn't say much a lot because I'd let things overlap and all of that. But I'm now saying stuff and getting things out. (P1:50)

Another client (Samuel) also sees the organizational value of Common Ground. Common Ground helps him prepare to meet with his prescriber. Common Ground helps him to remember things he might have previously forgot to discuss during the actual medication consultation. He says:

This right here kind of gets the mechanics going before you see the doctor. And then, when you see the doctor, like if you were to forget something, and that's like a reminder, so to speak, the computer is. So what I usually do is as I write down the computer and then I confer that information with my doctor and then we'll discuss it and he or she will make a recommendation and we'll go from that point. (P2:45)

For Bernice, the Common Ground report also helps her remember things she would like to discuss with her prescriber that she previously might have forgotten. Sitting in front of the computer helps her to stay more alert and focused. She is able to get out the information she

wants to discuss and since it's recorded on paper, she can now relax during the actual medication consultation knowing these things will be addressed. She says:

Like I said, it kind of keeps me more alert when I go in there, because it's asking all these questions beforehand, and when I go in there, they've got the paper. Because, I always, seems like I always would forget something, and even if I wrote it down, maybe I didn't pull, forgot to take the paper out and ask them. It would always be something I forgot. This helps me remember a little bit more. (P28:526)

Bernice also states:

I enjoy working with the computer and it brings out more of things I would like to talk to him about and it makes me think before about my health situation. (P1:182)

Once again Bernice confirms what she like most about the Common Ground process:

I guess asking the questions and making my mind more familiar, because a lot of times when I come in, and I probably should make notes on different things, but I forget, and it's just kind of keeping up with everything, especially how it prints it out at the end. I like that. (P28:66)

Another client (Maria) also confirms that using the computer helps her to remember things she would have previously forgotten to say in medication clinic. For Maria she also has to deal with a potential language barrier during the medication clinic, since English is not her first language. She says, "The computer makes me remember a lot of things" (P29:19).

Common Ground also seems to have the potential to help people with disorganized thoughts communicate information to their prescriber. One prescriber alluded to this earlier when he was talking about people from whom he'd seen the most drastic differences with. Another prescriber has also had the same experience of a person with disorganized thinking being able to communicate something that was relevant to them that they would never have previously discussed. She says:

I think I shared with you the story about the woman who is so psychotic every time she comes in, and she completes the report. And out of nowhere she asked me one day or she said, "I'm so depressed because of the amount of time it's taking me to heal." And I would have never heard that from her before without her experience on Common Ground. Then

she said, “When I come back, I want to know more about schizophrenia.” I said do you want to know now, and she said no, the next time. (P6:16)

The Decision Support Center supervisor confirms what several clients who were interviewed had to say about the ability of Common Ground to help them stay focused and organized during the medication consultation. The supervisor views this benefit of Common Ground being a very common response among clients. She says, “The most common phrase that we hear from people is that it helps them focus on what they need to get done in the med appointment” (P38:99).

Another factor that seems to allow for the invisible to become visible is when prescribers follow-up on the information that is being revealed. At the second interviews with client participants, most clients seemed well aware that what they responded to on the Common Ground report would be viewed by their prescriber and other staff. In the previous section, we saw how this had the potential to deter some clients from being completely honest in some of their responses. It also seems to be a facilitating factor for some clients to reveal previously undisclosed information. The thought that someone is now finally going to address something that had been a previous concern may be a motivating factor for some clients to open up. One case manager says:

I feel that the clients know if it’s on the Common Ground report, even if they’re not comfortable and come right out and tell you, it’s going to be addressed, because the provider’s going to address it with them or either, their case manager, when they look on that Common Ground report from med clinic, is going to go over it with them. So, I think it has been an excellent tool in helping facilitate the recovery process. (P35:226)

One nurse now views that clients are more readily disclosing information about themselves through Common Ground. As the conversations now in medication clinic are shifting to what the client is saying through the Common Ground report, clients seem to be opening up more in response to this. The nurse says:

I think how they used to respond was they would basically answer our questions, and we had kind of a set of questions that we would go through basically. That would be the main part of the conversations. They didn't really offer a lot of extra things that they would think about. Because of the questions that are on the Common Ground, it brings those to the forefront, so they bring them in the Common Ground report. Then that brings it to where we can discuss that with them and ask them to talk more about that. I don't think they would ever have said that in the first place without the Common Ground. (P12:12)

One case manager confirms that medication clinic staff are now focusing more on what is stated in the Common Ground report during discussions in the medication consultation. When clients are responding to questions for the Common Ground report, they are able to weight any concerns they are having. Concerns that the client responds with a "4" or a "5" are highlighted in red on the report and these are the ones that medication clinic staff will focus on most intently.

The case manager says:

Yeah, it's changed it quite a bit because they actually use, it's focused off of that Common Ground report that they bring in with them. They look at that and they see the highlighted red areas and they actually are able to ask them specifically what is your concern in this area? And then by them responding and answering that question, they are able to be more focused on what they need to address in the med clinic. (P4:36)

Another case manager views that the way the prescriber responded to a client in medication clinic changed the dynamics of how that client began to interact from that point on. Here the client was able to finally focus in medication clinic because she had the Common Ground report in front of her. You can sense that the client had something to say that was important and meaningful to her. An opportunity was created that would either serve as a positive experience where the revealing of information was reinforced or a negative experience leaving the client to question the value of opening up their personal experience. In this case the prescriber's response is a positive one for the client, now possibly setting the stage for the client to reveal information about her experiences in the future. The case manager says:

I think that the first time she had the paper and could focus and she said something and they responded in a positive way, I think that changed her; just changed the way that she was going to operate within the system. (P33:99)

One prescriber talks about how the Common Ground report has helped her focus on what the client is concerned about. Even if some clients are not talking more in medication clinic because of using the computers beforehand, the report created is at minimum opening up a window for clinic staff to ask more questions about what the client might be concerned about. The prescriber says:

Even if they aren't talking more, I think it's definitely helped me for people who are, tend to be, very brief or, yeah, might have, you know, because of symptoms going on, might not say much. It gives me a point to where, to talk about subjects that, you know, maybe if I brought up before, they might not want to talk about. So, that, I've found, you know, or they're a little bit more apt to talk about a concern they had because of that, because I'll, kind of, point to it and it's, kind of, that same thing. They had the independence of answering those questions, and now it's their answer to the question that we're discussing. (P41:99)

Another factor that might facilitate the invisible becoming visible is that the Common Ground report becomes a source of "proof" that validates what a client has been experiencing. Some clients may have previously tried to reveal this information in the past, but now they have the backing of the report to help them discuss this with their prescriber. Roberta is a client who has had difficulty sharing information about herself in the past because of information being used against her. Though still hesitant to share everything with her prescriber, she has become more assertive now during medication clinic because of having the Common Ground Report. Prior to Common Ground she was hesitant to make bold statements about what she wanted. Now she feels she can let the Common Ground assist her in communicating information to her prescriber. She says:

There's been a time when I had told them that I felt suicidal and they wanted to admit me in the hospital but I didn't want to go in the hospital. When they didn't have something on a piece of paper to back up what you were saying on what needs to be done. Now they have it in writing. (P9:154-158)

Since the questions on the Common Ground report do not get at all the things that Roberta would like to discuss with her prescriber, she does have to raise additional things in person. What Common Ground does though is provide a platform for her to initiate these discussions. Knowing that her prescribers will listen to her because of the Common Ground report, helps her to have the confidence to reveal more about what she wants in medication clinic. She says:

Well, but it don't have all the questions on there with all my symptoms added. So I still have to tell some things that's going on, but still they listen to me. They just don't make you, take you to court and make you take this medicine. It is all up to you. So yeah, I am more decision making on my own. I think I can read for myself what I need to be doing and also have questions I need to ask what would make me feel better and what I tried at home, it didn't work. Is there a way that they can have my medicine managed to me so I will feel better? (P9:158)

Conclusion

Common Ground has the potential to help clients communicate more clearly and effectively with their prescribers. It offers a window into the clients lived experience that was not revealed for some clients prior to Common Ground. By allowing what was previously invisible to become visible, treatment team members are able to be more responsive to the client's actual concerns or goals for treatment.

An interactive effect seems to be occurring. As clients feel more comfortable sharing information with their prescribers and this information is responded to positively, clients seem more willing to disclose more information about themselves. Also, when prescribers use the information from the Common Ground in a relevant way to assist the client with an important goal or address an important concern, clients seem more willing to disclose further about themselves. On the other hand, when clients do not perceive that it is safe to reveal information or relevancy to the information being disclosed is not established, then clients refrain from disclosing.

For the group of clients who were highly involved using Common Ground, the window into their personal experience continued to unfold over the course of the study. To varying degrees, their values, preferences, uncertainties, goals and concerns, became more explicit. For the group of clients that were not involved, the window into their personal experience was either shut after a momentary glimpse or never was opened in the first place. On one hand, this all could be attributed to client's individual preference in choosing what to reveal. But it is important to acknowledge that several of the clients for whom shared decision making eventually worked well, had some of the same misgivings about sharing information as some clients for whom the process did not work well. It should also be noted that some of the clients for whom the process did not work well, did make attempts to share information about their personal preference, values, uncertainties, concerns, and goals. It is important therefore to look further into the dynamics of the actual medication consultation and explore how the information obtained from Common Ground is used to make decisions and the interactions between client and prescriber in making these decisions.

Theme 3: The centrality of the goal: When goals that are meaningful and important to the client are made the focal point of medication clinic, clients feel heard and are more engaged in medication clinic.

The pinnacle of the Shared Decision Making process is the actual arrival of a shared decision between the client and the prescriber at the end of the medication consultation. Ideally, the process is intended to go as follows: After finishing work at the computer kiosk, the client would bring in their completed Common Ground report into the medication consultation with the prescriber. The prescriber would first review and read aloud the Power Statement as stated on the Common Ground Report. A well constructed Power Statement defines what is most important to the client and serves as the focal point of discussions that follow leading to the shared decision.

Second, the prescriber would review the numbers that reflect the client's responses to questions on the HIAD scale. The questions on the HIAD scale require a response ranging from 1-5 (1=least concern; 5=most concern). Numbers listed on the Common Ground Report in red correspond to areas where the client has major concerns (numbers 4 and 5). Numbers in black correspond to areas where there is moderate to no concerns (numbers 1 through 3). Concerns reported on the HIAD scale may or may not effect what is listed on the client's Power Statement. If the area of concern does affect the Power Statement (e.g. the anxiety I am experiencing [concern from HIAD scale] is impacting my ability to spend time with my family [part of Power Statement]) then the two items should be discussed together. If not, then the prescriber can continue to address the immediate concerns listed on the HIAD scale.

Third, the prescriber should discuss with the client options for alleviating the concern or concerns from the HIAD scale. On the Common Ground Report, any psychiatric medications

the client was previously prescribed, as well as personal medicine the client has been using, is listed. Clients respond to the degree to which they have been using psychiatric medication (i.e. Yes, Quit, Less, More, Didn't Start) and personal medicine (i.e. Yes, No, Sometimes) since their last appointment. The goal is to look at all current options that might help address the client's concerns. This might include adjustments to the client's current psychiatric and/or personal medicine or the exploration of new psychiatric and/or personal medicine.

Lastly, the client and the prescriber come to a decision based on the exploration of options discussed. The decision should be a culmination of the client's experience and the knowledge of medications that the prescriber brings to the table. The shared decision should be a statement that reflects what the client agrees to do between now and the next appointment, as well as reflecting the involvement of any other supports (e.g. prescriber, nurse, case manager, peer specialist, etc.).

While the layout above describes how the process was intended to work, in reality the process at the center in the study did not always flow in such linear fashion nor did all the components occur during each medication consultation. There was also variation between clients in terms of the degree to which they were involved in the actual decisions that affected them. Clients like William, Samuel, Roberta, Bernice, Maria, Marcus, and Mary were highly involved in the decision making process, and they were also able to achieve goals related to the medication that they desired. William, Roberta, and Mary, in particular were not always happy with previous decisions prior to Common Ground. Some factors that played a role in the effectiveness of the shared decision making process for these individuals were:

- 1) The clients concerns as expressed through the Common Ground report was heard by the prescriber;

- 2) Concrete steps were taken to help the client address these concerns and achieve a goal the client desired.

On the other hand, Helen, David, Andreas, Jason, and Albert were not as involved in the decision making process. Factors that seem to play a role in the shared decision making process not being as effective for these individuals include:

- 1) The clients concerns were either not expressed in the Common Ground report or the client's concerns were not heard by the prescriber;
- 2) The client's concerns were not addressed or the goal the client desired was not achieved.

A circular pattern seems to occur. When prescribers address the concerns that clients express on the Common Ground report, clients are more likely to be involved in the shared decision making process. When clients are more involved in the shared decision making process, they tend to be more invested in the Common Ground report and ultimately work with their prescribers to achieve a goal they desire.

Ideally, the discussions that occur between the client and the prescriber during the medication consultation should revolve around the stated goal(s) of the client. This was intended to be reflected in the Power Statement that clients constructed prior to their first use of the Common Ground software. Power Statements can change over time as clients become clearer about what they want out of medication clinic. The Power Statement was intended to be the lens that the prescriber looked through as they went over the concerns that clients had expressed through the Common Ground Report. The concerns could be viewed as things that might be getting in the way of the client achieving a goal that was meaningful or important to him or her.

The Power Statement also was intended to reflect the expectations of the client in terms of any decisions that were to be made. For example, the client may express in their Power Statement that certain side effects were unacceptable to them, and that they wanted the prescriber to help them find options to help them reach a certain goal without a medication that was associated with these particular side effects.

Table 2 shows the Power Statements that were listed on each client's Common Ground Report during the course of the study. The initial Power Statements did not change for any of the clients throughout the study except for Mary.

Table 2
Power Statements Listed on Common Ground Report

| Client | Power Statement |
|---------|---|
| William | My family is the most important thing in my life and is vital to my recovery. I'm not willing to sacrifice my relationships to schizophrenia or to medication side effects so I need meds that won't interfere. |
| Samuel | Music helps relax me. I need to listen to music in order to recover. Listening to music is powerful personal medicine for me. I want to work with you to find a medication and dosage that does not interfere with listening to music. -- Full of happiness, Clearness of expression, Delightful. |
| Maria | Spending time with family relaxes me and makes me feel loved. This is part of how I stay well and is powerful personal medicine. I need to find a medicine that will not interfere. |
| Bernice | Shopping & art are most important to me and are vital to my recovery. We need to find a medication that will support, not interfere with my ability to go shopping and complete art projects. |
| Roberta | Doing my personal medicine daily will help me feel better as a person and is vital to my recovery. We must find a medicine that will not interfere with my opening the blinds, personal grooming and listening to the radio. This will most certainly help with my self-esteem. |
| Mary | Working with people is vital to my recovery. We must maintain a minimal dosage with my medicine. It's not acceptable to sacrifice my job to improper dosage of meds or medicine side effects. |
| Marcus | Being able to shopping for music or food is vital to my recovery. I need to find a medicine that helps me be able to do this and where the side effects don't interfere with my enjoyment of it. |
| Helen | Spending time with my grandchildren is vital to my recovery. We need to work together to find medications that will support, not interfere with my relationships with my grandchildren. |
| Albert | Working is vital to my recovery. I don't want schizophrenia or medication side effects to interfere with being able to work. |
| David | Watching sports helps me relax, focus, and is part of how I stay well; I need to be able to watch sports to recover. Watching sports is powerful personal medicine for me. |

| | |
|---------|---|
| Jason | Being kind and interacting with others while being kind is important to my recovery. You and I must work together to not let my medications or illness interfere with this. |
| Andreas | Art and reading is the most important thing in my life and is vital to my recovery. We need to find a pill med that will not interfere with my ability to enjoy my arts and crafts as it is my personal medicine. |

The fact that Power Statements did not change over time for any of the clients except for Mary may possibly be attributed to process. For example, Samuel's goals for medication clinic were changing over time, but the Power Statement on his Common Ground report was never updated. This was also true for Roberta. In these instances, there was not any specific communication between the prescriber, the case manager, and/or the peer support worker to change the language of the Power Statement to more accurately reflect what the client wanted. Shared decisions were occurring during the medication consultation for these two individuals, it was just based upon the stated request of the client at the time of the appointment, rather than going off what was recorded on the Power Statement on the Common Ground report. Mary's Power Statement changed, but this was because Mary specifically asked for it to be changed. Contributing to this was that Mary also worked as a peer support worker and had an understanding of how the Power Statement was supposed to be used in medication clinic. The Power Statements of William, Marcus, Maria, and Bernice did not change because the statement continued to reflect what they wanted out of medication clinic during the time of the study.

The fact that almost all of the Power Statements did not change over the course of the study can also be attributed to reasons related to practice. The Power Statement is not a part of the Common Ground report that prescribers tend to focus on routinely. As one prescriber states:

So far, that's not been a piece of the system which is useful to me, as is the How I'm Doing Scale and the Decisional Uncertainty Profile and the personal medicines, so I haven't really

pressured anybody to do a power statement, but I have asked people to work on their personal medicine list with their case manager. (P40:131)

What prescribers have tended to focus on primarily is the stated concerns of the client (either reflected in the HIAD Scale or the Decisional Uncertainty Profile), and base the shared decision process off of those concerns. While the stated concerns of the client are important, these concerns are absent of a larger context of what the client finds meaningful or important in terms of their overall recovery.

For the Power Statement to be useful during the shared decision making process the Power Statement: 1) needs to be connected to something that is truly meaningful to the client. For example, William wanted to establish stronger relationships with his family; 2) needs to be validated by the prescriber by making it a focal point for the discussion that ensues around the client's medication. For example, Bernice and her prescriber discussed various options around medications that would enhance her ability to continue doing her art and be able to go shopping; and 3) needs to be updated to reflect the clients changing aspirations and goals for medication clinic. For example, as Mary's focus turned to keeping her current job, her Power Statement changed from a general statement about dealing with side effects to specifically finding a medication that would help her keep her job without disabling side effects.

What seems to be occurring is that the Power Statement only comes into focus during the medication consultation when the client makes it apparent. This works well for clients who are more vocal and clear about what they want out of medication clinic, but this could limit the effectiveness of a shared decision making approach for clients who are less vocal or are not yet clear about what they want out of medication clinic.

Changes in medications during the study

An interesting finding is that all of the participants were able to make a change in medication that they desired at some point during the study with the exception of Roberta. In Roberta's case this was still a desired outcome because she wanted to stay on an older anti-psychotic medication she was currently taking rather than change over to a newer anti-psychotic medication that was recommended by her prescriber. What this suggests is that on some level prescribers were amenable to going along with client's decisions regarding their medication. Table 3 below shows all the medication changes that were made during the course of the study. Medication changes that were specifically requested by the client are noted in parentheses.

Table 3
Medication Changes/Adjustments During the Study

| Client | Medications prior to Common Ground | Medication changes during study |
|---------|---|---|
| William | Haldol Deconate 150mg Benadryl 50mg Haldol PO 10mg | January 2007 - Decreased Haldol Deconate to 140mg (client's request) February 2007 - Decreased Haldol Deconate to 130mg (client's request) June 2007 - Decreased Haldol Deconate to 100mg (client's request) Increased Haldol PO to 15mg (client's request) November 2007 - Decreased Haldol PO to 5mg (client's request – still too sleepy during day) January 2008 - Increased Haldol PO to 10mg (client's request) Decreased Haldol dec to 90mg (client's request) April 2008 - Decreased Haldol dec to 75mg (client's request) Increased Haldol PO to 20mg (client's request) May 2008 - Stopped Benadryl 50mg |
| Samuel | Clozapine 100mg Effexor 75mg (increased to 150mg in March 06) | April 2007 - Increased Effexor to 225mg (clients request) |
| Maria | Amitriptyline 50mg Clonazepam 1mg Abilify 15mg (started in August 06) | March 2008 - Increase Abilify to 30mg (may not be taking it though) June 2008 - Increase Abilify to 45mg (may not be taking it though) |
| Bernice | Zoloft 200mg Remeron 30mg Risperdal 4mg Trazadone 200mg | January 2007 - Stopped Risperdal 4mg Started Invega 12mg (client's request because Risperdal didn't seem to help with symptoms) May 2007 - Increase Trazadone to 300mg (client's request to help with sleep) |
| Roberta | Prolixin 10mg Artane 2mg (helps with head tremors) | No changes |
| Marcus | Risperdal Consta 50mg | April 2007 - Added Seroquel 25mg (mother's request) |

| | | |
|-------|---|---|
| | | <p>August 2007 - Added Abilify 15mg (client's request)</p> <p>Stopped Seroquel 25mg (client's request)</p> <p>Stopped Abilify 15mg (client's request – concern about side effects)</p> <p>September 2007 - Started Risperdal PO 1mg (client's request - only takes PRN)</p> <p>November 2007 - Increased Risperdal PO to 2mg</p> <p>December 2007 - Increased Risperdal PO to 3mg (client already started doing this on own)</p> <p>February 2008 - Increased Risperdal PO to 4mg (client's request)</p> <p>April 2008 - Increased Risperdal PO to 5mg (client's request)</p> |
| Mary | <p>Geodon 320mg</p> <p>Lamactal 100mg (stopped in July 06 – developed rash)</p> <p>Prozac 20mg</p> <p>Gabitril 4mg (stopped in October 06)</p> <p>Buspar 20mg</p> | <p>January 2007 - Stopped Prozac (client's request)</p> <p>February 2007 - Decreased Geodon to 200mg (client's request)</p> <p>March 2007 - Decreased Geodon to 180mg (client's request)</p> <p>Started Benadryl OTC 50mg (to help with akathesia)</p> <p>Decreased Geodon to 160mg (client's request)</p> <p>May 2007 - Decreased Buspar to 15mg PRN (client's request)</p> <p>August 2007 - Decreased Geodon to 140mg (client's request)</p> <p>September 2007 - Increase Buspar to 30mg (client's request)</p> <p>February 2008 - Increase Buspar to 45mg (client's request)</p> <p>March 2008 - Increase Buspar to 80mg (client's request)</p> <p>May 2008 - Started Vistaril 50mg (client's request)</p> <p>June 2008 - Started Prozac 10mg (client's request)</p> |
| Helen | <p>Abilify 15mg (stopped in November 06 – clients request)</p> <p>Effexor 150mg</p> <p>Xanax .5mg PRN</p> | <p>January 2007 - Increase Effexor to 225mg (prescribers recommendation because of risk of suicide)</p> <p>February 2008 - Helen reduced Effexor to 150mg on own. After discussion with prescriber, she agreed to go back to 225mg (she stated she actually felt</p> |

| | | |
|---------|--|---|
| | | better on 225mg) |
| Albert | Haldol Deconate 50mg Haldol PO 5mg Cogentin 1mg Diazepam 10mg (Stopped prior to study) Seroquel 300mg (Stopped prior to study) Amantadine 100mg (Stopped prior to study) | January 2007 - Increased Haldol Deconate to 75mg July 2007 - Increased Haldol Deconate to 100mg (went into hospital) August 2007 - Stopped Haldol PO (wasn't taking) September 2007 - Start Seroquel XR 300mg (in order to start decreasing Haldol) October 2007 - Decrease Haldol Deconate to 75mg (client's request) Stop Seroquel XR 300mg (wasn't taking) May 2008 - Increase Haldol Deconate to 150mg (went into hospital) |
| David | Risperdal Consta 50mg (Decreased to 37.5mg in Dec 06) Lexapro 30mg Risperdal PO 2mg (started in May 06) Cymbalta 60mg (started in May 06) | February 2007 - Stopped Cymbalta 60mg July 2007 - Started Lexapro 20mg September 2007 - Stopped Lexapro 20mg (client's request) July 2007 - Stopped Risperdal Consta 37.5mg January 2008 - Stopped Risperdal PO 2mg Stated Risperdal Consta 37.5mg |
| Jason | Risperdal Consta 50mg (stopped in March 06) Geodon 80mg (stopped in July 06) Seroquel 900mg (stopped in July 06) Haldol Deconate 200mg (started in September 06) Benadryl 50mg (started in October 06) Propranodol 10mg (started in October 06) | September 2007 - Stopped Benadryl 50mg (wasn't taking) Stopped Propranodol 10mg (wasn't taking) November 2007 - Started Benadryl 50mg December 2007 - Started Propranodol 10mg April 2008 - Decreased Haldol to 175mg (client's request) |
| Andreas | Abilify 15mg Zyprexa 15mg (stopped in April 06) Trazadone 50mg Risperdal 3mg (stopped in November 06) Cogentin .5mg (stopped in November 06) Seroquel 600mg (started in November 06) | May 2007 - Changed Seroquel to 300mg BID (client's request) September 2007 - Decreased Seroquel to 300mg once a day (client's request) |

When the shared decision making process works well, there is: 1) an identified goal for the medication consultation (the Power Statement) that the prescriber and client can both focus on; and 2) concrete action steps that can be taken to help the client to achieve that goal. William is a client for whom the shared decision making process worked well. William's Power Statement reflected the importance of spending time with his family which he was not able to do when he was not feeling well. At the same time, the Haldol injections which he was prescribed were negatively affecting these relationships because he felt drowsy and lethargic most of the time. William went into the Common Ground process wanting to make a change in medication that would help him feel well enough to spend time with his family, but not sacrifice the quality of those relationships to the side effects he was experiencing on his current medication.

William had been on Haldol injections for most of his life. William says, "I've been getting, you know, shots every, about for 20 years...ever since I was 18. I'm 43 now" (P11:20). This was not a decision made by William. William was put on an outpatient court order because he would regularly stop coming in to receive his injection, then would become violent towards his family and others and eventually go back into the hospital. William perceived that the medications were being forced on him:

That was like in some of these hospitals...Every time somebody bother me and they think it's my fault they'll rush me some medicine, even after I went in there and got some or they tell me I need it prn and the next thing you know I'm into it and they're rushing me some more. You know what I mean? I didn't like that. I had it done to me quite often. (P11:66)

When the Decision Support Center started up, William's case manager helped him construct a power statement which said: "My family is the most important thing in my life and is vital to my recovery. I'm not willing to sacrifice my relationships to schizophrenia or to medication side effects so I need medications that won't interfere." Prior to the Decision Center, William was in a cycle of coming in grudgingly for his monthly injections because of the outpatient court order.

Now, William had a language he could use to describe why he might be willing to take any medication and what the parameters would be that would gauge their effectiveness. William's case manager states:

Before it was you have to get your shot and he just complained that he had to get the shot and didn't really see any real benefit in it and didn't think he needed it. But when you put it on the level of how it affects his family and he actually was able to meet with me and discuss how this affects his relationships, he's more invested in making sure that he's actually on his medicine and is not, because he has a real tight relationship with his nephews and his nieces and when he's not on his meds they are all scared of him and he doesn't like that. (P32:50)

While William was starting to come to an understanding of how the medications were helpful in maintaining important relationships with his family, he still did not like the idea of taking the injections. He says:

I've been on the needle too long...I've been in and out of here since I was 18. Well, they just take the needle and just, you know, and I didn't like that part of it and I just got tired of it. (P11:28)

Using his power statement as a guide, William decided to ask his prescribers if he could stop taking the injections and try an oral medication instead. He says:

I asked them if there was a chance that I could be off the shot, because I've on that for twenty years, and they said, well, do you want oral? I said, yeah, I should go with oral. They said, we'll see how you do once you get off of the shot, and slowly, gradually take you off of it. (P25:62)

William talks about the prescriber's response to changing William from the injection to pill medicine:

No problem. It's just going to decrease it to where my shot going to be lower, and then they give me the oral medicine, and eventually the shot medicine is going to be lowered to where I won't have to take the shot. I'll just be on the oral. (P25:50)

William's prescriber admits this wasn't an easy decision to go along with for medication clinic staff. Because of William's history of non-compliance with medication, coupled with his violent history and the presence of a court order, traditional protocols would have called for declining

William's request. But his prescriber's buy-in to the Shared Decision Making process had oriented her toward placing client self-determination at the forefront and considering the possibilities of making this happen. The prescriber says:

It's so scary because he wants a lower and lower and lower dose of Haldol and if he is on out-patient court order I feel like I have a higher level of responsibility to the community versus respecting his desire to lower the Haldol. And it's so tough because he does become extremely violent when he isn't doing well and it's such a tightrope. But at least I feel comfortable talking to him about that. (P39:67)

By exploring the possibilities, and putting together a plan of what William and his various treatment team members would do during the transition, the gradual movement from injection to pill medicine was entered in as the shared decision between William and his prescriber.

William's prescriber agreed to slowly reduce the dosage of his Haldol injection at each monthly medication consultation, in addition to slowly introducing and increasing the dosage of an oral medication. William agreed to work with his case manager to increase the personal medicine he was using and also to answer the questions on the Common Ground report each month to gauge how he was doing. Together they would review the Common Ground report during each visit and use that to guide their future discussions. William says:

I'm living with my sister and once I get my place, you know, I'll just keep my meds there and take what was required to take and watch the street drugs and alcohol and all that because I ain't no big alcohol or street drug person. I watch that and I just try to stay, but as soon as I start feeling depressed or blue or somebody bothers me, you know, that machine will let them know that I ain't the same as I was when I was taking the shot or if I was taking the shot. (P11:38)

During the course of the study, William was able to effectively eliminate taking the Haldol injections and solely use the oral medication and his personal medicine to deal with symptoms he was experiencing. William moved into his own apartment and even considered going back to work. One thing that William's noticed was that he was starting to feel fatigued on his oral

medications which hindered him from doing things that were important to him. William talks about his experience with the oral medications:

It helps me a little bit too much, because I've been sleeping a lot. She took me off one of my orals to try to get my energy back and reduce my sleeping, because I was going to try to go to work. (P25:98)

William talks about how medication clinic staff have been a support to him:

They go on the computer, and then they read out my results. I mean, they give me my results to me, and I give it to the nurse or (my prescriber). And then, they'll look at my results, has anything changed, or...what they want to talk about...it's going pretty good. You know, it's fortunate...because they give you an outlook on whether...you need to go in the hospital, you need your medicine reduced, or you need to see the doctor. But, you see the doctor every time you go in. But, it's pretty good, they're a support group. (P25:110)

William mentions that medication clinic staff always ask him about his power statement and personal medicine each time he comes in:

Yeah, they do. They always ask me have I been with my family, and was I listening to music any time too soon, or did I take a walk, you know, exercise. (P25:118)

The dynamics that are at work here in William's situation is a clearly stated Power Statement that serves as a focal point for William and his prescriber in terms of discussions at medication clinic. This Power Statement is acknowledged by William's prescriber and concrete steps are taken to help him find a medication that will help him meet his goal of spending time with his family. In the past, the prescribers focus had been on the reduction of symptoms. While the Haldol injections had impacted the symptoms, this medication introduced side effects that William found intolerable. In the past, William's response would be to disengage from medication clinic and stop coming in for his injection. This would lead to William eventually being hospitalized and being reintroduced to the injections. The dynamics of the mental health systems interactions with William changes once the Power Statement is acknowledged as the overarching goal for William. As William feels heard by his prescriber and concrete action steps

are taken to help William achieve his goal, he starts to become more engaged in medication clinic. As he views the Common Ground report as being instrumental to him achieving his goal, he begins to invest more energy in paying attention and completing the report. The additional information that he provides also increases the quality of discussions between William and his prescriber.

Bernice is another client for whom the shared decision making process has worked well. As with William, what was expressed by the client through the Common Ground report was heard by the prescriber and concrete steps were taken to help the client achieve her stated goals. Bernice was able to construct the following Power Statement with her case manager: “Shopping & art are most important to me and are vital to my recovery. We need to find a medication that will support, not interfere with my ability to go shopping and complete art projects.” In Bernice’s situation, doing her art and shopping were things that kept her well in the past. While she had gotten away from doing these things prior to the start up of Common Ground, she developed a renewed interest in taking better care of herself in order to better care for one of her sons who had recently moved back in with her.

Her case manager talks about how this desire to better care for herself because of her son led to her involvement with Common Ground:

She was pretty reclusive when I first got her. She was in and out of the hospital constantly. She really didn’t talk much and you couldn’t get much out of her. And she was just there. But she wasn’t invested in doing anything. As she started becoming more involved with the decisional support center and personal medicine, she’s actually become more vocal and more involved in a lot more programs...And so one of the factors that prompted her to be more involved, her adult child moved back with her. And he has bi-polar disorder and some other mental problems that she feels she has to manage. So in order to assist him, she figures she needs to manage her own symptoms better in order to be an effective assistant to him because she feels like when she was younger she didn’t speak or fight for him as much as she should have because she didn’t know what was wrong with him. And so...she’s trying to make up for what she didn’t do in the past. (P32:90)

As with William, a context has been set which draws both Bernice and her prescriber into a mutual discussion during medication clinic. The overarching goal for Bernice is to be able to care for her adult son, so her primary goal brought to medication clinic is to find ways to better care for herself in order to do this. Through her Power Statement she has identified a few means that help her to stay well.

Some important factors are at work here that make the shared decision making process work. First, there is a reason for Bernice to actively engage in medication clinic whereas prior to Common Ground, she passively went through the motions of attending medication clinic appointments, getting her prescription, and leaving. The format of Common Ground facilitates clients being able to make explicit the reasons for seeking help at medication clinic. Second, there is a mechanism for prescribers to become actively engaged in what really matters most to the client. In Bernice's situation, the prescriber is tuned into Bernice's renewed interest in finding ways to better care for herself in order to care for her son. Third, there is a mechanism to evaluate progress on whether decisions made are actually helping the person achieve their stated goal.

Guided by Bernice's Power Statement, Bernice's prescriber started to discuss with her how each of the medications she was currently taking helped her with symptoms that were interfering with her ability to do her art and shopping. Bernice communicated that the Risperdal was not doing anything for her and asked that it be discontinued. Bernice also marked on the Common Ground report that she was not getting enough sleep which she felt contributed to her symptoms at times. Bernice's prescriber took her off the Risperdal and added Trazadone. Bernice talks about these changes that were made:

We felt it (Risperdal) wasn't doing as much, because I still wasn't sleeping, but they were trying to get me medicine that would help me sleep more, so they added Trazadone and

pped the dosage. I do get more sleep than I was getting....That's been a problem for me. (P28:178)

Bernice remained engaged in medication clinic, just as William did, because each medication visit was viewed as an opportunity to make progress toward their stated goal. Contributing to Bernice's increased involvement in medication clinic was the fact that her prescriber was paying attention to the concerns she marked on the Common Ground report. Bernice says, "One thing, I'm giving all the answers and I'm seeking the help when they get the paper. This is what I have said that's wrong and I'm concerned about" (P1:208).

Like William, Bernice is placed in a role of self-determination at medication clinic. She has determined her goal for medication clinic. It is her expertise that is brought to the forefront in terms of what she is experiencing and what might be keeping her from reaching her goal. Bernice's prescriber reinforces this position of self-determination by helping her look at options to staying well so that she can achieve her goal. Bernice's satisfaction in medication clinic increases because she likes that they give her options to choose from. She states, "They do a lot of talking and asking and ask me even about the medicines, if I want to try it and give me a say so. I like that" (P28:290).

An important aspect of the shared decision making process is that the client has the final say in what medication they accept and which they will not. Bernice confirmed that she gets the last word on the decision at medication clinic. She says:

I mainly get the last word. Unless it's something that a doctor needs to do or say. But he discuss with me like if I want my meds to change. Now they are letting us make decisions and if I want to continue with this same plan...The last three visits it seems like I've been pretty much in control of everything. (P1:86-88)

And also:

I just usually go in there and just talk and say what I need to say, and they ask me a lot of questions, and we always decide on the medicines kind of together, and they do, usually,

give me the last (word). I have never had one say, well, this is what we're going to do without letting me have a say so. (P28:302)

In the past, Bernice has not always had control of the decisions that were made for her.

Bernice was also not as engaged in medication clinic prior to Common Ground as she is now.

The fact that her prescribers are working with her around an area that she finds important and steps are being taken to help her achieve her goals contributed to Bernice's further engagement with Common Ground. Also the fact that she perceives that she has control in the decisions that are made contributes to her satisfaction with medication clinic.

The same dynamics are present with other clients for whom the shared decision making process has worked well. For Mary, Maria, Samuel, Roberta, and to some extent Marcus, there was a goal present that guided discussions that eventually led to a shared decision regarding medications. For example, Mary wanted to keep her current job and wanted to find a minimal dosage of medication that would help her effectively manage the symptoms she was experiencing but without side effects that would negatively impact her ability to work. Maria wanted to spend more time with her family. She wanted a medication with minimal interference for her being able to do this as well as alternative options for staying well. Samuel wanted to find a medication and dosage that would help him manage symptoms as well as enjoy everyday life activities. Roberta wanted to be able to care for her son and was willing to tolerate a high degree of side effects as long as the medication kept her symptoms in check so she could do things with her son. She also wanted to find activities that would help her stay well besides just taking medications. Marcus did not have a specific long term goal, but just wanted a medication that would allow him to continue to enjoy the things that currently brought him peace in life.

More importantly than just having a goal, which is also present with some of the clients for whom the shared decision making process did not work as well, the treatment team (prescriber,

nurses, and case manager) all acknowledged this goal and it was kept at the forefront of the decision making process. Specific action steps were taken during each medication consultation that related to the goal the client desired to achieve. An evaluative process was used (i.e. client input through the HIAD scale and the Decisional Uncertainty Profile) to assess whether progress was being made toward achievement of that particular goal.

Achievement of the goal was also something each of these clients was passionate about. Bernice and Roberta were both passionate about caring for their children, Mary was passionate about working, Maria and William were passionate about wanting to spend time with their families, Samuel and Marcus were both passionate about wanting to enjoy life. The passionate nature of their goals sparked an internal motivation that renewed their investment in caring better for themselves, which included the management of specific symptoms. For each of these clients, managing symptoms was not their primary goal, but rather secondary to something else that had meaning or value in their life. While these goals were most likely held by the clients prior to Common Ground, the Common Ground process brought these goals into focus and made them relevant to discussions around medications.

What worked well was that the above clients saw a connection to using the Common Ground report in helping them achieve their stated goal. The fact that there was a passionate goal present, which was acknowledged by prescribers, and using the information reported by the client on the Common Ground report to move toward that goal, seemed to facilitate an increased use of the report by both the client and the prescriber.

For the clients for whom the shared decision making process worked well, we find clients who perceive they are in control of the process. It is their goal, their input, and their decision that is acknowledged and valued within the medication consultation. A feeling of satisfaction

with the process developed over the course of the study for William, Bernice, Mary, Maria, Roberta, Samuel and Marcus. This is especially noteworthy since all of these clients except for Samuel had expressed not feeling in control of the decisions that were made prior to Common Ground. Samuel had experienced not being in control of his decisions in the past at a different mental health center, but not in the three years since he arrived at the mental health center in the study.

Trust and a positive working relationship were also developed between the client and the prescriber as the Common Ground process unfolded over time. While this positive relationship existed prior to Common Ground with Samuel, Bernice and Marcus and their prescribers, this was not the case with Roberta, Mary, William, and Maria. Roberta, Mary and William initially withheld information from their prescribers until they perceived that the environment was safe for them to communicate what they were experiencing and action was being taken to respond to their concerns and the outcomes they desired. Maria did not necessarily withhold information at the startup of Common Ground, but did not necessarily feel heard. When her prescriber started to become more in tune with what she wanted, she became more comfortable with her prescriber and started opening up more during the medication consultation. Once again, the presence of an agreed upon goal and specific action steps taken toward achieving that goal contributed to a more positive working relationship built on trust.

For Albert, David, Helen, Jason and Andreas, the shared decision making process did not work as well. One commonality among these clients is that there was not an agreed upon goal that guided discussions during the medication consultation. Each of these clients developed Power Statements with their case managers at the startup of Common Ground, but it either did

not come to the forefront during the shared decision process or was not molded into a statement that the client could fully invest in.

For each of these clients, the Common Ground report did not become a routine part of discussions at medication clinic. For starters, each of these clients was initially skeptical of using the Common Ground Process to begin with. This is not unlike some of the clients for whom the process did work well, such as William and Roberta, so it doesn't completely explain the breakdown in the process. These clients were less likely than the other group to be actively engaged in other services at the mental health center (e.g. case management, peer support groups, psychosocial groups, etc.). They also tended to be more sporadic in coming to medication clinic even prior to Common Ground, though William was similar in attendance from among those for whom the process worked well.

The major factors that seem missing with the clients for whom the shared decision making process did not work well is the presence of an agreed upon goal to guide discussions within the medication consultation and specific action steps taken toward achieving that goal via shared decision making. Albert is an example of this. Albert's initial Power Statement read: "Working is vital to my recovery. I don't want schizophrenia or medication side effects to interfere with being able to work." Albert had tried going back to work shortly prior to the start up of Common Ground, but was unable to keep the job due to side effects of medication. He says, "Three months ago, dishwasher job. I liked it, just couldn't do it. I had to quit" (P30:123,131).

The Haldol injections he was prescribed had caused some severe pain in his joints which made it difficult for him to move around. Even though Albert's Power Statement of going back to work remained at the top of his Common Ground Report during each of his subsequent visits to medication clinic, it was never mentioned in any of the prescriber's progress notes. What

ensued was Albert becoming increasingly frustrated with taking the medications he was prescribed.

Albert communicated that he was unaware of why he was even taking medications. He reports:

I sure don't. I just listen to them and they go over my head. Just take this medication and go home. Let me give you your shot so I can get you out of here. But they keep reminding me when I need to take the shot. Because I go off. Nobody gives me (a) reason....because I go off. And maybe that's the reason they give it to me so I won't go off. (P30:237-245)

Albert regularly stops taking his medication because he doesn't find it provides him any benefit and the side effects he finds completely unacceptable. He states:

I don't know. The medication I'm taking right at this time hurts me and I let her know that this is, this is not right. Because it hurts me and I'm not supposed to be hurting from this medication. I have let her know. And she's dealing with it right now to find some other medication that I would be comfortable with. (P16:170-172)

And also:

I haven't been taking the Haldol. It makes my neck hurt. I had brought it to her attention. I had brought it to her attention that it makes my neck stiff and hurt. So I quit taking the Haldol and I told her I had quit taking it. So she said Cogentin will stop that. (P16:184-194)

Albert finds himself in what Pat Deegan (2005b) calls a Side Effect Trap. Albert wants to work, but finds that certain symptoms keep him from doing this. As Albert states, "Visions of people messing with me and just hearing voices. I'm not comfortable yet. I'm not comfortable yet around the people" (P16:216-220). So Albert seeks help from medication clinic and puts his desire to work on his Power Statement as the reason he is seeking help. But he is put on a medication that neither helps with the voices nor his ability to work. In fact, the side effects he experiences are as equally disabling for him being able to work. So he stops taking the medication and eventually he becomes overwhelmed by the symptoms again.

Without a goal providing a context to discuss medications with Albert, the focus at medication clinic remains centered on symptom reduction, which had been the traditional focus prior to Common Ground. But why would Albert want to manage the symptoms he is experiencing? Albert offered this piece of information during his initial Power Statement when Common Ground first started. He wanted to be able to work.

Albert finds it difficult to stay engaged in medication clinic because there is not anything passionate for him to invest in. He stays at home struggling with the symptoms. When asked about his current life situation he responds, “Rough. I’m out of work, too. Just sitting at home doing nothing. Every day it’s rough. In pain, in pain, in pain” (P30:117). He does not perceive that coming into medication clinic offers him the help that he desires because he perceives he is being forced to take a medication that is not helping him. While Common Ground is intended to help the person become more involved in guiding their care, Albert does not perceive this to be occurring. He states:

Everybody is trying to tell me what to do, but I have to do it myself. Nobody, don’t control my life. Then the experience, if it’s wrong, I will try to make it up where it be right...I was sent down to Larned (State Hospital). I was sent to Osawatomie (State Hospital) and they told me what to do. And I didn’t like it. (P16:228-234)

Albert’s current experience of the shared decision making process is that it’s a continuation of the treatment that he previously received. Albert’s former case manager talks about Albert’s negative experience with medication prior to Common Ground:

He still has all the symptoms, and he needs some help with that, and they’re saying, the only option you have for that is pills, and he’s saying, ‘I told you that I’m not going to take the pills’, because he’s somebody that said he was taking pills and they weren’t working, and so they increased them, and they weren’t working, and he finally went to the hospital, and they gave him the dose that we said we had prescribed for him, and it almost killed him. It was too high of a dose to start at, so he stopped breathing, and he had to go to the emergency room. (P34:291)

And also:

He's just, 'they tried to kill me', but he consistently says, I don't want pills, and they consistently tell him that's the only option you have, and not considering that the shot that he's on isn't necessarily what's working or even really talking to him about that as much. He's on the Haldol shot. And, that's the one that he's been on for years, but they're considering, they're recognizing, that he might not be responding to that, instead of just increasing it to the point that his joints hurt. (P34:299-303)

While Albert's treatment team has still not engaged with him around a common goal, such as going back to work, there are certain aspects of the shared decision making process that are keeping him engaged in the process. Over the last few months of the study, Albert was assigned to a new case manager and a new prescriber. Reviewing Albert's Common Ground reports over time, the treatment team is starting to acknowledge Albert's statements that the medications are not helpful. This has opened the doors to look at alternative options via the shared decision making process. As his case manager states:

Albert is interesting, because, he was somebody that would not give the full picture when he went into med clinic. He's been in the prison system, so he is very used to telling people what he thinks they want to hear, and so, but that report kind of shows a different picture than what he's telling, and, so, that helps the staff to be able to say, I hear what you're saying, but, your report is also saying something different, so, what's going on...is there something different we can look at here. He's been on the same medication for years and years and hasn't been responding to that very well, and I think, through this system, and through his feedback through that program, they've finally come to the point to say, well, maybe this isn't the best choice for you. Can we try something different? So, I was pretty excited about that. (P34:175)

It's possible that things might begin to work better for Albert. For starters his new case manager has a positive working relationship with him and has validated Albert's reasons for not wanting to take the injections he has been prescribed. His current case manager states:

He feels comfortable in me asking him those concerns and then sharing information with me about why he doesn't want to take it. Because, when we met last week, it was so funny. He was like, 'I'm not going to med clinic.' I was like, 'okay, why are you not going to med clinic?' 'Because, I'm not doing the shot anymore'. I was like, 'okay, Albert'. And, I was like, 'well, are you comfortable with me going in with you to your med clinic appointment to...help you convey the reason why you don't want to do the shot anymore?' And, he's really up front about his beliefs or why he doesn't want to do the medications. (P35:162)

Albert's case manager discussed Albert's concerns with his nurse who in turn advocated for the dosage of his injection to be lowered, which was. His case manager talks about these events:

Actually, (his nurse) advocated for his Haldol shot to be decreased. And, that's what they did. And, he was actually scheduled to come in to med clinic this week...and he's willing to allow me to go in with him, so he can convey his concerns to (his prescriber) about not wanting to do the shot. Because, he really wants to come off of the Haldol shot... and he reports that he's not taking his Seroquel anymore. He stopped taking his oral medication, so, I think he's just going through some...uncertainty right now about what meds he thinks will be best for him. (P35:150-154)

His case manager talks about prescribers not forcing clients to take medication. Here she talks about Albert telling them he wasn't taking the Seroquel anymore:

Well, he wasn't taking it anyway, so we really can't force them to take it, and there's no use in having him get mad that he's not taking it anyway. So, I believe they discontinued the Seroquel. And, so, if I'm not mistaken, (my supervisor) said that they now was probably going to look at trying to do something different anyway, because it doesn't look like he's responding to the Haldol. He's been on it for years, I believe, if I'm not mistaken, for a very long time, so it doesn't look like he's an optimal responder to it, so, they're going to try something different, hopefully, in the near future, if he's willing to, anyway. (P35:166)

The case management team's supervisor mentions that Albert wouldn't do Common Ground if he didn't have to:

He wouldn't do it. Because, he's tried to talk me into why he doesn't need to do it. But, our position has been, well, this is how med clinic works, now. It's for your relationship with med clinic. (P34:175)

The case management team's supervisor talks about how prescribers adjusted to language that Albert was more familiar with:

Well, Albert is a good example...one good thing about this is that they talked to him in terms that he understands at this point. It's not, are you hearing, do you have more auditory hallucinations? Yeah! Are you hearing the T.V. talk to you, you know. Is the lady talking to you, are people threatening you. (P34:283)

She also says that now they are in a holding pattern with Albert:

But, this month, he is not wanting to take it all, and the last visit he said, if you would just take me off of it all together, because he doesn't believe that it works, which there's evidence for that. (P34:307)

She says this has continued since Common Ground started with Albert, but at least he is now coming back in to discuss his decisions with the prescriber:

Yeah, he was doing that at that point. He was just, no. And, he came in, did the report, and said, I'm not getting a shot. Oh, it's been a couple of months that he's had it. I'd say two months in a row, now, but he's saying he's not going to come back in this month....So, maybe that's been an improvement for him, just that he feels, because I know, before we started this program, that he would just not come back, but now he feels like he can go in and say, I'm not going to take it. (P34:343-355)

Albert talks about his role in making decisions about his medications:

After she evaluates me and talks to me, I make my own suggestion about what I'm going to do about the situation. Then sometimes I make the wrong decision and then I have to back up and go another way. That's all that I, I'm bothered by people, and I try to deal with that at the certain time. But I'm just this way. No other way I can be. It's not going to be no other way. I'm going to be this way and this is who I'm going to be, whether you like it or not. You're not changing me for nothing. (P16:152-166)

A possible factor to consider is that prescribers might have an easier time with the shared decision making process when a medication can be found that works to alleviate symptoms. There seems to be a difficulty in Albert's case, because he does not seem to respond to any of the medications that have been tried. It's almost as if there is a reluctance to discuss the possibility of aggressively pursuing non-pharmacological options without the use of medications for non-responders. Prescribers seem to view in Albert's case that some type of anti-psychotic medication (pill or injection) must be used. For Albert this is an obstacle into further engagement with him in medication clinic. He doesn't want pill medication and none of the injections tried to this point have been helpful. While it appears that Albert is simply non-compliant, from Albert's perspective the medications are not working and therefore not worth taking, especially considering the side effects he experiences.

A critical absence seems to be in the fact that a context is missing for discussing well-being with Albert. Albert has identified through his Power Statement that work helps him to feel well.

But the discussions in medication clinic revolve around symptom reduction. It seems that work should be the guiding factor and symptoms should be placed into the context of how it interferes with his ability to work. Common Ground could be used as a tool that allows Albert to express how his symptoms are interfering with his ability to get and keep a job. The HIAD scale could be tailored toward this.

We see the same difficulty with David, where there is not a specific context to guide discussions around use of medications. David mentions in his Power Statement that, “Watching sports helps me relax, focus, and is part of how I stay well; I need to be able to watch sports to recover. Watching sports is powerful personal medicine for me.” Yet, medication clinic and case management progress notes do not reveal that helping David use this personal medicine as being the focal point of medication clinic visits. As with Albert, the focus turns again to symptom reduction. For David there has been no difference since starting the Common Ground process:

It hasn't been any different. Except for the computers, it's all the same as it always has been. I go in, they ask about the medications, they say what they think I should be taking and they write out a script. Not really much difference. (P21:88)

Rather than a passionate goal to drive David forward, David's sole reason for remaining engaged with medication clinic is to avoid being sent to the hospital. As David states:

I don't always agree with the decisions, but I accept what they say. They are the experts in what they do. I may not always like the decision they have for me, but the alternatives are being here and I don't like being here. (P21:90)

David talks about why he accepts the decisions made in medication clinic even when he doesn't agree with them:

I do what I have to do. It's more important to be free and living your life than worrying about every decision that's made. If I take the medications then I can go on being who I am. (P21:92)

As with Albert, partial aspects of the shared decision making process are being followed. David does mention that they listened to him in regards to one medication he didn't want to take anymore. He states, "I mean they did listen to me on the Lexipro and got me off of that. So they do try to listen to your concerns, but as for the decision...I don't always agree with it" (P21:90). The focus of David's treatment team seems to be around how to get him to take his medications without understanding David's framework for even considering medications as an option. David talks about what his ideal life would be like:

Have my place...watch some sports, get out of the apartment from time to time, have some people to talk to...just a regular life. (P21:96)

This is the context to engage David in discussions around medications and David has revealed this partially in his Power Statement. Without the Power Statement guiding the discussion at medication consultation, a struggle between compliance and non-compliance resumes.

David's case manager discusses David's lack of involvement with decisions at medication clinic:

It's difficult to get him to see that because he really doesn't care to see if it makes a difference because he really doesn't care. And according to him, he wouldn't even be taking medicine, but he's on a court order so due to the court order he takes the medicines so he doesn't have to go to the hospital. (P32:122)

Is it that he doesn't care, or does David just not see how medication clinic can benefit him?

David does not perceive the medications are helping him and he does not perceive medication clinic staff or his case manager are listening to him. David's goals for life are not at the forefront of medication clinic discussions.

Conclusion

The centrality of the goal seems to be an indispensable component of the shared decision making process. In fact an argument could be made that without the presence of an agreed upon goal, true shared decision making does not occur. While there were decisions where both

prescriber and client concurred within the group that was not highly involved in the Common Ground process, these decisions lacked several elements that are commonly associated with shared decision making including: discussion of the context or nature of the decision, exploration of the client's preference, discussion of the alternatives, discussion of uncertainties, and assessment of the client's understanding of the decision made (Braddock, Edwards, Hasenberg, Laidley, & Livinson, 1999). In many instances, the prescriber agreed with a client decision because the client had already decided not to take a particular medication. Prescribers were inclined to go along with client choice, barring any perceived negative consequences (i.e. acute psychosis requiring immediate hospitalization or perceived danger to self or others), because of their training in Common Ground. But what was missing amongst the group that was not highly involved in Common Ground, was an interaction between client and prescriber where the context of making these decisions were fully understood by both parties. In many ways the decisions made were a reaction of one party to the other, either the prescriber acquiescing to the client's action or the client accepting the prescriber's decision without fully consenting. These interactions also lacked the mutual sharing of information based on the Common Ground report that fully explored the values, preferences, uncertainties, and personal experience of the client, as well as the range of options that existed for helping the client achieve a stated goal or addressing a stated concern. The decisions lacked a context, derived from the Common Ground report, that afforded each party a role in the decision making process. Without this context and established roles, there was rarely any continuity from one medication consultation to the next where the understood context could unfold and decisions be subsequently evaluated.

While the shared decision making process did not necessarily unfold as completely or distinctly as the process is ideally described in the literature, basic elements of what is considered

a shared decision generally occurred. The identification of an agreed upon goal was the hinge pin that united all the client participants for whom the process worked well. It brought relevancy to various aspects of Common Ground that contributed to shared decision making around this goal.

A question that is not completely resolved is why some prescribers engage in this shared decision making process with some clients but not others. One explanation is that clients are bearing the burden of creating the context for shared decision making to occur and keeping this context at the forefront of medication clinic discussions. When prescribers perceive that the client is engaged with using Common Ground and the client is enthusiastic about achieving something, the prescriber's energies are directed toward using the various elements of Common Ground to which the client is engaged to help the client achieve their goal. If the client is not engaged with Common Ground, the relevancy of Common Ground seems to be reduced to answers the client gives on the HIAD scale, which at least allows the prescriber some context for making a decision. Prescribers do not seem to elevate the importance of the client's goal or the Power Statement, unless the client makes this explicit to the prescriber and keeps it at the forefront of medication consultation discussions.

On the other hand, prescriber's actions are critical to the process as well. Even if clients provide information to frame a context for decision making, the prescriber must acknowledge this goal or concern that the client has stated and work with the client to take concrete steps towards achieving the goal or addressing the concern in a way that is satisfactory to the client. Prescriber's belief in the client's ability to achieve a particular goal could possibly be a factor or even the prescriber's belief in the client's ability to participate in shared decision making around a particular goal.

In the next theme, a particular element of Common Ground that distinguished the two groups is explored. This element, personal medicine, may further explain prescriber's varied actions in the shared decision making process.

Theme 4: The concept of personal medicine shines a new light on ordinary activities and causes a transformation in philosophy and practice that empowers clients in a new way.

In a qualitative study by Deegan (2005b) on the resiliency of people with psychiatric disabilities, a major finding was that when research participants were asked to describe their use of psychiatric medications, they also described what she termed personal medicine. Deegan defined personal medicine as “self-initiated, non-pharmaceutical self-care activities that served to decrease symptoms, avoid undesirable outcomes such as hospitalization, and improve mood, thoughts, behaviors and overall sense of well-being (2005b, p. 31). Deegan identified two main categories of personal medicine: 1) activities that gave meaning and purpose to life (e.g. singing in a choir, spending time with children, taking college classes, having a job, etc.); and 2) specific self-care strategies (e.g. exercising, meditating, changes in diet, etc.).

The concept of personal medicine was introduced to staff at the mental health center prior to the actual start-up of the Decision Support Center through a series of trainings and on-going meetings. Case managers, specifically, were asked to complete Personal Medicine Worksheets with every client that was participating in the Decision Support Center. These worksheets asked for responses to the following statements:

1. The things I do that make my life worth living are:
2. The things that make me feel good about being me are:
3. The things I most enjoy in my day or week are:
4. When I’m feeling unwell, the things I do that help me feel better are:
5. If you were to photograph the things you enjoy in your life, what would you take pictures of:

The answers to these statements were the client's personal medicine and these were listed in the order of importance to the person. The completed sheets were then submitted to the peer specialists at the Decision Support Center who entered them into the proper fields of the Common Ground Software. Clients were able to view their listing of personal medicine when they logged on to the computer at the Decision Support Center and could respond to whether they had used their personal medicine since their last medication consultation (i.e. yes, no, or sometimes).

Each of the twelve clients in the study, except for one (David), had personal medicines listed on their Common Ground Report (see Table 4). Six of the clients (Bernice, William, Mary, Marcus, Samuel, and Roberta) were very familiar with the term personal medicine, actively used them in their daily life, and understood their importance in contributing to their personal well-being. Two of the clients (Maria and Helen) were unfamiliar with the term, but were using what we would call personal medicine to help with symptoms and promote their own well being. The remaining four clients (Albert, Andreas, David and Jason) were not only unfamiliar with the term personal medicine, but also did not seem to be using a personal medicine with any consistency to consciously promote their well-being.

What is of significance here is that of the clients for whom the shared decision making process is working well (Bernice, William, Mary, Marcus, Samuel, Roberta, and Maria), all of them are actively engaged in using personal medicine. The opposite is true for the clients for whom the shared decision making process is not working well (Albert, Andreas, David, and Jason). Helen, another client for whom the shared decision making process is not working well, is actively using what we would call personal medicine, but she is unfamiliar with the term and her personal medicine has not been incorporated into the shared decision making process.

In this study, some clients became activated by the concept of personal medicine because it shined a new light on the activities they were already doing for themselves. These activities came to be viewed as something they could “do” to take an active role in their own care. For some, personal medicine was something they added to their existing psychiatric medication regimen. For others, personal medicine allowed them to lower the medication dosages that they previously were prescribed. For others, it allowed them to use personal medicine as a replacement for taking psychiatric medication.

In the last theme, we saw that placing the client’s goal at the forefront of discussions during the medication consultation helped the client feel heard, which led to increased engagement in the process and provided a context for constructive shared decision making. What we also learn from those individuals for whom the shared decision making process is working well is that personal medicine is an inseparable and indispensable component of shared decision making. Personal medicine can serve a few valuable functions in shared decision making:

- 1) Personal medicine expands the options available to clients, in addition to pill medicines, when making shared decisions within the context of achieving a particular goal;
- 2) Personal medicine can redefine the role for clients in the medication consultation from passive recipient to active participant;
- 3) Personal medicine offers hope for clients that they can get better therefore serving as a pathway for clients to begin thinking about goal directed behavior.

Table 4 shows all the personal medicine that was listed by clients in their Common Ground reports as well as the personal medicine that each client mentioned during interview sessions. As was the case with power statements, the personal medicine that was listed on client’s Common Ground report did not change much over the course of the study. At the same time, clients for

whom the shared decision making was working well continued to add personal medicine to their life. It was just not updated on the Common Ground report. On the other hand, clients for whom the shared decision making process was not working well, with the exception of Andreas, had what we would call personal medicine available to them but was never reflected in their Common Ground report.

Table 4
List of Personal Medicine by Client

| Client | Personal medicine as listed on Common Ground | Actual personal medicine the person reports using |
|---------|---|---|
| Maria | <ol style="list-style-type: none"> 1) Time w/family 2) Mall shopping 3) gardening | Spending time with granddaughter, travelling, swimming, exercising |
| Bernice | <ol style="list-style-type: none"> 1) shopping 2) art 3) travel | Shopping, art, writing poetry |
| William | <ol style="list-style-type: none"> 1) family 2) health 3) music | Spending time with family, playing basketball, weightlifting |
| Helen | <ol style="list-style-type: none"> 1) grandchildren 2) scary movies 3) drinking coffee | Spending time with grandchildren, shopping, having all my collectables in my house, watching scary movies, hearing other people's problems, talking to her ghosts |
| Albert | <ol style="list-style-type: none"> 1) working 2) spending time alone 3) smoking | Working, spending time alone, smoking, watching soap operas, drinking coffee |
| Mary | <ol style="list-style-type: none"> 1) working 2) going to church 3) reading the Bible | Working, higher power – Jesus Christ, going to church, reading the bible, calling friends on the phone |
| Andreas | <ol style="list-style-type: none"> 1) art/reading 2) pics from space 3) rest | Not mentioned |
| Jason | <ol style="list-style-type: none"> 1) being kind and getting kindness 2) TV or radio 3) Sleeping | Working |
| David | None entered | Watching sports on TV, |

| | | |
|---------|--|--|
| | | walking |
| Marcus | <ol style="list-style-type: none"> 1) shopping 2) listening to music 3) family and friends | Shopping, buying new clothes, meals that I make |
| Samuel | <ol style="list-style-type: none"> 1) speaking to my case manager & psychiatrist 2) listening to music/reading 3) attending social activities | Reading books on positive thinking, listening to classical music, walking the dog, playing rummy with my neighbor, spending time with girlfriend |
| Roberta | <ol style="list-style-type: none"> 1) opening blinds to let the sunshine in 2) personal grooming 3) listening to the radio | Shopping, learning new things, sitting on the porch, opening blinds, watching TV, listening to music, reading the paper |

The fact that personal medicine is not being routinely updated on client's Common Ground reports may suggest a few things. First, the personal medicine area on the Common Ground report may not be used to the fullest in the shared decision making process. There is evidence from clients that prescribers are discussing people's personal medicine with them, but prescribers may be relying more on the oral reports of clients regarding personal medicine rather than working directly off the Common Ground report. We know that prescribers are routinely looking at client's answers on the HIAD scale and the Decisional Uncertainty Profile, but there is less evidence for this regarding people's personal medicine. Second, personal medicine may be only fully incorporated into the decision making process when clients are vocal about the personal medicine they are using or prescribers are at an impasse with people on taking pill medicines as prescribed.

Personal medicine expands the options available to clients

For the clients for whom the shared decision making process worked well, the concept of personal medicine expanded the options available to them, in addition to using pill medicine, when making shared decisions within the context of the goal they wanted to achieve. William, Bernice, Roberta, Maria, Mary, and Samuel all had goals that framed the discussions at medication clinic. With a goal at the forefront, discussion between the prescriber and the client turned to options for how to achieve this goal. All of these clients were wary of taking too much pill medication or had concerns about the side effects from pill medication. The concept of personal medicine offers a means of keeping the client and prescriber engaged in medication clinic.

This is exemplified with Maria. While Maria does not use the term personal medicine, she was activated by the idea of doing things for herself to get better. For years, Maria's prescribers and nurses were trying to talk her out of an older medication that didn't seem to be working for her. Her prescriber notes that on Maria's Common Ground report, which is brought into the medication consultation, that auditory hallucinations, concentration, and anxiety are still areas of concern she occasionally marks on the How I Am Doing (HIAD) Scale. While Maria acknowledges that the older medication does not completely eliminate all the symptoms she experiences, she recognizes that the medication does have certain benefits to her including: 1) keeping her from crying all the time; and 2) not feeling as suicidal. Maria did try other suggested medications prior to Common Ground, but they made her feel sluggish which made it difficult for her to do the things that were important to her.

When Common Ground was introduced, her prescriber stopped pushing her on trying different medications and accepted the fact that she was more comfortable on the older one.

While her prescriber continued to offer the options of trying a different pill medication, she also shifted her attention to the personal medications that Maria was using. Having personal medicine as additional options for Maria kept her engaged in the process. Her prescriber states, “She is placed in the...driver’s seat...I’ll say, okay...I know you’re not feeling comfortable with these options. Can we talk about at least the personal meds?” (P41:319). Maria’s prescriber talks about Maria’s personal medicine:

Maria, she has some really good personal meds, and we really try to focus on that. She takes care of her (grand)daughter, and really enjoys doing that, keeping busy with taking care of her (grand)daughter, anything she can do with her family...her daughter visits her, and she’s very close with her. She goes to Denver a couple times a year and will visit family. (P41:303)

Maria has also been working with her case manager to further explore personal medicines that might help her, including joining a 24-hour fitness center where she can swim. The fact that Maria’s prescriber and case manager are engaged with her desire to seek natural alternatives to stay well helps Maria to feel heard and in control of the decision making process regarding her life. Here she refers to her prescriber’s willingness to listen to her:

She agrees with me, I mean whatever I decide. ... by my age I want to help myself is the way I feel. (P29:71)

Roberta is another example of a person who has benefitted from the expanded options created by the use of personal medicine. Roberta continues to take her psychiatric medication routinely, but has now added personal medicine to her repertoire. For nearly thirty years, Roberta had been in and out of the hospital on a regular basis. She attributes the addition of personal medicine to helping her change this:

I like to go shopping, and I like to go do stuff that’s going to teach me stuff...I think I can gain a whole lot, because this is the first time since 1978, this is the first year I haven’t had a relapse, so, I’m waking up more and more to more challenges within myself. (P26:39)

Roberta is similar to Maria in that she refuses to change from an older medication to any of the newer medications that the prescriber has suggested. She has tried several of the newer ones and the side effects were intolerable for her. She does experience some significant side effects on the older anti-psychotic medication she is taking, but she is willing to tolerate these side effects because they at least allow her to achieve her goal, which is to raise her child.

Since she hasn't changed medications since the start-up of Common Ground, something else must be making the difference in her being able to stay out of the hospital, which she had previously been unable to do. Roberta was activated by the concept of personal medicine. It helped change her from passive recipient of medications to an active participant in her own care. Having a goal that was acknowledged by all members of the treatment team provided her a context for staying well, but the concept of personal medicine increased her options for doing this. This has been an empowering experience for Roberta because she sees that there are more things she can do to help herself rather than just take medication. Roberta has come to an understanding that medications can only do so much to help her. She understands how the medications benefit her, but also realizes that more is needed to help her be the parent she wants to be. This has led her on an active exploration to increase the personal medications that she uses in her life. Roberta's case manager is on board with this and has helped her with this exploration.

Bernice is another person who has been able to stay out of the hospital for a prolonged time since the inception of the Decision Support Center. Her case manager discusses how personal medicine has had a big impact on keeping her well:

She actually has increased symptoms, but...when she's had her increased symptoms it's the stress levels because of her son. And so she starts using her personal medicine more to manage her symptoms so that she doesn't have to go into the hospital and actually to be able

to tap into that personal medicine has really been good for her. It's kept her out of the hospital for the longest period of time that I've been working with her. (P32:98)

Here we see some of the more specific mechanisms at work here. Bernice is using personal medicine to manage symptoms caused by the stress she is experiencing in daily life. Bernice, like Roberta, has continued to use psychiatric medications to help with symptoms. Personal medicine is viewed as an adjunct to psychiatric medication that increases the options at her disposal for staying well. This was common among participants who were activated by the use of personal medicine. While viewing psychiatric medication as an important aspect of their treatment, there was recognition that there were limits to what psychiatric medications could actually accomplish. Samuel echoes this in his response to how psychiatric medication and personal medicine work together:

Oh! They're hand and glove. They're hand and glove. That personal medicine is very good and then with the medicine, because...the medicine...it's not capable of doing everything. It's not going to alleviate all your problems. You're still going to encounter them, but with your medicine and your personal medicine, you're good to go. You're good to go... my personal medicine is in harmony with my medication. So I get a very good effect. (P2:93)

Samuel's view that there are limitations to what psychiatric medication can accomplish is shared by one case manager. Here the case manager talks about how helping the client use personal medicine expands the person's options for managing stress in her life:

So it's not just pill medicine; there's something else that can help you and you can use it on a regular basis and making it part of their routine and the structure of their day. Right now I'm working with a person. I've really been working with her on personal medicine because she's using so much pure medicine. I say that's not going to do it, so we created a structure in her day, and using the personal medicine, it has sparked her daily activities. (P20:46)

One prescriber talks about the limitations of psychiatric medications being able to impact all the things a person is experiencing. She discusses how personal medicine is something she helps people consider as an additional option:

Sometimes I notice...People who always want to come in and change and take a med for everything are wanting to change meds in a quicker fashion, but, at the same time, I think there's been a little bit more room to explore, you know. Meds aren't always going to work for this. Let's go look at the other things that you have listed here as personal meds. So, there's one particular person who I know...used Common Ground at least twice, because I remember changing meds each time...We were talking about...what other things could be helpful instead of meds, and...that helps her to be realistic...about...are the meds going to actually take care of this or not. (P41:291)

While some clients viewed personal medicine and psychiatric medicine as a complimentary relationship, some clients became activated to the point that they started to actively explore the idea of reducing or possibly eliminating psychiatric medications. The concept of personal medicine allowed them additional options to view this as a possibility. One case manager sees this in some of the clients that she works with:

I really have been...more encouraging of people using their personal medication. Because...around the time that we review the quarterly treatment plans with them, like, every ninety days, we also update their personal medications, which is really great... I've had people that are doing some...experimenting whether or not they actually want to take their meds, or whether their meds are benefiting them. So, having those personal medications or the activities to fall back on has really been great. And, it's also helping people kind of look at their resiliency, because a lot of people don't really think about every day things that they do and how to manage their symptoms. But, that has really, that has really helped, so, for me, being able to look at personal medications, look at their worksheet more often than I had in the past, has allowed me to help my clients better manage their symptoms. (P35:11)

One case manager gives an example of a client who struggles with the decision to take medication. In this instance, the client views her personal medicine as a viable alternative to taking psychiatric medication:

I had one that was really, really so in tune with wanting to do her personal medicine, she didn't want to do medicine at all. And so she was working, she was taking care of her grandchildren, she was doing a lot of stuff that we had identified in her personal medication worksheet. And then she lost her job and so that kind of disturbed her routine and so she came back in and wanted to get back on medicine....She was on her medicine and then she had started working again. Things had started to improve in her life. So she wanted to get off the medicines because it caused her to be too drowsy and then she couldn't work and she couldn't spend time with her grandchildren and do those types of things that she had identified had really helped her when she was depressed. (P19:25)

Here we see a client who wants to do things for herself to self-manage the symptoms she is experiencing. The concept of personal medicine has activated her to the point of making the decision to forgo psychiatric medication, which for her has negative side-effects which impact her ability to do the things she most enjoys. When the job does not work out, she returns to using psychiatric medication for a time. After achieving stability, she decides again to stop using medications and rely on personal medicine.

Here another client has made a decision to no longer use psychiatric medication, so the case manager's attention turns to personal medicine to help the person deal with symptoms that might possibly lead to hospitalization.

One of my clients, she was coming in to med clinic, and she was on outpatient court order, but she doesn't do oral medications or shots. She doesn't do any type of medications, so we really focus on her personal medicine to help her in managing her symptoms...through us working together, she identifies that she might be having panic attacks, but she is just against medications. So, being able to have...personal medications to fall back on has really been key in keeping her stable so she doesn't have to go into the hospital. (P35:75)

Case managers have noticed that many clients have entered an active exploration phase around the use of psychiatric medication since the introduction of personal medicine. One case manager views it as a trend:

It also gives you something with the personal medicine. Okay, this is what I can use. I had someone that decided to get off meds right now...I'm seeing a trend right now. So we're working with the personal medicine right now. (P20:130)

Personal medicine can redefine the role for clients in medication consultation

Personal medicine is an empowering concept because it is an active self-initiated response to wellness, rather than relying solely on the more passive action of taking a pill. Since personal medicine draws upon activities that a person is already doing that impacts their life positively, it helps the person view themselves as an active participant in their own treatment. One case

manager notices this pro-active stance being taken by clients who have embraced the concept of personal medicine:

For most of the people, for most of my guys I probably would say out of all the ones I've done power statements with and personal medicine worksheets, I would say probably about 80%, well, maybe 70% of those that did it have really embraced it. To me it's making people more proactive in their treatment, especially in not always relying on medications to help them in managing their symptoms. And I think that's probably one of the most important components of the whole shared decision making center because we're helping people look at activities they do on a daily basis, what they routinely do that will help them. (P19:47)

William is an example of a person who has taken a more proactive role in his treatment because of personal medicine. William had been on Haldol injections for most of his life, but he hates the side effects of the medication. When William stops taking his Haldol, his symptoms increase dramatically and he at times becomes violent. This has led to him being on an outpatient court order to keep him on this medication. Though William's treatment team knew that he didn't like receiving the Haldol injections, they were more willing to listen to him via the Common Ground process. The concept of personal medication was a significant turning point, because it increased the options available to the treatment team in deciding to make a change from injections to oral medication. For many years William had been a passive recipient of medications, but now he had terminology to view his own active part in taking care of himself. As William made the transition from injections to oral medication, his personal medication increased. William's case manager was in tune with his goal of spending more time with his family (from his power statement) and helped him continue to explore personal medicine (basketball, weightlifting, etc.) to help him feel well.

William has become more activated in his own treatment, because he sees that there are things he can do to promote his own wellness rather than solely relying on the pill medication to help him get better. He states:

It's just that, if you don't have it, it's just like you relying on your medicine to do everything for you, and if you ain't got your family or listen to music or do what you like doing, seem like you'll be depressed all the time, at least I would. My family's my personal medicine. (P25:34)

While some clients immediately embrace the idea of personal medicine after being introduced to the concept, others require efforts by their case manager to increase awareness and use of their personal medicine. One case manager states:

And so one of the young ladies I'm thinking about, she just lost her benefits because she didn't do the review process. And so I was encouraging her, you know, these are the things that you identified that helps you when you're not taking medicine or outside of your medicine. And encouraging her to fall back on those things since she didn't have access to her meds at that time. So I think it's been a really good thing. (P19:47)

This reinforces the role of the case manager around personal medicine. The concept of personal medicine has created a vernacular for them to use when discussing options to deal with a stressful situation. What is empowering here is that stress is unlinked from the "stress equals symptoms of mental illness equals need for medication" equation. Stress is seen as a daily life occurrence. The case manager helps the client explore what she has previously identified that helps her when a stressful event occurs. The client does not have to remain powerless in facing these events waiting to get in to see the doctor and get a prescription. There are things that she can do to manage the stress on her own.

One case manager talks about another client whom she prompted to use personal medicine:

I've had to pull out their personal medicine worksheet and just have them say it out loud when they were struggling. To me it really empowers them....And I really think that's helpful. (P19:49)

Once again the role of the case manager around personal medicine is emphasized here. When a case manager is activated around the concept of personal medicine they are able to present additional options to help the client achieve wellness. What is empowering here is that the case manager is reinforcing a language or a way of thinking for the client. When a client is

struggling, they do not need to immediately think that they need to turn to medications.

Medications are an option of course, but so are the non-pharmaceutical things that the client already does in their life.

Some clients continue to add to their personal medicine over time. This is common among those who have embraced the concept and actively use it in their life. Samuel is an example of a person who continuously adds to his personal medicine:

But see, me and my personal medicine, it constantly multiplies. You know, I might start off with two personal medicines and then four personal medicines and then six. And it's constantly. (P2:95)

While Samuel already had a lot of personal medicine at his disposal during our first interview, he was excited to relate new personal medicine that he had acquired since that time:

I got me a girlfriend. She works down at Wal-Mart. And I spend quality time with her. We go out to eat together. We go to Crowne Center, we go to Sheraton Motel, we go to... Cabella's. We go to Nebraska Furniture Mart, we go to New Legends, we go out to the movies, we go out to eat. So, that's good. So I think very highly of her. She's a sweetheart. (P23:352-364)

And also:

Little Spike, a Dachshund-Boston Terrier. Yeah, I usually take him a walk around the campus or I take him up to Wal-Mart, and him and I have developed a good relationship. He's a very pleasant dog. What I love about him the most is he's happy and he never complains. He's always jolly, he's always jolly. (P23:288-292)

Samuel says that he has been using personal medicine more now with regular visits to the Decision Support Center, because it helps him to stay focused on what activities he's doing to promote his wellness. Here he talks about the use of one of his personal medicines, positive thinking he has learned from the self-help books he reads:

I feel like my personal medicine is working good because for one reason, I'm a very positive person...I almost mastered the feel of positive mental attitude. I can be positive with a dime in pocket, raining outside, snowing. I can be happy as a millionaire. You know, there's a self-thought. And what I do is I train myself to be positive. It's an effort. Every morning when I wake up in the morning I say it's going to be a wonderful day, it's going to be a

wonderful day, it's going to be a wonderful day. And you repeat that suggestion over and over again and you wake up, it will be a wonderful day. Now when I was having the hallucinations I have to admit to you, I did have suicidal thoughts. But I didn't act on them. I didn't act, but the thought entered my mind. But I just didn't respond to it. (P23:298-310)

Samuel's case manager has noticed the great strides Samuel has made over the past year. His personal medicine is now a routine part of his life. She says, "Every day he's practicing his personal medicine. And, he knows, and he'll tell you, you know, this is what I want to do" (P36:139). Samuel was already engaged in medication clinic prior to Common Ground. He is always cheerful, pleasant, and open about what is going on in his life. Samuel is also a forward thinking person. He loves life and wants to find ways to live it to the fullest. What changes for Samuel with Common Ground is that the concept of personal medicine gives him a language in which to speak about this life he is trying to build for himself. It also reinforces the identity in which he views himself, which is a person who is in control of his life and can move forward in life despite having a mental illness. Because the concept of personal medicine fits well into his self-identity, he starts to quickly expand on the personal medicine he uses. The pursuit of personal medicine begins to define his recovery journey.

The most telling story for Samuel of how personal medicine plays a large role in his life is when he finally starts dating. He comes into medication consultation with a dilemma because the pill medication which he finds helpful in addressing the symptoms of his mental illness also have side effects that make sexual activity difficult to engage in (a new personal medicine for him). This was never a concern prior to him dating. Now that it is, he discusses this with his doctor. He is presented with a few options for dealing with this. He can change to a medication that doesn't have the sexual side effects or he can change the time of day when he takes the medication so as not to interfere with sexual activity. Samuel makes the decision to change when he takes the pill medication.

While Samuel has been increasing his personal medicine, Roberta reveals that people can also begin to lose interest in things they once considered personal medicine. She says:

I'm burning out doing the same thing on my personal medicine, and I need new ideas on what to do with my personal medicine... I can't find nothing that interests me. I done lost my interest. (P26:35)

Since Roberta values how personal medicine can positively impact her life, she continues to search for new personal medicine that can help her. She states:

Sitting on the porch, opening blinds...watch T.V., listen to some music, try to cut down on my cigarettes, just same old, same old...I need something fun. I started getting the paper today. Maybe I'll read this evening...I talk to my grandmother, and every morning, she would go out and get her paper, and then she's sitting there when I call her, reading the paper. So, I said, that seems like a fun thing to do, get the paper. (P26:247-251)

Roberta talks more about expanding her options for personal medicine, possibly even considering college:

If I do it, it would be art. That's the main thing I did in high school. And I tried to go to Penn Valley for art, but I had little kids and babysitting problems, and buses, and getting them there. I didn't have support in my family. (P26:267-283)

Roberta was activated in medication clinic by the goal to care for her young son. She was also initially activated by the concept of personal medicine because it gave her options to stay well and care for her son. In regards to pill medicine, Roberta made the decision in medication clinic to remain on an older anti-psychotic medication because it was the only medication she found helpful in being able to do this. It also had some severe side effects that Roberta was willing to tolerate if it meant being able to care for her son. The concept of personal medicine was helpful to Roberta because it gave her hope to keep pressing on. Personal medicine gave her things she could do for herself that promoted her own wellness. It helped with things that the pill medicine did not.

The concept of personal medicine has made some changes in the way she views herself. Roberta was a fairly passive person prior to Common Ground. She acknowledges that she rarely talked in medication clinic and her case manager notes that people often ran all over her. They both acknowledge that she has become more assertive now, both in medication clinic and outside of medication clinic since Common Ground has started. I think there are a few factors. One she has a goal to work towards that is meaningful and important to her. Second, she is activated by the concept of personal medicine which helps her view herself as being able to impact her own wellness in life.

The problem is that Roberta's personal medicine that she initially listed on her Common Ground Report (opening the blinds, sitting on the porch, watching TV and listening to the radio) stopped giving her the same desired effect that she wanted. My opinion is that the personal medicine is fairly weak to begin with. It was probably just what she could think of at the time, so her case manager wrote it down. Since she was activated by the concept of personal medicine, her treatment team should have made the pursuit of additional personal medicine a coordinated effort. We know what her goal is (care for her son), we know what her decision is (remain on the older anti-psychotic despite the side effects), and she is telling her prescribers through the HIAD scale that not everything is going well.

Here is where the HIAD scale can be a powerful assessment tool. It could be framed as, "Let's start to explore additional personal medicine to help you stay well and be able to care for your son. Your case manager can assist you with this and I'll write him telling him what we are trying to accomplish. When you come back in next month, we'll use the HIAD scale to assess whether or not your personal medicine is helping you get to where you want to be. With that information, we can re-evaluate our options and make a decision of what to try next." Roberta

is engaged in the process, but we need to continuously use Common Ground to help people keep moving forward in their recovery.

From passive to active client through personal medicine

As personal medicine starts to become incorporated into the decision making process during medication clinic, we start to see a shift in the role of the client from passive recipient to active participant. Some of this can be attributed to the prescriber drawing more from the clients own expertise in what is helping them to stay well. As prescribers see that clients respond positively to the concept of personal medicine, it changes the dynamics of how they worked with the person. We see this occurring with Samuel, William, Mary, Bernice, Roberta, Maria and Marcus.

The dynamics begin to change with Marcus. Marcus is a younger gentleman who always came in to medication clinic with his mother. The decision making process for Marcus was often a dialogue between the prescriber and Marcus's mother. Marcus did not say much at medication clinic. The concept of personal medicine was pivotal for Marcus because it allowed him to enter into the discussions at medication clinic. Prescribers started to view Marcus as a young person who just wanted to enjoy life, have fun, and feel at peace. Personal medicine opened a window into Marcus's world related to what helped him achieve these things. As the prescriber started to bring these to the forefront of every medication consultation, Marcus began to share more. He started to enjoy medication clinic more because they were discussing the things that were important to him, not what was important to his mother. As Marcus started to do better as reported on the HIAD scale, his mother stopped coming in with him to medication consultation as frequently. Marcus is now an active participant at medication clinic, possibly because it is his expertise that guides the discussion and the decisions that are made.

Personal medicine offers hope for clients that they can get better therefore serving as a pathway for clients to begin thinking about goal directed behavior.

Prior to the start-up of the Decision Support Center, case managers started to introduce clients to the concepts of power statements and personal medicines as a means of getting them ready to participate in the Common Ground Process. As a way of talking about personal medicine, case managers assisted clients in filling out personal medicine worksheets where clients began to think about the activities they were currently doing that helped keep them well. For some clients, this served as an awakening for them in thinking about their own wellness and recovery.

Bernice is a client who did not participate much in medication consultations prior to Common Ground. Bernice's case manager describes making this connection as a type of awakening:

Actually, the personal medicine started here before we actually got the Decision Support Center up. Bernice actually started coming out then...when we first started discussing personal medicine...she really started to ask questions about different things and started looking at things differently. (P32:108)

For Bernice, the concept of personal medicine seems to have activated her to start thinking about her own wellness. She was definitely overwhelmed when her adult son moved back in with her. She started to think that she needed to better care for herself, so she could in turn take better care of her son. Being a good mom was the motivation for Bernice to start taking better care of herself. Using her personal medicine to stay well became the context through which Bernice started investing in Common Ground.

Tying the concept of personal medicine to these ordinary activities seems to be a beginning point of activation. Personal medicine is similar to what Rapp and Goscha (2006) call "strengths" in the Strengths Model of Case Management. In this model, a Strengths Assessment

is used to help people identify the resources in their life, both personal and environmental, that currently contributes or in the past has contributed to a person's well-being. Shedding light on a person's strengths illuminates these resources, but tying these resources to the achievement of a particular goal makes them an active part of the person's recovery. With personal medicine, it is when these activities are seen as contributing to a desired goal or outcome that we see a higher level of activation occurring.

Since most of the clients were introduced to the concept of the personal medicine by their case manager, it is within these beginning conversations that the connection between these ordinary activities and their use as personal medicine seems to occur. Bernice's case manager discussed how she re-framed her view of shopping:

I used to take her to the store, but it was like she felt like it was a chore. And then she started realizing as we started looking at personal medicine what actually makes you happy and she goes 'actually going shopping'. And she was like 'can I do that?' And I said 'it's your personal medicine. Whatever you choose.' She goes 'actually I like to shop. I really do like it.' And she said 'I've been looking at it the wrong way'. She says 'I really do like it'. I said 'there's nothing wrong with that'. (P32:104)

What was once seen as an ordinary activity for Bernice, suddenly becomes a powerful personal medicine to help her stay well. What helps to frame these activities in a new way is that the case manager is in tune with Bernice's goal to stay well in order to care for her son. He starts to help her explore the variety of ways she is already taking care of herself. This is an exciting thing for Bernice who begins to recognize that she is making progress towards meeting her goal.

Marcus's case manager also introduced him to the concept of personal medicine. Accessing his personal medicine in order to enjoy life more fully is Marcus's goal in medication clinic. His case manager is aware of this from reading the Common Ground report. Exploring personal medicine becomes part of what he does with his case manager. Now in tune with the concept, he discusses the difference it makes in his life:

My personal medicine is shopping, food, and clothes. Shopping, food, and meals that I make. They're working good. Being myself, being relaxed and just like nothing, like there is peace and comfort. It helps me, it feels good. It's like talking about, it makes me feel like free. Like just calm and peaceful like something a lot different. (P10:25-29)

Marcus's personal medicine has become a goal for him in medication clinic. It's helps him to achieve the essence of what he wants out of life. Marcus is basically defining "being himself" as being free, relaxed, calm, peaceful, etc. When Marcus uses his personal medicine he gets these feelings. Basically these feelings are the active ingredients of personal medicine for him.

For Samuel, personal medicine was a concept he quickly grasped. He had multiple interests and activities prior to the start-up of the Decision Support Center. Here he discusses his personal medicine early on in the study:

Well, my personal medicine is reading, listening to easy music, meditating, taking my dogs out for a walk every other day of the week, watching programs on TV of good report, visiting with people....Playing rummy with my neighbor...I like that classical music...I love to listen to Mozart and Tchaikovsky, and Leonard Bernstein. And a personal medicine for me is reading books that are of a positive nature like George Dry, Pulling Your Own Strings and-have you ever hear of that guy called Norman Vincent Peel? The author of Positive Mental Attitude. That's personal medicine. I like to read his books. And that would be my personal medicine. (P2:83)

For Samuel, being able to enjoy his personal medicine became the context for the shared decision making process. Samuel's personal medicine gave meaning and purpose to his life. Using the Common Ground process, Samuel started to view that his personal medicine contributed to his well-being just as significantly as the pill medicine he was prescribed. It was important for Samuel to find a medication that not only kept the voices from interfering with his life, but also did not have side effects which interfered with his personal medicine.

While some people like Samuel were routinely involved in several activities that we would define as personal medicine prior to the start up of the Decision Support Center, the concept of viewing these activities as personal medicine elevated the importance of these ordinary activities

to vital components of their recovery. One case manager talks about how a client made a connection with how ordinary activities could contribute to her well-being:

I had a client who has a lot of positive activities that she does. She draws. She likes cooking. She enjoys just walking, going on walks around the park that she lives near. But she never really thought of those things as being...part of her recovery or anything. Once we started, she responded very quickly to it. Once we kind of shed light on paying attention to those things, she responded very well. (P42:32)

Personal medicine shines new light on ways to stay well. A sense of empowerment develops because she finds that she can do things for herself to contribute to her own well-being. She moves from the passive state of just waiting for things to get better.

Mary talks about the ordinary activities in her life that bring her hope and has helped keep her going in spite of life's difficulties:

My higher power, the Lord Jesus is my personal medicine, and I've been getting into the Bible, lately, even more so, and it's supporting me so much, and I'm able to get to church once a week. It's just not even nearly enough in my opinion...but I've got hope... My higher power and my friends that support me that I can...call on...the phone, is what's getting me through, and keeping me from a lot of things, I think. I thank God for my job. There's no question about that. That's helping, too. (P44:308)

Mary's goal is to keep her job. Medications help with the voices, but medications alone are not enough to get her through the struggle of each day. Mary is a person who was activated by the concept of personal medicine from the very beginning of Common Ground. The personal medicines that she identifies are the result of self-initiative. This is similar to Samuel. The concept of personal medicine was introduced to them through the Common Ground process and they seemed to take over from there. The treatment team engages with each of these clients around their personal medicine, but it is the client that keeps these things at the forefront.

Personal medicine is a naturally occurring phenomenon. Each of us does activities that bring meaning, purpose or value to our lives. Each of the clients in the study either listed a personal medicine on the Common Group Report or discussed their personal medicine during the

interviews. The question is not whether people have what we would call “personal medicine,” but rather do they view these activities in such a way that they can access them in a purposeful manner to enhance their well-being.

One case manager talks about how discussion about personal medicine finally revealed to the client ways she could positively help herself:

This was all new to her...it was Thanksgiving...the one the center was having, and I had invited her to it...I say to her, ‘this is Thanksgiving dinner, would you like to come?’ ‘I don’t know. I don’t think so’. I said, ‘oh, it would be nice and you get to have some turkey’, because...the only contact that she has is with me or with attendant care. There’s no other contact with anyone else. She lives by herself...so, she came out and said, ‘well, haven’t you read it in my file, I have a problem with people, you know, with crowds. And, that’s why I used to drink, because, then, I could relax, and I could be around people, and then, that’s when I started to do drugs’...and I said, ‘okay, so you used those things and gotten so down’, that’s when she really got the concept of...self medicating, and using that as a personal medicine. And, now, you have to find something else that can help you, and it’s just like, oh, the light bulb went on. I said, ‘there are things that you can do that will help you relax, that will help you feel better so that you can cope when you’re out there’, and, it was like, oh, you know. Then, the light bulb went on, but we we’ve been working, you know, a whole year on what the personal medicine is, and we wrote it down. (P36:103)

Here personal medicine has increased the options for this person to achieve wellness. While the client had been using alcohol as a coping mechanism in the past, she now is presented with an expanded array of options to achieve the outcome she desires. The concept of personal medicine taps into her internal desire to be well and offers her positive ways to attain well-being.

Using Personal Medication during the medication consultation

While the concept of personal medicine is usually first introduced within the case management relationship, an ideal of the Common Ground Process is that personal medicine is an integral part of the medication consultation. The intent is that all clients will have personal medicine listed on their Common Ground Report, which is printed out and then reviewed by the client and the prescriber during visit. Ultimately, personal medicines would be incorporated into

the shared decision. Here one case manager confirms that personal medicine is routinely brought up during medication clinic:

And what I really like about (the prescribers), they always ask them are they doing their personal medicine. Is it helpful, the personal medicine they have identified? So I think that's really helpful to me because it kind of reinforces these are the activities that you previously have identified that helps you. So are you doing that and if not, why aren't you doing it and how can we address that? And so I think that's really helpful. (P19:41)

Samuel mentions that he and his prescriber always discuss personal medicine during medication clinic. He also discusses that even if he didn't discuss personal medicine during medication clinic, his prescribers would be quick to address them:

Well, they say that if a person loses interest in the things that formerly brought him or her pleasure, there's a change in their behavior. So if I would lose desire in those things, I think they'll reintroduce that to me again. And say Samuel, try your personal medicines and see if that will help you feel better, because that too has helped you in the past. (P2:91)

One prescriber tries to read out loud the personal medicine that people have listed on their Common Ground report during every medication consultation. This way she can hear from the person whether or not their personal medicine has been effective for them. The prescriber states:

I gravitate towards the power statement and personal medicine, and I read those aloud with every client. Sometimes I wish they would change more because...if a client has said no I haven't used this personal medicine for the last three times, is it time to think about some new personal medicine and what can be helpful? So I use that a lot. (P6:40)

The prescriber also describes how the concept of personal medicine has impacted decisions regarding medications in clinic:

I think we don't change medicines as quickly. And I think we're now prescribing personal medicines more. If somebody comes in and says I'm hearing voices, I don't automatically go to always change up your medicine to see if we can get them to go away. It's more what do you want to do about that? Do you want to work on your personal medicine with that? Do you want to work in therapy on that? Do you want to change your medicine? There's options now and I'm finding that I'm changing medicine less and the clients are more apt to tell me don't change my medicine. I don't want my medicine changed. Even though I'm still hearing voices, I hear them less than I've ever heard before. (P39:57)

As mentioned earlier, the concept of personal medicine increases the options that are available to clients and the prescriber when making decisions about their well-being. Each of the three prescribers acknowledges that they are bringing personal medicines into the discussion when making a shared decision. Another prescriber mentions that it is important for her to know how people plan to use their personal medicine between medication consultations in addition to how they might use pill medicine. She states:

I try to include even if the meds didn't change what the client has said about personal medicine, how they're going to use both of them throughout the month... how it can be helpful, and also, at the same time, what sort of things having meds could hinder that...or help that. (P41:155)

Another prescriber refers to doing this as well:

And, sometimes we need to ask for their agreement to come to a schedule of using that personal medicine, or I'll try to use it once every day or something like that. (P40:159)

All of the case managers in the study were able to recall times when prescribers discussed personal medicines with their clients. They were also able to refer to specific instances where the inclusion of personal medicine in the decision making made a pivotal turning point for the client being more engaged in the Common Ground process, such as William, Marcus, Bernice, and Roberta. Though there still seems to be some inconsistencies of when and how personal medicines are addressed in medication clinic. One case manager mentions that the concept of personal medicine was new to prescribers and therefore it took some time for them to begin discussing them routinely during consultations. He states:

The personal medications - first of all, early on it wasn't that smooth of a transition. It wasn't really even brought up that well. But I have noticed it. I mean, nurses and doctors had to learn about it too. Once that has gotten better, a lot of it is kind of asking, "Well, are you doing these things?" You can tell when they're saying no, I'm not doing it that it's a good sign that they're struggling with things or something is not right. A lot of times, consumers notice that too. They're like, wow, I haven't cooked for myself in three weeks. (P42:68)

While prescribers seem to be gravitating more to the concept of personal medicine and incorporating it more frequently into discussions at medication clinic, it might not yet be to the point where personal medicines are a routine part of the shared decision making process. One prescriber's comments below might offer some insight into this:

I think we do tend to look at what the personal medicine is and we do tend to look at the power statement, but I think it gets addressed at sort of different degrees. The personal medicine, if we can incorporate that into the shared decision, I think if there's something we're trying to achieve, if somebody is stable and everything is, we don't need to really be striving to meet any goals, I think we may be less likely. But if the person is wanting to work on symptom control. I think we're pretty likely to involve them and their personal medicine in the shared decision. (P8:37)

This same prescriber admits that personal medicine is not discussed during every medication consultation. The prescriber explains more about that process:

Usually, if the person is doing well, if they mark that they are doing their personal medicine, we may focus on how that personal medicine's helping them to continue to do well, but generally, we, you know, we don't focus on so much. It's when they're not doing well. We made medication changes, or we're going to make a change that's going to take a little while to work, then we'll look back at the personal medicine list and make sure that the person's pulling those things in. (P40:159)

What the prescriber's comments suggest is that personal medicine is more likely to be discussed in medication clinic if the client has a goal of reducing certain symptoms. This would be consistent with previous evidence showing that prescribers often operate primarily from the scores on the person's HIAD scale rather than the person's Power Statement. When the Common Ground report reveals flagged red numbers on the HIAD scale, prescribers are more open to looking at a person's personal medicine in addition to pill medicine. But what about clients like Albert, Jason, David, Helen, and Andreas, who do not have symptom control as one of their goals? With each of these clients, the exploration of personal medicine has not been incorporated into the decision making process. In each of these cases the prescriber has solely pursued pill medicine to reduce symptoms. A few possibilities:

- 1) These five clients are not engaged in medication clinic. They have a lot of decisional uncertainty about even taking medications. While they come into medication clinic (even though sporadically at times), they would rather not be there. Since the prescriber perceives that the client is not invested in doing something to get better, the prescriber does not invest a lot of time in the client. They write the script for pill medicine and go on to the next client.
- 2) There was little evidence that case managers worked with these clients outside of medication clinic around personal medicine. None of these clients were familiar with the term. Helen and Jason had the same case manager, and there was little evidence that the case manager was actively exploring ways with them to improve their well-being. David tries to avoid seeing his case manager since he doesn't feel he offers him any assistance. Albert has a new case manager, who is starting to pursue personal medicine with him, but prior to that there was little evidence for this being done. Andreas is difficult to understand because he speaks in disconnected sentence fragments. There was little evidence that his case manager had taken the time to understand what Andreas wants to achieve or how personal medicine might benefit him. Bottom line, if personal medicine is not worked on outside of medication clinic and the client does not become engaged with the concept, it is less likely to be incorporated into discussion at medication clinic.

Prescribers do not have a lot of time to spend with clients during medication clinic (approximately 15 minutes). The quality of the shared decision making process depends a lot on how well the client is prepared for shared decision making upon entering the medication consultation. When the client has a goal (well written power statement that they are invested in) and engaged with the concept of personal medicine (which expands the options for the client to

discuss in order to achieve this goal), then prescribers seem to be engaged in the shared decision making process with the client. If there is no goal and no awareness of personal medicine, then prescribers go back into old ways of thinking. They frame the client's problem in terms of what they are observing (whatever symptoms seem most apparent) and prescribe the pill medicine they think will most likely improve that symptom.

Barriers to people being activated by personal medicine

One barrier seems to be people having difficulty understanding the concept. One case manager describes a client who misunderstood what he was getting at when he brought up the term personal medicine:

But I think she feels like her personal medicine is crack and so I think that's what offended her when I was asking her about personal medicine. I think she thought that's what we're looking for and it's not. We're looking for something completely different. (P4:86)

Albert's case manager talks about his lack of familiarity with personal medicine:

Albert, he is somewhat. It really depends on what day you catch Albert in, but, when we talk about personal medication it isn't always, like, Albert, your personal medicine, or the actual things that you do that help manage your symptoms. Because...he was one of them that was... 'I don't want to take no more pills', and I'm like, 'Albert, you know, activities that you do, is not the medicine that you take'. So, he's one of the ones that I had to, kind of, explain that to. So...when you say, personal medication, that might not ring familiar with him. (P35:178)

Albert's case manager had only recently been assigned to work with him at the time of our interview, so was only in the beginning process of discussing personal medicine with him. Since

Albert has not been doing well, she recognizes that it's time to explore the topic further:

Albert, he is one that I haven't had a chance to...update his personal medication...so, other than him smoking cigarettes, drinking coffee and watching soap operas, I don't know what all his personal medications are that he identified with (his previous case manager), but what he has told me, those are the three things that help him the most, drinking coffee, smoking cigarettes and watching soap operas. So, he is one that in the next couple weeks, when I go to update his treatment plan, we'll be updating his personal medications worksheet. (P35:174)

The case manager mentions what she believes would be his top personal medicine:

He wants to go back (to work), his passion, which would be one of his biggest personal medications, if he could, he wants to work. (P35:198)

The case manager also talks about his difficulty accessing this personal medicine:

But he can't work, because of the physical problems he has with his back that causes him troubles with his legs, but he would love to go to work. He wants to be able to work. And, he used to love washing dishes. I started in '05, so, like, for the first year or so that I was here, he would be down there at SIDE helping them in the kitchen, and then, he got a job at Hilton Gardens working in the kitchen, and then, that job stopped. But, he would really want to go back to work. That's his joy right now. That's what keeps him motivated. Because, he wants to be able to go back to work, so he's willing, to a degree, to work on some of these critical things, after they've improved his mobility, but they think he might have to have surgery, and at this point, he's not willing to do that. He used to work with our vocational facility. And, then, he got ill. He had to go into the hospital or what have you, and his physical health really started deteriorating, so we haven't did any strategizing around him trying to get a job, because, right now, he's more self comfortable wanting to be at home. He's wanting to be alone, because he can't really walk for long periods of time. He can't really stand. So, if his legs get better, he's wanting to go back to work, so, he has some hope. There's some hope there. (P35:198)

Framing personal medicine in the context of the goal the client wants to achieve seems to be a good way to help clients not only understand the concept, but also see the value of personal medicine. This dynamic can be seen in the work with clients such as Mary (keeping her job), William (spending more time with family), Roberta (caring for her young child), and Bernice (staying well so she can support her adult child). For Samuel and Marcus, their goal in medication clinic is being able to access their personal medicine which helps them to stay well and enjoy life to the fullest. These are all clients for whom the shared decision making process is working well. Each of these clients embraces the concept of personal medicine because they see personal medicine has relevance to what they are trying to achieve.

It's possible this same strategy would work for clients like Albert, who wants to return to work. The concept of personal medicine can be introduced as something besides medication that will help him stay well in order to return to work. Albert currently may have difficulty

understanding the concept of personal medicine because a goal has not been established that provides a context for discussing personal medicine or gauging their value.

Jason is another person who does not understand the concept of personal medicine and also is a client for whom the shared decision making process is not working well. When talking more about what personal medicine was during the interview, he was able to convey what things besides medications contributed to his wellness. He says, “Besides medication. Work. Work keeps me healthy....money would make me feel better” (P43:284-288). Personal medicine was not an idea that Jason had ever discussed with his case manager. While working is something that he identified that helps him, he says this is not something that his case manager is helping him with. He states, “she’s kind of, off the ball. She ain’t on the ball” (P43:380). It’s possible that personal medicine is something that could activate Jason in the shared decision making process if work was framed as the context for exploring options to help him stay well in order to do this.

Clients can also be potentially activated by the concept of personal medicine when decisions regarding use of pill medicine are framed in the context of how they either interfere or contribute to client’s ability to using their personal medicine. Below, one case manager refers to a person who initially did not understand the concept of personal medicine. The client did not want a medication that interfered with her ability to do the things in life that naturally contributed to her wellness. The case manager says:

As (the prescriber) was going over the Common Ground report for the first time, she misunderstood what (the prescriber) was saying about it. She took it that it meant that she wouldn’t be able to do her personal medicine, which was praying and reading her scriptures. And she was like I don’t want the medicine if they are going to do that. And ...I was like no, she was asking you does the medicine interfere with you doing your personal medicine. And so when she got that clarification she was fine. (P19:41)

Once the client's use of personal medicine is elevated to the forefront of decisions about medication use, the client is more willing to talk about medication options. We find a similar occurrence with Samuel (not wanting a medication that interferes with his ability to engage with sexual activity), William (not wanting a medication that makes him feel drowsy when interacting with his family), Maria (not wanting a medication that interferes with her ability to spend time with her grandchild), and Mary (not wanting a medication that interferes with her ability to work). In each of these instances the client's use of personal medicine was reinforced by elevating it above pill medicine in the decision making hierarchy.

Another potential barrier to people becoming activated with personal medicine is if personal medicines are not an integral part of medication clinic. As we saw above, personal medicine can be an empowering concept for some people, whether it is reinforced in medication clinic or not. Some clients will understand the value of personal medicine and actively make decisions on how they will use their personal medicine in relationship to their psychiatric medications. Some clients will openly discuss their personal medicine with their prescriber and want their personal medicines taken into account when making decisions regarding psychiatric medication. But what about clients who do not mention personal medicines during medication clinic or are not aware that personal medicines have any role in the decisions made at medication clinic? One prescriber's comments reveal something about the process of deciding when to draw in personal medicine to the discussions at medication clinic:

I think that probably is real dependent on the consumer and where the consumer is in terms of their illness. I think when people are struggling and we've done what seems reasonable with medications and that's not been effective, I think we're more likely then to be looking at the personal medicine...and trying to fit things together. I think if someone is doing well and they are not having issues, I think we may be less likely to focus on that, although I know that the case manager focuses on that pretty intensely with the person. (P8:37)

What seems to be referenced here is that personal medicines are sometimes viewed as a fallback when a client has not responded to the psychiatric medications that have been prescribed. While this does not mean that the prescriber does not value personal medicine, it suggests that personal medicine is not always given equal consideration along with psychiatric medication when making decisions about how to respond to client's concerns discussed in medication clinic.

For each of the twelve clients who participated in the study, none of the personal medicine changed on the Common Ground reports from the beginning of the study to the end, which lasted almost one year. Though personal medicine did not change on the reports, which is what is viewed by the prescriber and the client during the medication consultation, interviews with most of the clients revealed that their personal medicine was in fact changing over time. This might suggest that unless client's mentioned what personal medicine they were currently using in medication clinic, the prescriber would be acting on old information if they even referenced it at all.

One prescriber mentions that it would be helpful to have this updated information:

I hadn't thought about it, but it probably would be helpful in the clinic if we knew that it had changed, so, that could be significant if somebody has their personal medicine that they would talk to their girlfriend and now their personal medicine is to walk the dog or something instead. (P40:198)

In order to ensure that client's personal medicine is part of the medication consultation it must accurately reflect what the client is currently using at the time of the visit. Personal medicine also needs to be discussed during each medication consultation in terms of how it is helping the client achieve the goal they have for clinic, which is either achieving what is written on their Power Statement or addressing concerns they reported on the HIAD scale.

Time is a factor that impacts whether or not personal medicine is discussed during the medication consultation. One prescriber mentions that when medication clinic appointments

were reduced to fifteen minutes on July 1, 2008, regular discussion about personal medicine was affected:

I think, when we were doing 30 minute clinic visits, we probably spent a lot more time talking about personal medicine and other things like that, but we don't have the time to spend doing that, now. (P40:236)

One prescriber does mention though that when clients come in with personal medicine listed on their Common Ground Report, this saves time in the medication consultation:

In the past, what we would have to do, is spend our time trying to find out what their personal medicine is. We didn't call it personal medicine at that time, but you know, what can you do for yourself, and so you'd end up eating up a lot of the clinic time trying to figure out what it is that they do, and then trying to set up a pattern of how to use it and getting some buy in from them, but now they've already done all that, and so, all we need to do is, kind of, reinforce real quickly. (P40:159)

But prescribers also acknowledge that they do not have sufficient time during the medication consultation to help people develop or modify their personal medicine. As one prescriber states, "One thing I do not have time to do is develop power statement and personal medicine with clients" (P6:82). What this requires then is a mechanism for prescribers to at least flag when personal medicine is outdated or irrelevant for follow-up by others on the treatment team. This will be discussed further in the next two themes.

Conclusion

Personal medicine derives most of its relevancy to the shared decision making process by increasing the options available to the prescriber and client for achieving the client's stated goal or addressing a client's concern. Personal medicine broadens the discussion of alternatives beyond the options of changing medications or dosage. It offers a non-pharmacological alternative or compliment to pill medicines being recommended by the prescriber. Whether viewed as an alternative or a compliment to prescribed pill medicines, it offers a concrete strategy that clients can do to contribute to their own well-being.

For client's for whom the shared decision making process worked well, personal medicine was a concept that engaged them. For some, engagement around personal medicine came prior to the formulation of a goal that became the context for medication consultation discussions. With the assistance of one or more members of the treatment team, ordinary activities that were already available in the client's life became elevated in importance and attributed as a key factor in helping the person stay well. This seemed to offer a sense of hope to the client that there was more they could do for themselves than the passive taking of medications. Often discussion of personal medicine led to discussions of a goal that was meaningful to the client.

For other clients, engagement around personal medicine was established after the formation of an important and meaningful goal. For clients who had decisional uncertainty around taking pill medicines, this proved to be an extremely valuable concept for keeping the client engaged with Common Ground and the shared decision making process.

All clients were introduced to the concept of personal medicine at the beginning of the study, but not all clients were engaged around the concept. It's seems as if the relevancy of personal medicine and a goal that is meaningful and important to the client is intertwined. Clients who did not come to an agreed upon goal with their prescriber in medication clinic found little relevancy for personal medicine. While all clients had personal medicine listed on their Common Ground report, there was not a context for the prescriber to draw it into the discussion. Since personal medicine was not a routine part of medication clinic discussions, it receded to the background of subsequent clinic visits.

Similar to prescriber's use of the Power Statement in medication clinic; use of personal medicine likewise seems to be derived from the client's level of engagement with it. When prescribers perceive that clients are activated by the concept of personal medicine, they are more

likely to elevate discussions of it within medication clinic. For each of the clients who were not highly engaged using Common Ground, personal medicine was rarely brought into medication clinic discussions.

As prescribers have stated, time allowed for the medication consultation may be an important contributing factor. With only fifteen minutes reimbursable for a medication clinic visit, prescribers feel pressure to move medication clinic along quickly. For clients that are engaged with Common Ground and have an established goal, prescribers are presented with a ready-made framework for initiating discussions. If the client is engaged in Common Ground, the prescriber is willing to take the clients lead and support them in their decision making with various elements of Common Ground. When the client is not engaged with Common Ground, prescribers seem to stick closely to the HIAD scale. This is used to establish context for the consultation in the absence of the client requesting a particular focus.

What this speaks to is that effective shared decision making may be dependent upon factors that occur outside of medication clinic. In the next two themes, two auxiliary supports to the process will be explored. These two auxiliary supports, peer support and case management will emerge as important contributing factors to the success of the shared decision making process.

Theme 5: Peer Support enhances and in some cases is essential to the shared decision making process.

There is evidence to suggest that engagement around an agreed upon goal in medication clinic is an essential part of the shared decision making process. There is also evidence that increasing the options available to clients for achieving this goal further enhances the shared decision making experience. When clients view that they are heard by their prescriber and are making the decisions related to a goal they wish to achieve, they are more satisfied with medication clinic and engage more in using the Common Ground software to promote their well-being.

This describes the dynamics of the actual medication consultation when shared decision making is done effectively. But there are key elements that occur both before and after the actual medication consultation that contribute to effective shared decision making. On the front end, clients need to be able to communicate their goal(s) for medication clinic prior to entering the medication consultation as well as any concerns they currently have and/or any decisional uncertainty they have regarding the use of medications. They also may need help adding or changing their power statement or personal medicine that is used in the medication consultation. On the back end, clients need to have support available to carry out any shared decisions that are made during the medication consultation.

Auxiliary supports such as peer support workers and case managers can assist with both of these. For clients for whom the shared decision making process is working well (i.e. Roberta, Bernice, Mary, William, Samuel, Marcus, and Maria), we find the presence of one of these auxiliary supports available to either guide them in using the Common Ground software to create

a report that will communicate what they want to say to their prescriber or support them in carrying out decisions that were made during the medication consultation.

First we will look at the role of peer support and then turn to the role of case managers in the next theme. The peer support role is built into the shared decision making process to serve multiple functions. First, the peer support worker is to help create a welcoming environment for clients entering the Decision Support Center. With a new technology and process for going through medication clinic in place, the intention was to greet clients as they walked through the doors and help them to feel more comfortable. The second is to assist clients with using the computers to fill out the Common Ground Report. The intention here was not only to introduce the new technology, but help them learn to use it in such a way that it helped clients more effectively communicate with their prescribers during the medication consultation. A third function was to assist clients after seeing the prescriber if they needed any assistance following through on a shared decision made during the medication consultation or to explore additional information the client might request. This might involve assisting clients with internet searches or completing any of the variety of tools available through Common Ground (mood calendar, personal medication worksheet, medication chart, etc.). Overall, participants responded favorably to the assistance that peer support workers offered them, even clients for whom the shared decision making process was not working well (i.e. David, Albert, Jason, Helen, and Andreas). Another method of peer support that was found to be helpful to clients were the videos embedded within Common Ground which feature first person accounts of recovery.

Helping clients feel comfortable in medication clinic

The supervisor of the Decision Support Center talks about this first aspect of the peer support role at the Decision Support Center:

First is the welcoming. As a supervisor, my goal is to have folks actively welcome people. And by that I mean actually get up, go to the person, initiate the exchange, not wait for the person to come in...But to see somebody coming into the space and it's like hey, how are you? We're so glad you're here. What is it that I can do for you today? How can I be of assistance to you? And what that means is then doing that with everybody so that we don't not do it with somebody. And it also means that we might greet some people who are not using Common Ground. And that's completely okay. It's like so you're here to see the nurse. That's great. Why don't you have a seat here? Here's a magazine. And still explain what's going on. Why are there computers here when there weren't before? So the first step really is the active welcoming, which is a very different process than you get at most doctors' offices where you have to go and approach somebody and take that risk first. (P38:30)

One peer specialist makes the effort to greet clients once they check in with the receptionist. She views this as important to engaging with clients who may not feel comfortable yet with the Common Ground process. She talks about what has helped some clients feel more comfortable initially engaging with the process:

Shaking their hand when I go out to greet them, which I don't do every time. It depends on how, I try to feel their mood, you know. Sometimes people don't like to be touched. Going out there and just bringing them back to the Decision Support Center, where they just don't have to walk back themselves. I think that's a good thing. (P15:20-22)

And also:

Respect for them. It goes a long ways because a lot of them are low self esteem or have trouble that way, I believe. They just...and to treat them with great respect is important, I think. (P15:74)

The Decision Support Center supervisor views that peers acknowledging they are persons with a lived experience of mental illness helps set the stage for engaging with a client at the Decision Support Center. She states:

Usually the first contact will include self-disclosure. And it almost happens instantaneously. 'Hi, I'm so and so. I'm a peer specialist.' What that means is I'm a person who lives with a mental illness and I work here because I believe in recovery and I want others to. That would be kind of a real abbreviated way that introduction might happen. (P38:28)

With the Decision Support Center being such a significant departure from the previous way of doing things at medication clinic, it is understandable that some clients would need time to adjust

to the new process. Having peers available to greet people as they come into medication clinic seems to lessen the anxiety that some clients might feel. One client (Albert) has not always felt comfortable coming to medication clinic because of the anxiety he feels being around other people. He says, "I'm bothered by people, and I try to deal with that at the certain time. But I'm just this way" (P16:158;160). He also states, "Most of them I don't mess with. I don't know them that's why. I don't know the people that work out here. I know a few. But I only mess with the people I know" (P16:110-116).

Previously, Albert would have to sit around for long periods of time prior to seeing the nurse and/or prescriber. This only contributed further to his anxiety. He describes what it was like prior to the Decision Support Center and the availability of peer support staff there to greet him:

Because when we was out to the old, the old building, it was you sit down and wait an hour, an hour and a half and something like that until your nurse get ready for you and then you go in. But now you've got to go to the computer and you have more, you have attention, you know, when you come in here. Somebody is waiting for you, you know, to direct you to your nurse. It's not you've got to wait all that time. (P16:142-144)

While Albert has not always felt comfortable in his interactions with medication clinic staff, he has been very pleased with the assistance he has received from peer support staff. He perceives that they show more concern about his overall well-being than he has experienced from other staff. This has contributed to him being willing to sit down and use the computers to fill out his Common Ground report prior to the medication consultation. He says, "More, what's that word? I'm trying to think of the word...Concern. They're more concerned about my health and well being. It seems that way" (P16:72).

While the shared decision making process is not working well overall for Albert, he does seem to positively respond to the idea of peer support. A few things may be occurring here with Albert. One, he is nervous around other people so the wait to see the nurse and prescriber must

be excruciating for him. He also doesn't really want to be at medication clinic to receive his injection, so any long wait to get into clinic must feel like a waste of time. Since Albert is a restless person, having someone see him quickly is helpful.

It also helps that peer support seems to be a person he trusts or feels comfortable being around. Albert views that peer support are more concerned about his health and well-being. What this would suggest to me is that peer support workers might be listening to Albert in a way that his prescriber and nurse are not. He views them as being concerned about things that are important to him. His interactions with peer support would be around the filling out the Common ground report. He may be equating some of the questions that are being asked in Common Ground with the peer support worker who is helping him answer them. The questions from the HIAD and the Decisional Uncertainty Profile are all about what concerns Albert at the time.

Another client (Samuel) views the empathic nature of peer support workers as being important. He says:

Oh, that works out fine because I think there needs to be peers in certain respects, but I would think, I would think being a peer would be someone that could maybe console someone or help someone or something of that nature. (P2:81)

The Decision Support Supervisor views that the mere presence of the peer support worker is just as vital a function as actually assisting the client with using Common Ground and teaching them to use this tool to communicate effectively with their prescriber. She states:

But a lot of times peer support is a function of being rather than doing...the fact that the person is a peer and can carry into the exchange some intentional empathy or some intentional connection, that really drives the other two. (P38:18)

One peer specialist does not think some clients would come back to use the Decision Support Center without people there to greet them. She says:

I think that they would not necessarily do the Common Ground report if it was just left to them to do it and not be greeted and walked through it. I believe, I'm saying that because I just think that people wouldn't make their way back to the Decision Support Center to do that. (P15:6)

One factor that seems to help some clients feel more comfortable with the new process is when clients know the peer support staff that is helping them. One peer specialist acknowledges the fact that he knows a lot of the people that come back to the Decision Support Center. He says:

The good part about it is I like working with the people, the consumers. I know a lot of them so that's the best part I like about it. Yeah, either by association with the mental health center or actually being hospitalized with some of the people, too. (P37:11-13)

One case manager talks about how several of the clients he works with like the fact that they know someone with similar experiences is working at the Decision Support Center. He says:

People are coming back and saying yeah, I talked to so and so and in the past he had this wrong and this wrong and he dealt with it and so I talked to him and we're going to work on this. So they really like the fact they are able to ask somebody who's actually been through some real things that they actually know... They like the fact that they know these people already and so when they talk to them they're talking to people they already know. And so they are able to adapt to some of the things that they're talking about to their own life. And so they're looking at that and seeing the improvement and seeing how much their life has improved and it's their full time job now and so that's actually helpful to them to make sure that they use this tool the best they can. (P32:12)

A few processes seem to be at work here. Peer support facilitates engagement with the Decision Support Center and the front end of the Common Ground report. Clients view peer specialists as people who can understand what they are experiencing. This increases the likelihood that people will come into the Decision Support Center prior to their medication consultation. It also probably increases the likelihood that clients will fill out the Common Ground report. They are engaged in a conversation with the peer support worker facilitated by the questions on the Common Ground report. This part of the process is all about getting to know more about what is going on with the client. The client's expertise about themselves is

being listened to. The peer support worker then becomes a facilitator to make sure clients are communicating the story they want to tell about themselves.

One case manager has noted that some clients have decided to come in and use the computers only because they had a previous relationship with one of the peer support staff. Knowing that one of their peers is successfully using Common Ground to assist with their recovery seems to open this up as a potential option for other clients to use. The case manager says:

There's a couple that only came because someone was working in there and that's the only reason he actually came because he had a relationship with that person and because he trusted her. He came to the clinic because he felt that if she could use it and she was working here, there was something that he might be able to use, too. (P32:18)

The case manager gives a specific example of where a client he was working with started using Common Ground because of her interactions with peer support staff. He says:

That seems to be the biggest thing that's really helped improve is that the peers are able to talk with them and a lot of times because they talk to them, that anxiety is reduced and they actually will go ahead and use the computer. I had one lady that would not, would not, would not, would not, would not. And then she finally popped up and started using it out of the blue one day. And they hadn't put her on the list because she refused for almost a year. And then one of the peer advisors asked her and she said yes. (P32:20)

The peer support supervisor also sees the importance of having people who are familiar to clients working at the Decision Support Center. She says:

The kind of response to that can range from something as kind of simple and unsophisticated as having people in recovery staff the Decision Support Center and have other members take note of that and how that has elicited. Its like, "Oh, my God! I didn't know you could work here." You know? "We were in the hospital together and you're doing this now." And what a huge impact that has... That makes a huge difference to people. (P17:22)

Even David, a client who never fully engaged in the Shared Decision Making process was willing to come into the Decision Support Center and work on the Common Ground report

because of his relationship with one of the peer specialists. One peer specialist notes when David did come into the Decision Support Center, he specifically asked for her assistance. She says:

Well, this was this one man named David who had asked specifically for me and I knew him in the hospital. And it was, I think it was a good thing for him to see me working. (P15:48)

David, like Albert, is a client for whom the shared decision making process is not working well.

But, he engaged with the peer support worker at the front end of the Common Ground process.

This would suggest that even for clients who are not engaged with using Common Ground at the point of the medication consultation with the prescriber, a potential activation point may exist when interacting with peers at the beginning of the process.

One prescriber views the fact that peer support workers are there assisting with the computers increases the confidence of some clients that they can do it as well. She says, “I think it helps to see peers working on it... because the trust, you know, that, okay, I can do this” (P41:359). Another prescriber has seen some clients become more enthusiastic about using the computers at the Decision Support Center because of their familiarity with certain peer support workers. She says:

A couple of people that I have seen were initially sort of okay about it and now are excited about coming in and in fact ask for specific folks to work with them...and they feel comfortable with their routine. So I think a good chunk of them have come along. I haven't heard of anyone becoming more resistant to completing it or kind of growing into saying we don't like it. (P6:30)

Helping clients use the Common Ground software

A second function of peer support that seems to enhance the use of Common Ground is helping clients actually use the Common Ground software. The peer support supervisor also talks about the second aspect of the peer support role:

And so after logging on, the process is completion of the survey, which does have a couple of discrete kind of insertion points for the peer specialist...When a person moves into answering questions where they have the option to say more, the peer specialist explains

what that means; that if they choose to say more about a specific area of concern or conflict, that they'll be given options to choose from or can say Other. But it's helpful at least initially, the first couple of times that somebody uses the program, for them to see what that process is so that they'll be able to make an informed decision about whether they want to say more or not. And other than that, the program really is driven by the person, the pace, the deciding, how to respond to questions. The peers are in the immediate area and often right by the person if the person wants that to provide clarification or support or encouragement if needed. (P38:36)

There are multiple options for how people can choose to interact with the computer software. They can choose to either read the questions themselves or use headphones to listen to the questions being read to them. The peer support supervisor explains that since the Decision Support Center has been up and running, clients have found additional options for interacting with the program. Assistance from peer support staff have made these options possible and creates an environment where the client can answer the questions for the Common Ground report according to their own comfort level. The peer support supervisor explains:

As soon as the person is logged in, though, they become the driver of the program. And they are immediately asked to make a decision in terms of how they go about using the program, which is to read the program or listen. What we've learned over the past year is that people then create additional options for themselves from those two. We have people who will want to read, but may have impaired literacy skill. And what they really want is for the peer specialist to read to them, which is a fine and dandy option because again the peer specialist's role in that is to help the person overcome any barrier that might prevent them from using the program. So if that means that they read every word to the person, great. And we're glad to do it. If that means that they use the mouse or use the touch screen on the behalf of the person, then great. But we don't make assumptions that the person needs that. The person drives the decision making process. Do you want to read or listen? Do you want to use the touch screen or the mouse? And another skill for the peer specialist is to kind of read at the comfort level of the person. And if it looks as though the person needs more information to make an informed choice, then to provide that. (P38:36)

None of the client participants in the study had much familiarity with using computers prior to starting Common Ground. This raised two common sources of anxiety for clients. One is that they would have to read the questions. The second is that they would have to type their

responses. The peer support supervisor talks about how the simplicity of using the software on the computers was designed to alleviate these concerns. She says:

Incredibly low learning curve even for people for whom reading and language tasks are difficult. We have a number of users who have kind of impoverished reading skills and at least one user who has virtually no reading skills were able to use the program. We also have a number of users for whom English is a second language and having both the written word and the spoken word as an option helps because typically, as one acquires a second language, they have a strength either in spoken or written word. And so by having both available we're able to play off people's skills that they come in with. (P17:14)

Roberta is one client who did not have any experience using computers prior to Common Ground. Having peer support to assist was something she found very helpful. She says, "Like me, I'm not computer smart and since they have the lady sitting there helping you, I think it's a good thing. I think it really is" (P9:242).

Albert is another client with limited reading abilities. His case manager thought he would need assistance doing the Common Ground report because of this. Because of the various options available to Albert in interacting with the computer software, he had the confidence to do this on his own. His case manager states:

I've been working with Albert for about almost four weeks, now, and the first appointment that I had with Albert once he was transferred to me, I brought him in to med clinic, and I asked him if he needed me to go back with him. Because, he had some difficulty with reading, and he was like, no, because I can listen, so I don't need you to help me. So, he was able to listen to it...He told me he enjoys, he enjoys the Common Ground part. Now, he might not so enjoy the med consultation part, because he has a lot of delusions around his meds, increasing his physical problems that he has, so that part isn't enjoyable, but he enjoys the computer part, because he's able to listen to it, and he doesn't necessarily have to show that he's not a strong reader. (P35:147)

William was a person who also had limited reading abilities. He found the peer support worker to be helpful if he got stuck.

Yeah. Sometimes, because I ain't got used to it yet... That was helpful because I'd be stuck if, like I said, I'm not computer person. I be stuck. I'll probably get it now because it's probably the fourth or fifth times to do it by myself. But if I have problems I can call her. (P11:168)

While the peer support staff are willing to help clients when they need it, they try to allow clients to do as much of the report as they are able by themselves. Samuel confirms this. He says:

Oh yes, they'll assist you. What they like to do is they like for you to try and do as much as you can without intervening. And then if you experience something difficult, then they'll be there to assist you. But they like for you to try and initiate it all by yourself. What they'll do is they'll just sit down there, and you operate it, and do whatever you want to do. If you experience complexities, you know like push the wrong button or get off track...I've did that on numerous occasions, and they'll be there to assist you. (P23:210-218)

Roberta also confirms that peer support workers do not tell clients how to answer the questions for the Common Ground report. Roberta appreciates that she is not there alone when using the computer, because she can ask for assistance whenever she needs it. She says:

Well, the people in that department, they sit there and if you forget how to work it, they will give you, they will show you what's your next step to get to the next page so you're not there alone. You always have an instructor there to help you. They don't tell you what answer to choose. But they tell you what to do, what's the instruction on how to use it. (P9:88-94)

Samuel was not familiar with using computers prior to Common Ground, but found the presence of peer support helpful during the learning process. He states:

Overall it's very positive. And I'm not too familiar with computers because I've just been introduced to them since I got here, but it's basic and it's very simple. It's auditory or you can read it, either one. And there is someone that sits there with you after it's done, make a few inquiries if you have any questions or anything of that nature. (P2:13)

Even though Samuel quickly learned to use the computers because of their simplicity, he has at times needed assistance. Having peer support there to assist him has been helpful. He talks about a time he had difficulty navigating the screens on the computer:

Well, yes I did. And one of the reasons why because I was having, I pushed the wrong button and it went to a whole different realm. And then I addressed her, I said, "Would you please assist me. I've gotten off track.," and she was there to assist me. Because I'm not educated in that department of computers. I'm not educated in that area. (P23:220-224)

One peer support worker acknowledges that even some clients who frequently use Common Ground still need assistance at times. She says:

I think that when the people come in to do the report that it's, the ones that are repeats just kind of come in and do it without a lot of attention, but some of them come in and have done it eight or nine times-or not eight or nine but six or seven times, and they need just as much help almost as the first time. (P15:10)

Albert is a person who cannot read that well. Having peer support available to them has helped so he can understand and respond to the questions on Common Ground that are being asked. He says:

I have been on them. And I don't know how to read that good. The lady in the office, she helps me out...With the computer and if I don't understand something, she'll tell me what it means or what it don't mean. Helpful? Yeah. (P16:36,68-70)

Bernice is a client who chooses to use the headphones to listen to the questions being asked. She appreciates this option being available and also having peer support there to help her if she needs it. She says:

I'm not too familiar with computers. Not me doing things with a computer. I kind of like how it, you can read it yourself or then get the auto and I like that it talks to you. And you do that and it's just you and the computer and there's somebody there always to help if you need it. And I kind of like that. (P1:26-30)

Andreas is another client who has found it helpful to be able to listen to the questions being asked with the headphones because of limited reading abilities. He says, "Yeah. I've done it before. It talks to you and you can see it, and it said to me at the same time, so I...listened to it talk and then push the buttons" (P5:9). William was initially resistant to the idea of using the computers at the Decision Support Center because of his difficulty reading. Once William found out he could use the headphones and listen he was receptive to doing the Common Ground report. He says:

See, I wasn't a big computer person so I was kind of skeptical... I ain't no big reader...And once I found how you can just push the computer and listen to it instead of read it, I said,

yeah... Because at first they was asking, like I said, I was skeptical and then I just had to say I'm going to try and then I tried it and I said I liked it because, like I said, I don't know the computer. I thought I had to get on the key and all that and spell words. And I'm like I don't want to do that. And they told me it read out the questions to you. It got earphones and you just press buttons. And I'm like, yeah. I'll do it then. But if it was as far as pushing buttons, I wouldn't have did it. I wouldn't have done it because I don't know how to use the computer. (P11:40, 144-146)

This is important for clients like William and Bernice who are now both highly engaged with using the Common Ground report as part of the medication consultation. Without this option being available, they might never have even tried using the computers.

Having someone to help the client with using the computers and filling out the Common Ground report seems to be an indispensable component of the shared decision making process. Above we find quotes from people who are highly engaged in the shared decision making process, but might not have used the computers in the first place if there wouldn't have been someone to help them. William is now comfortable with filling out the Common Ground report, but he was initially resistant. Getting him through the front end of Common Ground was critical for him being able to use the information collected on the back end.

Bernice is a person who prior to Common Ground often forgot what she wanted to discuss with her prescriber once she was in the medication consultation. She finds it helpful that the peer support worker goes over the Common Ground report after she completes it to help her focus in on what she wants to discuss with medication clinic staff. She says:

Well, we meet with someone...so they can ask us do we remember how to work the computer. They'll sit with us and start us off and we go on from there. Yeah. It has. It's been helpful. Just like when, if I don't understand something they're right there to answer for me. I don't have to wait until I get to the nurse. And even if I forgot what I wanted to say or something. (P1:64-70)

Bernice and Roberta are both clients who never said much during medication consultation prior to Common Ground. Even after being engaged in Common Ground now, they often forget what

they want to talk with their prescriber about. The peer support worker seems to help them gain focus on exactly what they want to talk to their prescriber about.

Some clients reported that some of the questions on Common Ground are confusing to them. Marcus talks about peer support being helpful, but still having some difficulties answering some of the questions. He says:

They take turns sometimes. Yeah, that's helpful. Sometimes it's helpful but sometimes not. Well, it just, because there's certain questions that have the wrong answers, I mean the answers they don't fit what I'm trying to say. (P10:49-51)

The HIAD scale can be customized by the prescriber to elicit individualized responses from the client. This does not appear to be a feature that is being utilized by prescribers. If a person is saying that a question doesn't fit what he or she is trying to say, the prescriber is able to change the question to something that is more applicable to what the client wants to communicate. This could be applied to Albert who experiences people trying to bother him. These experiences can be extremely disabling for him, especially when he perceives that people are trying to break into his apartment and violating him. A HIAD question that speaks to this could be added if this is what he is concerned about. It could also be framed in terms of the Power Statement. For example, "Your goal is to get back to work, but it seems like you are still experiencing people breaking into your apartment and violating you. These experiences must make it difficult to sleep, which is also marked on the HIAD, which could impact your ability to go back to work."

One case manager acknowledges that some of the questions on the Common Ground report have been difficult for some clients to understand. He also states that having peer support available has been helpful to some clients in gaining a better understanding of what each of the questions mean. He says:

There were just some things, when you label whether or not it's a five or a four, they were kind of unclear on what it meant. It was confusing about what those things meant...they

provided more supports and wanted to make sure people were actually filling it out correctly because a lot of people were saying when they got into med clinic, no, that's not what I meant. So now they've been able to clarify that and get a little clearer picture...they provided a person that was more, there's a full time staff down there. There were three of them I thought. And so they are more hands-on with making sure the individual is clear on the questions so they like the ability to be able to ask somebody immediately instead of trying to figure it out on their own so they feel like it's really supporting them. (P32:10-12)

One nurse noticed that some of the early Common Ground reports did not have accurate information on them. When the nurse or prescriber went over the Common Ground report with them, they would find that some clients had pushed buttons that did not accurately express what they wanted to say. The nurse attributes some of this to times when some clients might be dealing with a lot of stress and anxiety at the time of the medication consultation. If clients do not understand how to use the computers then this can elevate their stress level and potentially become an obstacle in medication clinic rather than a helpful tool. Having peer support help people feel comfortable and know how to use the software correctly is seen as an essential component. She says:

I think it can be worked through, but sometimes for clients that are dealing with a lot, there's been a few times that it does come up and everything is not at all accurate. I feel that it's helpful because I think they get to put some input or they'll come in, and I think the thing that can get in the way sometimes when they don't know how to use it or just there's so many things going on, they're not able to use it in a way that would help us gain information. Then we're kind of just sitting there trying to figure out what that even means. So the initial process of learning how to do it is going to be really important and having peer support there pretty much a lot at the beginning. (P13:44)

The actual time for the medication consultation is very limited (approximately 15 minutes). Using this limited amount of time trying to find out what the client is trying to communicate may not be the most efficient use of the prescriber's time. If this is occurring, more time may be needed outside of medication clinic helping the client understand how to use the HIAD scale and Decisional Uncertainty Profile to communicate what they want to their prescriber. Once again, getting the right Power Statement is essential. After that, it is important to think of what

information is needed from the client to help make better decisions on how to achieve the goal reflected in the Power Statement.

One of the peer specialists acknowledges that peer specialist can modify power statements and personal medicine for clients on the computer, but he also states that currently he's never done that. He states:

I've never done that, but I tell them that it can be changed, modified, you know, the power statement, personal medicine....peer specialists can do it with them or their case manager or the doctor or the nurse. (P37:51)

He acknowledges that helping clients change their power statements and personal medicine is part of the training for peer specialists. He states:

That's part of our training and like I said I offer that and then I offer them the option that they feel more comfortable with their case manager or maybe even the therapist or like I said the doctor or nurse. The doctor and nurse's time is limited so they can rely on the peer specialists or case manager. (P37:57)

One prescriber has noticed that peer support has been very helpful to some of her clients. She says:

Peer support I think has helped a lot of people who aren't really sure. Just having someone who is really just calm and helping them through it, I've noticed that has helped a couple of my clients. (P13:26)

One case manager talks about a client who was misreading the questions on the computer when he first started using Common Ground. The case manager's client may be typical of some clients who may be hesitant to ask others for help. An important aspect in this process will be having peer support workers gauge the comfort level of the people using the system and knowing when to step in and offer their assistance pro-actively. In this instance the client is developing more of a trusting relationship with the peer support worker over time. As this relationship develops, the client is able to open up more regarding the areas he needs help with and through this interaction is able to successfully use the program. The case manager says:

It's actually getting easier. I think the first time he came he was a little bit hesitant with the person working with him. But the more he's come to answer the questions, he's gotten more loose with getting more involved in asking more questions of the person assisting him. So he's got a clearer picture of some of the questions. But I think more so on his part, an aspect of not reading the question completely and not wanting to ask anyone. So he's actually more interactive now and so he asks questions now. So sometimes it was really him misreading the question that prompted his confusion. And by asking, he's been able to get a clearer picture of what they want. (P4:42)

One peer support worker views the peer support role as essential, especially when clients have difficulty answering questions because of symptoms. She says:

Well, I've seen where they are, it's very difficult for them to do the report. I've seen that happen and some people never do get done and then I have to help them with that, or at least they haven't yet. And that's one reason why I think that they should always have somebody there like myself working with them because when they're in their symptoms and stuff they can't read real well or even listen. They still don't know how to answer a question and I have to clarify the question for them. (P15:46)

The peer support supervisor explains that the role of peer support is not just helping people navigate the screens of the Common Ground report, but also to help them understand the questions and use them to communicate more effectively with their prescribers. She says:

It seems like there's two aspects sometimes and there may be more, but of a role there with the peer specialists in terms of them helping people at the computers, and one is a technical aspect of just how to get through the program and there's also a teaching component to help people understand certain things that they're doing. (P38:17)

One case manager views that the clients he works with have felt supported by peer specialists in understanding the questions that are asked of them through Common Ground. He states:

And so they are more hands-on with making sure the individual is clear on the questions so they like the ability to be able to ask somebody immediately instead of trying to figure it out on their own so they feel like it's really supporting them. (P38:12)

Samuel finds that the peer support worker helps him to gather his thoughts after completing the Common Ground report so that he can communicate what he wants to his prescriber. He says:

And what they'll do is after we're done, they'll give me a blueprint of what I said on the computer. And then they'll share that information. Now what I do is like if I have trouble

with my medication, I'm hearing voices or having visions or just feeling depressed and inactive, I document all that before I see the doctor. (P23:228-230)

One case manager views that peer support workers present things in a way that is different from other staff. He says:

The peer specialist actually breaks it down into a different level. So they don't, my people don't attach that to the doctor and nurse. The doctor and nurse they still see asking the same questions, but the peer specialist puts a new spin on it. (P4:46)

One prescriber notes that a peer's perspective might have more credibility for some clients because of having a shared lived experience. For clients that prescribers have had difficulty engaging in the past, the prescriber views that interactions with peers at the Decision Support center might re-open doors to engage with people around Common Ground. He states:

Where they have other peers that can give them a message, it's much more credible than what I could ever say. And, I think having peer support structure center at DSC is probably ultimately going to do that as well. I can certainly help people, but you know, if somebody doesn't buy in to it, the medical profession, or they don't buy in to the diagnosis or they don't want to take the medications, I don't think I have a lot of credibility with that person. But, when they talk to a peer for a little while and find out that somebody who seems that they can identify with is, has schizophrenia and is in recovery, then, we can, kind of, start over again. (P40:244)

Helps with the completion of Common Ground tools following the medication consultation

A valuable function of the peer support role is the support they can offer clients following their medication consultation. One thing they are able to do is help people access information they might want regarding the diagnosis they have been given or the medications they have been prescribed. A crucial element is that peer support workers do not provide people with answers to their questions, but rather shows them how they can find information about the questions they do have. The Common Ground software has embedded within it multiple links to exploring additional information for each question on the report. While these options are available to everyone using the software, some clients might not explore these links without prompting from

the peer support worker. As the peer support supervisor points out, clients have to be exposed to the fact that they have these options available. She says:

Right. Which underscores the importance of the peer support. Simply having an option doesn't support people in choosing an option. Sometimes you have to get a glimpse of what the option means. If somebody says here, take a bit of this, I want more information than that. If somebody says I have three spoonfuls of something, you can choose. I want more information than that. And historically we've not given people that extra information. So the peer support really can be that extra source of information, and even there's value in saying well, if you were to push here, these are the kinds of things you would see. And they can actually push the button and show the person. (P38:14)

The peer support supervisor views that peer specialists have a role in helping clients find out needed information via the internet that would help them to make better decisions during the medication consultations with their prescriber. She states:

A person for example is saying that I don't think the medication I'm prescribed is even working. It seems kind of like there's an expertise that would say that would you like to find more information about the current medication you're taking, which may include also its success rate. Or if a person for example said that I'm feeling some side effects from a particular medication, I noted that on Common Ground, of asking a person would you like to find more information about the side effects that are commonly associated with this medication? To me this is valuable information for a person to be able to have, so maybe even go into a doctor appointment and saying I've looked at some of this information. Can you talk with me more about it? (P38:81)

The peer support supervisor states that this is something that peer specialist are not currently doing, mostly because they are still learning their role in medication clinic as it relates to what the prescriber will be doing in the actual medication clinic. She states:

And that's going to be a lengthy process because the peer specialists have to learn that they can do that and be comfortable with it. And we're asking them to learn that and become comfortable with that while surrounded by people who aren't doing it. (P38:71)

What the peer support supervisor is referring to is her perception that there is still not a clear framework developed for consistently using the shared decision making process in medication clinic and making use of multiple sources of information that can be obtained through Common Ground to enhance decision making. The peer support supervisor views that some prescribers

have started to make more requests for information from the peer specialists following medication consultations, but also views that further clarity on the role peer specialists and prescribers play in the Common Ground process and mutual trust between prescribers and peer specialists still needs to be developed. She states:

The software program allows the access to that information at various points. So the consumer can access it. The peer specialist can access it. The prescriber can access it. Right now, though, I can tell you the prescribers are going to be uncomfortable if the peer prints out an information sheet and says here's the information about the efficacy of this medication and so why don't you take that in to your appointment? Because the minute that happens, there's going to be an accusation about scope of practice. But what does exist now are decision aids that people can take somewhat softer and safer steps towards that, that the consumer can use before or during or after an appointment and get peer support with that. And kind of where we are in that process of developing bi-directional trust in each other, there are prescribers who will come out and say this person would like some information on this medication. Can you help them get it? And that wouldn't have happened a year and a half ago. But it's happening now. (P38:83)

Another support that peer support workers can offer is helping people fill out tools associated with the Common Ground report. Some of these tools include: Decisional Balance Worksheet, Trade-off Worksheet, Medication Trial Calendar, Personal Medicine Worksheet, Mood Diary Worksheet, Exploration Calendar Worksheet, Time Capsule Worksheet, etc. Each of these worksheets are possible interventions that can be used to address concerns that a client and prescriber might discuss during the medication consultation. While time limits prescribers from being able to do these tools with people in medication clinic, it seems like a perfectly suited role for peer support to assist people following the medication consultation. One case manager views peer support as being helpful in this area. He talks about one client who is now using some of the tools:

He's actually working on a calendar and some other tool that he set up with one of the peer advisors downstairs, which I'm really proud that he's doing it himself because he also has issues with reading and writing. And usually I have to support him in everything he does. But he met with one of the peer advisors downstairs and they developed this calendar that he's been following... It's something to do with symptoms and medications and how his

symptoms act each day because of the medication adjustment. So he's keeping a record, a calendar of how his symptoms are while he's having the medicine reduced...And he hasn't asked me to help him with it at all. (P32:52)

William, Bernice, Samuel, Roberta, and Mary are clients in the study that have used the tools embedded within Common Ground to help them move forward in achieving their goals. Marcus and Maria were the only two clients from the group of participants for whom the shared decision making process was working well that were not actively using the Common Ground tools. None of the clients for whom the shared decision making process was not working well use the Common Ground tools.

One prescriber talks about using peer support to help with Common Ground tools following the medication consultation. While he still refers to case managers when completing tools that require a longer term commitment, he sees a role for peer support in helping with certain things that may need immediate follow-up. He states:

You know, it's kind of split. A lot of the different diary type things we may ask the case manager to help with, or we may just give it to the consumer, and they may do it on their own. Different internet searches, I've tended to ask the DSC to help with that, and there are some really helpful coping tools for hallucinations, and I've tended to ask the DSC to help people with that. The things that tend to be short that I'm afraid will just get forgotten if we don't do now, I tend to ask the DSC to do that. (P40:304)

Now with three peer support staff available to help people, one prescriber says he is using peer support workers more to assist clients. He says:

I think, now that we have more staff in the DSC, I'm able to refer people back out, consumers back out, to the DSC after their visit to work on internet searches or that sort of thing. I think that's going to be more helpful to be able to continue to do that. (P40:300)

The peer support supervisor talks about the role of peer support in helping people use Common Ground tools:

The program is structured in a way that allows the shared decision to indicate who's involved in the follow-up. And there's an array of people who could be involved. And at its best that's going to be driven by the client. Who are they most comfortable working

with? As a matter of course, I would really love to see people come and do a check-out for a couple of reasons. I think that people should leave with a copy of the shared decision, a printed copy. And then if any kind of decision aid is referenced, that is a printed decision aid, I think they should leave with a copy even if they're going to be doing it with somebody else who has access to it, so that they can begin pondering it. I mean much like homework, not that any of us do it, but frequently if you start it immediately it's easier. (P38:89)

Having a check-out would be a great way for the peer support to help make sure the client understands their next steps in the decision making process and has the support they need to take these next steps. Of course this will work better if a real shared decision has been made in medication clinic that the peer support worker can follow-up with. For example, "It says here that you have decided to try a new medication and that you want to start a side effect calendar to monitor any possible negative effects of the medication. Let me print this tool out for you and show you how to use it. Will you be the one filling this out or would you like some assistance?"

Videos

Another method of peer support that was found to be helpful to clients were the videos embedded within Common Ground which featured first person accounts of recovery. These videos seemed to resonate with people's experiences, give hope, or encourage them to go further in their recovery. All of the clients for whom the shared decision making process worked well responded positively to the videos except for Bernice. None of the clients for whom the shared decision making process has not worked well viewed the videos, except for Helen, who responded positively to the videos.

Samuel talks about watching the videos:

I come here for my doctor's appointment and prior to going to my doctor's appointment, they have a video of people and what they talk about, they talk about their recovery plan...And what happens with the video, we see that progress in the doctor and what that does is that educates people about, you know, mental illness and avenues that they use to help them with their mental illness. And overall it's very positive. (P2:11)

Roberta became engaged with the videos because they had one that resonated with her life experience. She was able to relate to the woman on the video because she also had a child. Since Roberta's goal for medication clinic was to be a better parent for her young son, she was able to apply what she learned from the woman in the video to her own life circumstances. She says:

Then they have films on there. You have an option that if you want to listen to a film and I always push no. And the instructor, peer instructor, she told me go on and pick one. And I went on and there was a lady with a little girl and it was about me; me and how I felt the way I wanted to be with my kids and what did she do to get through her healing process of a mental illness. And it was a positive feeling for me. And I applied it to my life. I went on and got into a group. She went to group and stuff like that. And it was like a push for me that there are things that I can do that would make me better for me and my child. (P9:96)

Roberta now views the peer on the video as a role model for her in her own recovery. She states:

And I had withdrawn from groups because I had so much going on at home. After I seen that film on that lady with her little child, she went to group and it was helping her with her recovery. So I'm sticking to it because I found a positive role model. (P9:204)

Roberta looks forward to coming into the Decision Support Center just to watch the video. It increases the hope that she can move forward in her own recovery and achieve the goals she wants to achieve in life. She states:

I looked forward to it because I want to hear that tape again so that lady can remind me how I can be well. That's what I look forward to. You've got to have inspiration people around here. (P9:238)

Samuel also finds the videos encouraging in his own recovery journey. What helps Samuel is listening to the struggles that each of the clients on the videos has faced and how they went about overcoming these adversities. He says:

I watched the one about the middle-aged lady. She was talking about her struggles with mental illness and her being hospitalized, and you know, how she had her positive statements and things of that nature, and that was terribly encouraging. To see someone, you know, go through all those adversities and complexities, and then they've developed a, you know, good stable life. You know, I'm very pleased with that. (P23:190-192)

The videos have the same impact on Marcus. He states:

Like how they got over their mental illness. How they started their life different. How they got new things for their life. How things are better for them as far as it ever was and getting over their illness and like what they're doing now with their life and how they're productive and they talk about the parents or having children or getting a job or something. (P10:101)

The videos gave ideas to Marcus about what he might look forward to in his own recovery journey and what things he might need to be aware of. He states:

What happens when people recover from medicine. What people are heading for after recovering. What they were careful of doing after recovering from mental illness. (P10:173)

William also finds the videos helpful in this regard. He states:

Yeah. I listen to those... You know, they talk about their problems because they've been through it or they have a problem around depression or alcohol... They let you see all their situation and how they got over it but you can do the same. (P11:156-158)

One peer specialist notes that at times she has seen clients become overwhelmed with emotions after watching the videos. She states, "There have been people coming in crying or started crying in the middle of the tape" (P15:6).

One case manager reports that the clients he has worked with have responded favorably to the videos. He states:

I just know it always asks do you want to watch a video, and they're always saying yes and they enjoy that. I've just gotten good feedback on it. That's been positive. (P42:142)

Bernice was the only client from the group of those for whom the shared decision making process is working well that did not enjoy the videos. She explains her reasons below:

I don't watch them at all. It seems like it triggers me. It doesn't help me. It seems like, and if it's something negative, I just don't want to hear it. I'm the opposite, but I know a lot of people that listen to them. I just don't want to hear the negative. I got a problem with hearing negative things. Even if it didn't happen to me, I just don't want to hear it. It just bothers. It just traumatizes me, I guess. It's kind of like trauma to me. I don't know what brought that on, but it, that's kind of where I'm at. (P28:546-554)

Helen was the only client from the group of those for whom the shared decision making process has not worked well to watch the videos. She was overall positive about the videos because some of the things said by peers gave words to things she was not able to express herself. She says:

I like to hear their stories, yeah. I mean I'm sorry that they go through it, but it makes me feel better because some of the things they say that you can't say, they've said it for you. And you listen to what they've done and they are getting well. (P22:129-133)

But Helen does not relate to all the people on the videos and views their experiences as different from hers. She says:

But some of those people on that video don't have the problem that I have. They conquered theirs, yeah. It's kind of nice here that somebody has made it. (P22:161)

But Helen still holds out hope for recovery from watching the videos. She says:

I have hope, but I'm just hard. Maybe I'll be like one of them people. (P22:141)

Conclusion

Currently, the role of peer support is evolving. They are an important component to the process in terms of helping clients feel welcome upon entering the medication clinic and being comfortable using the Common Ground software. Peer support seems to be critical in helping some clients use Common Ground as a means to effectively communicate with their prescriber. Peer support also seems to serve as a visible symbol of hope to some clients. Some clients already knew peer support staff prior to using Common Ground, others felt they could relate with peer support because of perceived commonalities.

For those for whom the shared decision making process worked well, peer support was viewed favorably. At times, some of these clients continued to need guidance in filling out the Common Ground report. Besides providing concrete technical assistance, the mere presence of peer support seemed to offer reassurance or instill confidence for some clients. Even the clients

for whom the shared decision making process did not work well spoke favorably of peer support. At minimum, this suggests that peer support was not a barrier for these individuals engaging with Common Ground or the shared decision making process.

At the same time, it seems that peer support might be underutilized. One function of the peer support role is to assist clients with developing or changing power statements and personal medicine. This does not seem to be an activity that peer support regularly performed, and it did not occur at all with the clients in the present study. While there is some indication that peer support is more involved in doing this since the study's completion, it might still be important to re-emphasize this role considering that power statements and personal medicine rarely changed on the actual Common Ground report for any of the clients in the study.

Keying in on the clients power statement might be a good starting point for peer support engaging with clients around the Common Ground software, especially in light of the importance of the client's goal to shared decision making discussed in theme three. They might consider asking the question "What do you want to achieve by coming in to medication clinic?" They should be able to recognize a passionate Power Statement from a weak one. They should be able to probe a little with people. If people are talking about reducing symptoms or addressing a particular medication they are taking, they should follow with "And what do you hope to accomplish by doing that? Most of the clients in the study had something passionate that they desired to achieve, but the Power Statements that were on their Common Ground report did not reflect this. Peer support workers may be in the best position to flag this for either the prescriber or the case manager to follow-up on or to explore some of this with the client themselves by pulling out the Power Statement Worksheet.

The same could be considered with personal medicine. Peer support workers could ask if there is additional personal medicine they may have been using that is not listed on the Common Ground report. Each interaction peer support has with clients could be an opportunity to engage with the client around personal medicine, and when possible tying the relevance of personal medicine into the goal they have for medication clinic.

In the next theme, we will look at the role of another auxiliary support, case management. Some of the functions peer support provides overlaps and sometimes duplicates functions intended for case managers in the process. After the next theme, we can review how these two supports might fit together.

Theme 6: Case Managers vary in the extent to which they support client's use of Common Ground, but can serve as important auxiliary supports in the shared decision making process.

Case managers can be a strong source of support for clients using the Common Ground process, but the level of support by case managers varied among participants in the study. At one end of the spectrum is the support that case managers offer at the front end of the process. This consists of encouraging clients to use the Common Ground process and assisting clients with preparing for medication clinic visits by helping clients identify personal medicine and developing power statements. Case managers can also be a support during the medication consultation by helping facilitate communication between the client and the prescriber. At the back end of the process, case managers can be a support by helping clients follow-through with various aspects of the shared decision arrived at during the medication consultations or working on various Common Ground tools that will help provide more information for upcoming medication clinic visits.

A few factors seem to impact case managers' involvement in the Common Ground process. One is the case manager's belief in the importance of the Common Ground process. Some case managers view the Common Ground process as important to the client's overall well-being and see a connection between what occurs in medication clinic and the work they do with the client outside of medication clinic. Other case managers may value Common Ground, but there appears to be a disconnect between what transpires in medication clinic and the work they do with the client in the field.

Another factor has to do with the case manager's perception of time they have to devote to supporting clients with Common Ground. Several potential barriers exist that can impact a case

managers attention to Common Ground. One of these is current caseload sizes. Some case managers have difficulty fitting in activity specifically related to Common Ground because of needing to devote time to all clients they are working with. Other potential barriers stated included the agencies emphasis on meeting productivity standards, crisis situations, paperwork and other administrative demands.

Case managers supporting client's use of Common Ground

For some clients it is important for the case manager to be patient, yet persistent when engaging the person around the use of Common Ground. As mentioned previously, the shared decision making process is a significant departure from how medication clinic appointments were structured in the past. Some clients may feel intimidated or uncomfortable with the presence of computer kiosks at the Decision Support Center. Others may be unsure of what will be expected of them once they enter medication clinic. One case manager finds that a client she works with initially did not want to use Common Ground prior to her medication clinic appointment, but did not give specific reasons why she didn't want to use it. Her case manager gave her some time and then re-introduced Common Ground later. The case manager says:

I have another girl that she said she didn't want to do it and didn't want to explain. She really didn't give me a particular firm reason why she did not want to do it. She just didn't want to do it. Then I presented it to her at another time like within maybe two months. I gave her enough time so maybe it was a different day kind of thing, and she signed for it. (P20:26)

Since most clients that were approached with using Common Ground agreed, most case managers probably had an easy time with their standard spiel on the benefits of the new process. It is for the few clients that were initially resistant or reluctant to use Common Ground that case managers needed to extend themselves beyond the initial invitation. Here a case manager's perception regarding the value of the Shared Decision Making process might be a factor in how

they engaged with a client around Common Ground. If the case manager perceives that the process could potentially make a difference for the client they are working with, they may be more likely to continue to engage the client around trying the process. Here one case manager struggles to think of ways she might be able to engage a particular client who initially did not want to go through the new process. She says:

There's one lady that I tried to engage her with it, and she seems to be apathetic and I keep trying to bring the subject back to her, and I keep wanting to find out ways on how I can present it to her differently. So now I'm trying to think okay how else, you know, would it work for her. She comes regularly to the clinic because she gets shots. And I really would like her to use it because it's something that's she's been doing like for 15 or 20 years, and there are other things that I think she could really benefit from. But she does not like computers. So I said I understand but give it a shot. At least she did try it. (P20:8-16)

Another case manager also views persistence on the part of the case manager as being important in helping clients become engaged with the Common Ground process. Initially many clients might not see how the Common Ground process can help them with what they want to achieve, but the case manager views that over time more clients begin to make these connections.

He states:

They really don't make a connection of how it is really going to help them. They probably kind of see it as silly, unhelpful. I'm hearing less of this is worthless type of things and less complaining about I've got to go and do and the eye rolling and stuff. There's a lot less of that. I think people are slowly starting to understand how it works. I think when it's new information and change, it's always kind of difficult. I think it's just adapting to the change. I think it's the persistence. You end up drawing the connection of "Oh, actually I do see that" after you hear it a few times or think about it more than just being presented, like the first time it's presented, you're kind of like yeah, great. I always try to be as consistent as I can so I feel that I'm not changing anything, so they're making the changes. And they do it because - and that's the persistence on our part just telling them to work through it and maybe it will help you. Finally sometimes it does. It does help. (P42:18-30)

As mentioned earlier, some clients are resistant to using Common Ground at first or do not see the immediate connection of how Common Ground can be of benefit to them. The case manager can be another source of support on the team to help them make this connection. One

nurse talks about one client who started to take more of an interest in Common Ground through his discussion with his case manager:

I had a client who told me that yesterday he actually read through the questions, thought about it, and then answered with what he really thought, whereas he said all the other times he had come in, he just pushed buttons because he really didn't care. He said yesterday was the first time that he had not just pushed buttons just to get through it because he didn't want to really deal with it. I think he and his case manager had discussed it quite a bit, and he had kind of admitted to her that that's what he was doing. (P12:54-58)

One case manager uses the analogy of driving a bus to help clients understand how they can increase their level of self determination at medication clinic. Here he refers to how he uses this analogy to convey being a passive recipient of decisions during the medication consultation versus being an active participant. He says:

I try to use that analogy (driving the bus). It just depends on what they like to do. So I use the analogy of what they like to do and how they can obtain it. And a lot of people want to drive so when I equate their med clinics to driving as opposed to being a passenger or driver sitting in the backseat, they seem to understand that a little better. (P4:68)

Table 5
Change in Client Responses to Common Ground by Case Manager

| Case Manager | Client | Initial Response | Current Response to Common Ground |
|--------------|---------|------------------|-----------------------------------|
| Perry | Bernice | Open | Engaged |
| Perry | Marcus | Open | Engaged |
| Perry | David | Resistant | Resistant |
| Perry | William | Open | Engaged |
| Perry | Andreas | Resistant | Resistant |
| Kim, Perry | Roberta | Open | Engaged |
| Kim, Monica | Albert | Resistant | Resistant |
| Kim, Rose | Maria | Open | Engaged |
| Liz | Jason | Resistant | Resistant |
| Paul, Liz | Helen | Resistant | Resistant |
| Monica | Mary | Open | Engaged |
| Rose | Samuel | Open | Engaged |

Each of the case managers involved in the study had at least one client who was engaged in the Common Ground process except for Liz and Paul. All of the clients that were initially open to using the process eventually became engaged in the process to some degree. Two of the clients who were highly engaged in the process, Samuel and Mary, would probably have engaged in the process even without case management support. These were two individuals who already had well established goals prior to Common Ground and easily made the connection to how Common Ground could help them achieve these goals. Marcus was introduced to Common

Ground by his case manager, but actually became engaged in Common Ground because of his interactions with the prescriber around his personal medicine. While Marcus's case manager supported his use of Common Ground, there was no evidence to suggest that his case manager was a key activation point for helping him further engage with Common Ground. The same could be said of Maria. Maria eventually became engaged with Common Ground mostly because of her positive interactions with her prescriber around the shared decision making process.

Of the three remaining clients who are now engaged with Common Ground (Roberta, Bernice, and William), efforts by the case manager proved to be invaluable to helping them become engaged in the process. While all three were open to using Common Ground initially, each of these clients had some reservations about using the process. For Roberta, it was the fact that she had experienced information being negatively used against her in the past, therefore was cautious in sharing information about herself now. For William, he had not felt heard in the past and therefore was cautious in how the current process could help him. Bernice was used to a more passive role in medication clinic and did not view herself as being able to contribute much to the discussions. What helped each of these clients was being engaged around a goal that the case manager supported (Roberta – caring for her young son, William – being able to spend more time with his family, Bernice – taking better care of herself so she could support her adult son). The case manager was able to communicate the benefits of Common Ground in the context of how it might help them to achieve this goal. Once they started making progress on these goals in medication clinic, they became further engaged in the Common Ground process.

This also lends some insight into the individuals who are still not currently engaged in Common Ground. Neither Jason, David, Albert, Helen, or Andreas were engaged in a goal that

was important to them with their case managers. This made it difficult to help the client make connections to how the process might help them. While all of them tried the Common Ground process, each of these clients did so more because they thought it was a requirement of seeing the prescriber. Without a goal guiding the discussions during medication clinic, these clients became further resistant to using Common Ground as time progressed. David and Jason have now stopped using Common Ground completely, and the rest remain sporadic in their use of Common Ground.

Besides engaging with clients around goals to communicate the benefits of Common Ground, engagement around the client's personal medicine seems also to be an avenue for case managers to introduce the value of Common Ground. In some cases, the discussion of personal medicine can lead to discussions about goals that eventually become Power Statements to guide the shared decision making process in medication clinic. This can be seen with Bernice, William, Samuel, Roberta, Mary, Maria, and Marcus.

One case manager talks about strategies she uses to help people think about personal medicine:

I'm trying to bring magazines or something. See what would interest them. Take them to a bookstore, and see what else would you like to read. Is there anything else that you would like to, be interested in looking at? You know, to try to balance things out a little bit.
(P36:175)

The concept of personal medicine has not only initiated a transformation in some clients, it has also led to the transformation of some staff. One case manager talks about this transformation for team members after the introduction of the concept:

I think for the most part our whole team just has a different, well, we had our own paradigm shift. And I think we're all pretty excited about Common Ground. So at first it was like no more power anything, but once we really started seeing breaks, I know at least for me when I really started seeing breaks, what personal medications were all about, it's just another part

of what we do to help our clients have a good quality of life so I think it's very beneficial. (P19:81)

One case manager talks about her own personal transformation:

And then it made me kind of challenge some of my own beliefs because at one point I was like okay, 'are you taking your medication? You need to make sure you take your medicine.' And they would get more depressed and they are more psychotic and then after really just reviewing my own beliefs and realizing that it's more to life than just taking medicine. Now I'm quick to ask them do you recall when you stated that going outside and walking helps you with your depression? Are you doing that? And so I can say once my mindset changed about personal medication, and I actually started embracing it, it didn't become such a challenge. It wasn't like extra responsibility. It was what can I do to help my clients? This is really helping our clients, helping them to be their own advocates, helping to empower them. So after I changed my mindset, it wasn't such a burden anymore about helping them complete their personal medication worksheet. (P19:77)

The concept of personal medicine seems to change the dynamics in which case managers' talk to clients about their medicine. Prior to Common Ground, there was evidence some case managers were limited to a compliance/non-compliance framework of medication use. With the underlying philosophies of Common Ground, they began to view medications as one means among many to help the client achieve something. This change in viewpoint allowed some case managers to begin thinking about a person's goals for life. This change was important for clients like William, who had been receiving injections for almost 25 years. In William's case, compliance with his medication was often stressed and reinforced through the use of an out-patient court order. Through Common Ground, his case manager started to engage with William about what was important to him (spending time with his family) and framing the use of medications within that context. In viewing pill medication as only one means to benefit him in this endeavor, the case manager also started exploring the use of personal medicine with him. The dual components of placing a goal at the forefront and elevating the use of personal medicine alongside the use of pill medication provided a powerful combination for engaging William in the Common Ground process.

The transformation in philosophy has resulted in some case managers making discussions about personal medicine a routine part of their practice. One case manager says:

I do, on a regular basis...when I meet with people...talk about the personal medicine, you know, the things that make them feel good. How've you been doing this, how often are you doing that, the things that we had established that they have told me that they enjoy doing. How...can I help you, or how can you work it into your schedule, or how can you get to do those things that make you feel good. I do that on a regular basis. (P36:171)

Another case manager views that the language of personal medicine is becoming more commonplace within the agency. Whereas previously case managers would place a strong emphasis on clients taking their medications, they seem more willing to explore personal medicine when they decide not to. The case manager states:

I've heard it from several consumers, and I've seen it in a lot of treatment plans, so that's encouraging, and I've heard a difference in philosophy from case managers and consumers when they've decided not to take medication, that there is something active or proactive that they can do still, instead of just waiting for something to happen as far as their symptoms, so, that's been very positive. I've liked that. (P34:107)

Some case managers in the study reported they had clients that decided to go off medications or drastically reduce them. Rather than make compliance the issue, there was evidence that many case managers supported clients in their decisions around medications and sought other means to help them stay well. One case manager talks about how Common Ground gives her direction on what personal medicine can be used when clients make the decision to reduce or forgo pill medicine:

It also gives you something with the personal medicine. Okay, this is what I can use. I had someone that decided to get off meds right now...I'm seeing a trend right now. So we're working with the personal medicine right now. (P20:130)

Some of this change in role around medications for case managers may be attributed to the fact that these decisions to reduce or forgo medications are supported by the prescribers in medication clinic. Another case manager also confirmed that she was doing more work with

clients around personal medicine to support clients when they decided not to use pill medicine.

The case manager's stance regarding the client's decision not to take medications seems to take its directive from the philosophy that prescribers hold about medication compliance. The case manager says:

One of my clients, she was coming in to med clinic, and she was on outpatient court order, but she doesn't do oral medications, or shots. She doesn't do any type of medications, so we really focus on her personal medications to help her in managing her symptoms. Through us working together, she identified she might be having panic attacks, but she is just against medications. So, being able to have personal medications to fall back on has really been key in keeping her stable so she doesn't have to go into the hospital. (P35:75)

The case manager talks more about her prescriber supporting the clinic in the use of personal medicine rather than forcing the issue of taking pill medication. She states:

Like she (the prescriber) said, she can't force anyone to take medications. We can't force people to take meds. All we can do is recommend it...But, she was really supportive of her not wanting to do meds. She was like, okay, if you decide that, eventually, at some point, you want to do meds, you can come back into the med clinic. But, she didn't force the issue with her at all, so, I thought that was really good because she didn't push the meds on her. (P35:83)

A factor that helps in this is the level of communication between the case manager and the prescriber. In the instance above, the case manager and prescriber are continuously e-mailing each other. Plus, prescribers are coming to the case management team meeting where specific situations can be discussed in more detail. When the philosophies of the prescribers and case management staff are aligned and sharing of information between the two providers occurs regularly, an environment is created in which the client can be supported in their decision by all those involved. A case manager describes how communication is kept open between the case manager and the prescriber:

They know what's actually going on coming to our team meetings, and plus, we were emailing each other, because when (the client) told me that she wasn't doing medicines...I conveyed that to (the prescriber). I sent her an email, then she came to team, and we also talked about it personally. Plus, when she was going into the med clinic, (the prescriber)

would email me, or she would catch me in the hall and let me know that (the client) told me she wasn't taking her meds. We just had a really open dialogue. We made sure we both were on the same page, and what she was telling each of us was adding up. So, (the prescriber) was supportive of her not taking meds, and I was supportive of her not taking meds, because I knew she wasn't going to take them anyway, so there was no use in forcing the issue. So, we fell back onto the personal medications. (P35:87-91)

The case manager mentions that the case manager and prescriber being on the same page has helped them both work together to help the client become more engaged in the Common Ground process. She says:

It does, because when we first started working together, she was like, well, how often do I have to meet with you and how often do I have to go to the center to that med clinic thing, and so now, she doesn't focus on that, because, she knew she wasn't going to take medication. And, she didn't want anybody to force her to take medication, and it was kind of, at a point in time, kind of making her resistant to engaging in treatment. She was wanting to meet with me, because she didn't want to be seen as not following her outpatient court order, but once (the prescriber) told her, you know, we can't force you to take meds, you don't even have to come to the med clinic if you don't want to, it kind of seemed like a burden was released off her. Her rapport with me has been really great, and we get a chance to engage in things in the community. Now...just we focus so much on the things that she enjoys doing that helps her in managing her psychosis. To me, it has made our relationship just so much better, because we can get out there in the community and actually work on things that will give her enjoyment and make her move along in her recovery. And, she's not focused so much on being compliant with her outpatient court order. (P35:95)

Another case manager also reports being in constant contact with the prescriber regarding specific clients. Case managers report that sometimes they may need to mediate communication between the prescriber and the client. The case manager talks about how sometimes communication breaks down between one of her clients and the prescriber following medication clinic. By checking the information on Common Ground after the appointment, she is able to meet with the client to discuss further what is going on. The case manager says:

I'm able to get (the prescriber's) perspective and then get the client's perspective on what's going on because sometimes those are different. And then I can either get in there and mediate or I reiterate something that was said in the clinic to help her be able to further understand how these medicines are supposed to be working. (P31:83)

This case manager's style was more to let clients do the Common Ground process independently of her and for them to initiate conversations around the Common Ground report if they wanted. While this might work for clients who are actively engaged in using the process, it does not work well for clients like Helen, who are suspicious of how the information is going to be used. For people like Helen, who acknowledge needing some type of help, this would be an opportune time to help them see how the information collected on the Common Ground report could be helpful to them in meeting stated goals or overcoming difficulties they are facing.

Case managers supporting clients during the medication consultation

Most case managers did not attend the medication consultation with their client unless the client specifically asked them to or if the case manager was worried about the client not being able to communicate with the prescriber what they were currently experiencing. One case manager reports currently attending medication clinic appointments with about 20% of the people on her caseload. She discusses the reasoning behind why she might go into medication clinic with one of her clients:

It's only about two or three of my clients that I go in with, that they personally ask me to go in with them to help convey their symptoms or convey their concerns. Normally, if they don't ask me to go in with them, or if they're not symptomatic at that time and I'm not concerned they might not disclose what they've really been experiencing, I tend to let the med clinic be...their own responsibility. Because, they have the rapport with the psychiatrist just like they have their rapport with me. So, I don't go in too often, unless they ask me to go in there with them. (P35:35-43)

A benefit for the case manager being present with the client during the medication consultation is that the case manager gets to hear directly the shared decision that is made between the client and the prescriber. This allows the case manager to follow-up immediately if they need to be involved as a support for the client between visits. Since the case manager has access to the

information on the Common Ground report at the time of the appointment, they might not go back and access the report later. One case manager says:

The clients that I go into med clinic with, we don't go back in and look at it, because I'm there. I'm typically there with them, and I'm looking at their report, and I'm in there with (the prescriber) when they're discussing what their shared decision is....so I'm getting that information, plus hearing what their shared decision is. (P35:107)

One case manager notes that for the clients she brings in to medication clinic, but does not attend the actual appointment, she routinely asks them if she can view their Common Ground report. Since the Common Ground report provides a historical record of how the client states they have been doing in various areas over multiple clinic visits, the case manager can readily see if there are significant changes. As with prescribers, case managers are often drawn to the areas highlighted in red, which signify an area of concern that the client has noted. Being present with the client immediately after medication clinic allows the case manager to discuss this with the client and take action if needed. The case manager says:

I try to make sure, especially for the people that I'm actually bringing in to med clinic, say, I'm just bringing them in, and I'm not going through it, we discuss beforehand things that might be different for them at that time than when they went in to med clinic last time, and then I ask them do they mind me seeing their Common Ground report. And, if they have any red highlighted issues, we discuss that, so, to me, that kind of justifies me not going to the website so much and seeing that (the Common Ground report), because I ask them to see it when they leave out of med clinic. (P35:143)

Another case manager rarely goes in to medication clinic appointments with her clients. As with the previous case manager, the level of symptoms that the client is experiencing becomes a deciding factor. In this case manager's case, language barriers also become a factor determining whether or not she is present. The case manager says, "As needed. No, not a lot of them. It depends on if they are very symptomatic" (P20:48-52).

Another case manager tries not to talk much during the medication consultant when she does attend with her client. Her approach is to encourage the client to enter into the decision making

process with the prescriber, since she believes what is being discussed at medication clinic impacts the client's life not hers. The case manager describes her role as prompting the client with responses that she knows the client is concerned about. She says:

Because I am not really supposed to say a whole lot in those med clinic appointments. It's not my intervention with her and I can just prompt her. "Well, remember when you said this?" I can't say it for her...It's a good thing. (P33:58)

One prescriber views that the level of case management involvement with medication clinic is split between the members of the team in the study. Some case managers are highly involved and communicate regularly with her, while others she rarely hears from. She says:

It's always better when you know the case managers and certain ones...really like to be involved with med clinic, and then, and they'll email you about everything...which I really like. I think some people might not be sure about what goes on in med clinic, and so, then, some people are a little bit hesitant to necessarily talk with you, but, I would say it's half and half. (P41:423-427)

The prescriber notes that there are clear benefits to case managers being involved. She views that when case managers are involved they are able to help the client better prepare for the medication consultation. She also sees case managers as a valuable source of information that can enhance the decisions being made in medication clinic. For clients that she is just starting to work with, the presence of the case manager can also help to facilitate the building of that relationship between the client and the prescriber. The prescriber also notes that areas marked in red on the Common Ground report are often ones that the case manager should be aware of since they are things that could possibly be addressed outside of medication clinic. She says:

It would be nice if they wanted to sit in on...an appointment...because they really do prepare people for what is going to be going on with it...I mean they have a lot of helpful information, and a lot of times, they have already developed that rapport, so...if I haven't developed the rapport with someone, maybe just the fact that their case manager is okay with me really helped. Or, their case manager knows about this, then, it helps. Well, I'm just thinking that if a person marks in red sleep, that's not something that just happens in med consultation. I mean, it's something that happens when they go home and the next week and

the week after that. And, I think for a case manager to be very aware of that...meds aren't the only thing that impacts sleep. (P41:435-445)

The prescriber seems to refer to a potential disconnect for some case managers in terms of the relationship of what goes on in medication clinic and what case managers do with clients outside of medication clinic. Ideally, case managers would help a client set a goal outside of medication clinic that would serve as the basis for the work they did together. This goal would become a power statement if the client wanted assistance from the prescriber in achieving this goal. What occurs in medication clinic would be directly related to what the client and case manager worked on outside of medication clinic. Case managers would then be interested in what occurred during the medication consultation because it would relate to their own efforts in helping the client achieve a particular goal.

This seemed to occur with clients such as Bernice, Roberta, and William, clients for whom the shared decision making process is working well. The case manager's involvement throughout the process seemed to encourage a higher level of engagement with Common Ground as time went on. Samuel and Mary were highly engaged with Common Ground from the beginning, so their case managers seemed to take their direction for involvement from the client. What occurred in medication clinic came mostly from the client self-reporting, though case managers did often ask them how things went at medication clinic. The case managers for Maria and Marcus did not seem to follow closely what was occurring in medication clinic, but since these two clients were not as highly involved as Samuel and Mary in the Common Ground process, they did not self report as much to their case managers about what they were working on in medication clinic. These two clients could possibly become further engaged with Common Ground with more involvement from their case manager around the goals they are working on in medication clinic.

For the clients for whom the shared decision making process is not working well, we find little case management involvement with the client around the Common Ground process. This might be starting to change with Albert who has a new case manager who is starting to explore goals that Albert is interested in and reintroducing him to the concept of personal medicine. The case manager is also starting to find out more about what he is working on with his prescriber in medication clinic.

Case managers supporting client's use of Common Ground following the medication consultation

Another way that case managers support clients in using the Shared Decision Making process is reviewing the Common Ground report following their medication consultation. Case manager's varied in the extent that they initiated discussions with clients around their Common Ground Report. One client (Samuel) discusses his Common Ground report with his case manager after every medication clinic visit. He notes that she always asks him how things went after seeing the prescriber. He says, "The case worker and I get together and she'll ask me about how did things work out in my doctor's appointment and I brief her in that regard" (P2:13). Helen's case manager also states that she follows up with her after her medication clinic visit. She says, "So after she goes through the Decisional Support Center in her med clinics, which I kind of just let her do independently, her and I talk about it later when we meet" (P31:31-33).

Some clients report that their case manager is mostly involved around the Common Ground Report when the report shows that the client is having a difficulty in a certain area. This would be areas marked by the client with a 4 or 5 and highlighted in red. One client (Bernice) talks about how her case manager notices whenever she has concerns marked on her report. She says:

If I am going through some problem or something, I would have to talk about it (P1:110)...Yeah, he does. He views it. Because he tells me about it, talks to me about it. I

see you got a lot of fours, and that's a low score, meaning something ain't right, quite right, and then we'll go over that. (P28:478)

Some clients were not aware of their case manager going over the Common Ground Report with them. While a client like Marcus actively uses the Common Ground report in medication clinic with his prescriber, it is not something that is routinely checked on by his case manager.

He says:

I'm not certain. I forgot but, I think he could be told about it or see the, I don't know. I don't think my case manager has seen, well probably once. I think my doctor, I give it to my doctor but I think I can give it to my case manager. (P10:195)

Some case managers reported that it was beneficial for them to follow-up with the Common Ground Report. By knowing how clients responded on particular items from one month to the next, they are able to engage clients in discussions about what might be causing the change. One case manager talks about this level of engagement with one client:

There's one guy that we keep a file on all his med clinics because change is so subtle that it's hard to figure out when it's happening. And it's easy to pull those up and compare them to say oh look. Last month you were at a three on this and this month you're at a five. What's going on with that? You know, so it seems like it's easier to grab onto those things, the whys of a lot of behaviors. (P3:110)

This same case manager tries to do this with all of the clients she works with. By following up on the Common Ground Report, she is able to better focus on the supports the client might need to resolve any difficulties outside of medication clinic. She says:

I try very hard with everybody that's on my case load to be very interactive and aware of where those numbers are at (from the How I Am Doing Scale) and what we need to be focused on in the next week...It also helps me figure out how intensive my services need to be. It kind of just helps me figure out where I need to be with them. (P3:124;102)

One case manager views that reviewing the Common Ground Report with clients following medication clinic also helps with engaging clients around things they can do for themselves to address any difficulties they are having. This case manager views helping the client to

understand how to use the information on the Common Ground report as another opportunity to promote the self-determination of the client. She says:

I think where the clients' major concerns and issues are, and it informs me kind of what kind of things I can do to help aid in not just alleviating their worries or stress or anxiety or frustration or whatever it is or symptom. It helps me help them to learn how to do that themselves instead of waiting to see me until the 17th of next month. So like I said, the proactiveness, and then being responsible on caring for their symptoms...they're learning how to do it on their own Saturday and Sunday. (P3:152-154)

Some case managers track when clients have their medication clinic appointments. One case manager has started to re-arrange her schedule so that she has time to view a person's Common Ground Report on the same day that they have had a medication consultation. She views the information contained within the Common Ground Report will help her in providing follow-up with the client and determine what next steps she can take to support them. She talks here about her plans to follow-up with one particular client after an upcoming medication clinic appointment:

I pull it up on Power Face. Like I said, I've just now started rearranging my schedule to encompass time for Common Ground so I can start using that to be more aware...I think it's actually tomorrow that she's got her appointment. So tomorrow evening I'll pull it up and see what's going on....They're (the Common Ground Reports) very helpful. (P31:67-81)

Another case manager also goes over the Common Ground report with clients after their medication consultation. This case manager makes a point of letting the client decide what areas on the report they want help with. The case manager says:

I usually basically try to find out what's the area that they are having more concern with. Because there are certain areas that are on the tool, but it's really not my decision what they want to work on. So I review and I look at it and then I talk with them and they determine which area we're going to work on first. Or if they have a shared decision that wants me to do a certain thing with them, we'll go ahead and do that. (P32:150)

Another case manager initially did not find that many of her clients talked about the Common Ground Report much between medication clinic visits. The one client that she did go

over the Common Ground report with seems to be initiated by the client. The case manager says:

One of my clients does. The one I'm thinking about...He always refers back to his shared decision making and how I can help him with that because normally, whatever he decides it always involves me being able to assist him in some type of way. Or us being able to work together in some type of way. And so he makes reference to it and he does a great job in helping me remember this is what he came up with and this is what he wants me to help him on. Outside of him I can't think of too many that talk about it back and forth, will talk about it in between med clinics. I can just think of him because he consistently talks about it. (P19:55)

By the second interview, this same case manager had started to be more proactive in asking her clients about what they did in medication clinic. Some of this can be attributed to the fact that peer support workers were starting to use some of the Common Ground tools with her clients, which in turn they were also discussing with their case manager. The case manager says:

I started asking my clients when we would meet weekly, what did they discuss in med clinic, and what with a shared decision like that, they have homework, because some of the peer supports were giving my guys, like, tracking calendars that would help them recall, and help them log information so they can report back in med clinic. (P35:107)

One prescriber reports that there is variation in terms of the extent that case managers follow-up with things addressed in medication clinic. The prescriber reports that embedded within his progress notes are potential areas where case managers could be helpful in supporting clients. He states that some case managers will notice quickly and offer support to resolve difficulties while others will refer them back to the medication clinic. The prescriber says:

If sleep's been flagged as an issue, it's probably addressed in our progress note at some point. We will have in there what we discussed about sleep hygiene, and a lot of the times we'll find that somebody who has trouble with sleep is having a lot of caffeine late in the day, so there'll be something in there about recommending that they go to decaffeinated drinks, and so that's something the case manager could probably pick up on and try to reinforce and help the

person when they're out grocery shopping to make better choices. It's real variable. You know, we have some case managers that will get in and ask about that sort of thing and others that are more apt to tell a person just to talk about it when they come to clinic. (P40:288-292)

Some case managers reported that the Common Ground report helps shape the work they do with clients. In some cases it may provide insights on new interventions that might be tried or confirm the direction the client and case manager are working towards. One case manager refers to the Common Ground report as a validation. It validates the client's experience in comparison to what that case manager and other providers might think is going on with the person. The case manager says:

It gives me somewhere to go to, and it gives me something to work on and incorporate, and it gives me something to double check myself to see if I'm on the right track. You know, if something she's saying, is what she's saying what the clinician is seeing? Is she telling the clinician what she's telling me? You know, it kind of validates things, and it gives me ideas on what I can do or tells me you're on the right track or you're way off. (P20:130)

One case manager notes that is helpful to see when there are changes on the HIAD scale and interventions from the prescriber are suggested to follow-up on. She states:

If there is a suggested intervention, there's something that comes in and tells me this is what you reported. You can see what was reported at the last visit and what the change has been. So then that kind of like I have a case that alerts me, okay, she went from a three to a four. (P20:22)

Initially case managers were having the Common Ground reports e-mailed to them from the prescriber. This made it easy for case managers to know what was occurring in medication clinic without having to log on to the website and find out what occurred. One case manager found this helpful so he could follow-up with his clients after they met with the prescriber. He states:

I get an e-mail with the (Common Ground) report. It has their personal meds, if they're been using them or not, and then like a shared decision. I get it in the e-mail. I think it's immediate. So on the shared decision, it was cooperate with case manager on personal

medications that the client feels is more helpful. The next time I met with him, we talked about it, and I think it clicked for him. He just had some better things. I just think he further thought about the idea. The e-mail is just another way to get to know people. I go through my emails and I'll notice Tommy wants to draw and he draws all the time and he says he hasn't done it for a couple of weeks. And I'm like oh, I'm going to give him a call this afternoon. It's one more thing to keep you thinking. (P42:86-102)

Some case managers also assist clients with preparing for their next medication consultation by using the Common Ground Report as a guide. One case manager talks about the process he might go through with a client:

If they have areas of concern like symptoms or something of that nature, I'll go through and I'll ask them questions about what seems to be the problem with this. And then if they are able to verbalize it to me, I'll say why don't we write this down for next time when we come in (to medication clinic) so you can say it's not helping. I'm not sleeping as well as I should. I say did you talk with the doctor about that because...you didn't mark the sleep, that you weren't sleeping well? (P32:150)

One case manager reports that some clients might be dealing with so many difficulties that they become overwhelmed with where to start. One way the case manager can be a support is to help the client break down tasks into manageable steps. This case manager finds that often helping a client work on one of the difficulties they are having often leads to improvement in other areas of concern. He says:

So it just depends on what they really want to work on because a lot of times they answer the questions and then they are so overwhelmed with all the different things going on that they are not able to sit still and get a clear picture. They have all these things identified, but they only can really work on one thing at a time so I try not to give them too much to work on because I've got a few that sometimes have four or five red spots where if you try to give them four or five things to work on, it's not going to happen. But if you give them one sheet to work on, you'll find that the other four or five things also shift from red to black. Well, that's because now that they are able to verbalize what's going on with the meds, then other areas are actually being affected, too. So you don't necessarily have to attack all of them, but whatever they find would be the most troublesome you might discover actually changes all of it. (P32:150)

Barriers to Case Managers use of Common Ground

While there are multiple benefits to case management involvement in the Common Ground process, the level of support varies from case manager to case manager and even among clients on the same person's caseload. As mentioned earlier, a few factors seem to be involved that impact a case manager's level of support for clients in the Common Ground process: time and investment in the value of Common Ground.

Barriers Due to Differences in Philosophies of Case managers

The supervisor for the case management team views there are differences in how individual case managers on her team view the Common Ground process. She views these differences as primarily philosophical. Case managers that are already engaged with the concept of recovery seem to more quickly embrace the Common Ground process. These case managers were quick to begin helping clients identify personal medicine and develop power statements and get these entered into the computer. Other case managers did not move on these activities as fast.

Promoting the self-determination of clients is embedded in the philosophy behind Common Ground. There is a premise that clients have multiple options for addressing symptoms they may be experiencing or problems they may be facing. Medications are seen as one potential option among many. Case managers who are predisposed to clients having choice may also view the Common Ground process as an opportunity for clients to enter into a central role in their own care. Case managers who overvalue compliance with medications and are more restrictive in their view of client choice, may have difficulty seeing the value of the Common Ground process.

The supervisor talks about these differences between case managers:

There are some people who are very recovery oriented on my team. Love it, have worked in (other places) and so they know the punitive...the system more focused on pathology, and love recovery. So they really get it. They understand what this program is about and that medication is not the answer for everything and medication doesn't always work the way

it's supposed to... And there are some people, (one whom is) very caught up in the compliance versus noncompliance and he still calls people patients, too. But that's just his mindset. That's where he's coming from. And he has barely enrolled any of his clients in the program. So I think that case manager buy-in into the whole theory is very important. Because it's a new system and so it needs to be explained. What the consumer can get out of it needs to be understood by the case manager and the consumer. And so, yeah, I've seen a big difference from case manager to case manager. Because one of them, the one lady who is really into recovery and believes that people can recover, had all of her personal medicine done in the first two months. (P33:60-64)

Barriers Due to Time

One client (Mary) who seems to be very engaged with the Common Ground process acknowledges that her case manager does not have a lot of time to spend with her due to workload. In this particular instance, Mary could benefit from having more time with her case manager. She acknowledges that her case manager would devote more time to her if she asked, but the inference here is that case managers will only do this when the client initiates the discussion. Mary says:

I've got to get over there for the low income. I am not financially stable enough to go into regular housing, and I don't know what the waiting list is. I'm trying to get my case manager, nudging as much as I possibly can to get her to help me look into low income housing out there and the waiting list. **Is your case manager in tune with your goals?** Yes, I believe she is, but as case managers go, they have a load of people to work with, so she can't dedicate a whole lot of time to what my needs are. (P27:324-328)

Jason on the other hand is a client who is not engaged with the Common Ground process. He too seems aware that case managers possibly have high workloads. If requesting additional help is left to the client to initiate, clients such as Jason are not likely to get the help needed to more fully engage in Common Ground. Jason says:

They help, but you know, I'm thinking, you know, she's kind of off the ball. She ain't on the ball. I mean, she could do a little better, but I don't know if her case load is heavy or not. (P43:380)

Jason's case manager views the way she supports clients around using Common Ground as helping them to be more proactive. Her stance is to help clients get started and then allow them

to use the program on their own. While this may work for clients who become engaged in the process on their own, it may not offer sufficient support to clients who are having more difficulty with the process. The case manager talks about how she works with clients around Common Ground:

I'm a case manager that tries to...have them be pretty proactive in their own treatment. For instance, with therapy appointments, I really don't offer to take them to those unless it's a do or die kind of thing. So with this new program, when it first started up, I walked through it and did the personal power statements and stuff, but the computer program itself, I really kind of have them be proactive. I don't really offer them a choice on that one. (P3:26)

One prescriber has become frustrated with the intermittent support offered by case managers for clients using Common Ground. While she acknowledges that case managers have high workloads, she questions the commitment some case managers might have toward supporting clients with the process. While the prescriber e-mails case managers about the decisions made in medication clinic, she rarely sees follow-through on things that the case manager could help with. The prescriber says:

Case manager hadn't helped them with it yet. And quite frankly, the one trouble that I've had with this that's sort of my beef is when we do a shared decision and I e-mail it to the case manager, I've never had anybody come back and say okay I've done my work. There's no big follow-through on the other end about making sure that the work gets completed or the questions are answered. And I have had two or three times - at least twice and I think it's been three times - that the case manager said oh yeah we did that but I left it in my car or I left it on my desk. And I think again that's another message that the client will get that says if it's not that important to bring to my appointment, why am I doing it. You know, they have so much to do, but is this the priority? So that follow-through is an issue. (P6:86-90)

Another prescriber also sees the variation in which case managers support clients around the use of Common Ground. He views differences between the adult case management team that participated in this study and the young adult team that also piloted Common Ground. Because of the intermittent follow-through by case managers on the adult team, he has altered his behavior in terms of who he asks to assist clients with completing activities related to the shared

decision. For the adult team, he is more likely to have peer support help the client rather than involve the case manager. The prescriber says:

I think right now there's probably a pretty big spread. I think some of the case managers, the ones I typically have seen that are the most involved, I think are on...the young adults team. **That are more involved?** Right, engaging and doing the different worksheets and that sort of thing with the consumer. I'm not sure about the other team. It may be that I just haven't seen that. But it seems like the other team is where I often will take the consumer to the decision support center and ask if they won't help the person do a worksheet or an activity. I think with the young adults team, those case managers are more likely to come to the clinic appointment with the consumer and so we can decide right there that they are going to help the consumer with it. I think the young adult team does a little bit more intensive case management than our general teams. I think they have a little more contact with their consumers. (P8:29-33)

The peer support supervisor views the support of case managers as being important to the process. At the current time, the computer work done prior to the actual medication consultation is not built in to the scheduled time of the medication clinic appointment. If clients are given a medication clinic appointment time of 2:00 pm for example, they are told to arrive 30 minutes before that to fill out their Common Ground report. What tended to happen early on the process is that clients continued to show up at the scheduled time for their medication clinic appointment, which did not always give them time to work on the Common Ground report. Over the course of the study, clients that were highly engaged in the process began to make these adjustments on their own and show up early to work on the computer. The peer support supervisor's systemic recommendation here is to actually schedule a separate appointment, say 1:30 pm, for the Common Ground Report, and then 2:00 pm to meet with the prescriber. In absence of this, the peer support supervisor views that case managers can play a role in helping clients understand the importance of Common Ground to the work they do with prescribers and reinforcing the practice of arriving early. She says:

It's been real important to have the support of case managers to help educate and remind people about participating because at this point participation does require that people show

up early for an appointment. We don't have a system in place where the appointment itself is scheduled. And so it's kind of this struggle for almost all participants to be willing to show up early, which means that there's a cost to people in doing that. And the cost is in both effort and time. And so the more case managers can support that, the better. (P17:28)

One area where one prescriber has seen disparities between case management staff is helping clients identify personal medicines and a power statement to enter into the Common Ground report. The prescriber notes that most case managers have tried to get this done, but there are still some that have not. One factor that she views might be a barrier for some case managers is that it is just another piece of paper for them to fill out among all the other work they have to do. She says:

Some of the Common Ground things a few people are still probably lacking, but, the list of the personal meds for the most part, I think they're getting in, but still a little bit of a slow process, because I think just with all these changes sometimes there's a reaction to see another piece of paper or that sort of thing...another thing you have to enter...I think, sometimes there's that feeling, but I think in general, people are trying to get it in but there's been a couple that haven't. (P41:175-179)

The prescriber reports that asking case managers to submit personal medicine or a power statement is not something she has regularly done. Rather she just asks the client to work on this with their case manager. For clients that do not have personal medicine or a power statement entered on their Common Ground report, there does not appear to be a mechanism to ensure that these are getting entered nor is it clear whose responsibility it is. The prescriber says:

I have to be honest. Probably, if I think of it, I might say it to them, but I'm not necessarily going to guide the person to, hey, you know, can you fill this out with your case manager, or I might email. (P41:183)

The case management supervisor acknowledges that updating personal medicine is not something that case managers are regularly doing:

They haven't updated them that I know of. I've coached a couple people on how to do that on the computer when the consumer's here if they want to change something, but, updating is something we haven't started, yet...it's not part of the structure right now, but I'm hopeful that people can do that themselves or with a peer instead of (the case manager). I just don't

like to put people in a position where they have to wait on their case manager to get something done...I think that's something peer support can be really effective in doing, so, that's my hope. (P34:91-103)

One case manager talks about using personal medicine in the field:

I will have to accept the blame on that part because they don't actually have a copy. And that might be on my behalf because normally when we're in the community, we do the personal medicine worksheet. We're doing it somewhere outside where there's a copier at. And so it probably would be very helpful if they'd get a copy. But normally they don't have a copy. So I might be minimizing the power they could get from that. (P19:53)

In the second interview, the case manager talks about now making copies of the personal medicine worksheet:

I think the last time I met with you, I was telling you about how I wasn't good about copying the personal medication worksheet, but now, it's been really great, because I hate to have to worry about tracking them down and doing it again, so, we do copies of that, so I keep a copy and they have a copy, so that we're always able to have something to reference to, to review their personal medication worksheet. (P35:119)

One prescriber views that more needs to be done to better incorporate the involvement of case management within medication clinic. He acknowledges that when he asks case managers to assist with things between medication clinic, those things typically get done, but rarely does he communicate with the case managers between appointments. The prescriber says:

I think for us it's sort of a work in progress, though. And I think whatever we can do to get the teams a little bit more integrated around what's going on would probably be helpful. I know right now we send out the e-mail and then when we see the person a month later, they probably have the report that we decided they were going to do, but there's not much communication along the way and I don't know if that would be helpful or not. (P40:97)

During the course of the study, the mechanism for case managers receiving updates on what occurred during the medication consultation changed. When the Common Ground process started, the report was integrated into the agency's existing client information system called PowerFace. There was an accessible button embedded within the Common Ground software that allowed the prescriber to directly e-mail the case manager and their supervisor the Common

Ground report which outlined any actions requested of the case manager to support the client in the shared decision. Midway through the study, Common Ground became a stand-alone Internet-based software and the integration with PowerFace ceased to exist. The primary reason for the change was to allow for easier replication of Common Ground at future sites. Since not all mental health centers would have PowerFace as their electronic medical records (EMR) system, tying Common Ground to one EMR would have added a barrier to these efforts. Another reason was the ability to expand on the capabilities of Common Ground (i.e. feasibility of doing Internet searches through the program, embedding Common Ground tools within the program, etc.) that was more easily done as a web-based application. The process now required case managers to log onto a separate website to view the Common Ground report and see if there were any actions needed to support the client with the shared decision. This change seemed to have an impact on case management involvement within medication clinic. Prior to the change, some case managers were already sporadic in checking their e-mail. Now having to check into a separate site, in addition to checking e-mail, this further reduced the frequency with which some case managers viewed their client's Common Ground report.

One case manager talks about the process when Common Ground was still integrated with PowerFace:

It's (the Common Ground Report) actually e-mailed to me, all the ones I've gotten I believe have been e-mailed to me the same day. Now I'm not good at checking my e-mail daily like I should because sometimes I don't come into the office because I am in the field. But when I do check it, it's done in a very timely manner. (P19:59)

The case manager found these e-mailed reports helpful, even when there were no specific actions for her to take with the client. The reports helped her to always stay apprised of what was going on in medication clinic. The only barrier the case manager identifies with this is finding the time to regularly check her e-mail. She talks about the helpfulness of the report being e-mailed:

It outlines exactly what the client feels they need to work on to help them in their recovery. So I think it's very helpful. And even if the client doesn't identify something that I could help them with, it's still e-mailed to me just to let me know what they decided in med clinic. And to be truthful, I haven't always been the best about going in and looking at the psychiatric notes to see what happens in med clinic. So it gives me a chance to review what's going on in med clinic...I just don't always read the note as far as that. The note will tell me everything. I just don't always read the notes. (P19:61-63)

Another case manager acknowledges not checking her e-mail very often. She states:

I really think that a majority of it is just putting it into practice and taking the time to realize that change takes time. I know for me, I don't check my e-mail quite frequently, so those Common Ground reports aren't coming in very quickly to me unless I'm going to a med clinic with the client. If you just print it out and set it on my desk, I'm going to be more aware of it than checking my e-mail three weeks later. (P3:140)

Role of Supervisor

One support that case managers identified that helps them follow-up with clients regarding the Common Ground report is the involvement of the supervisor. Since the supervisor was also e-mailed a copy of the Common Ground report, the supervisor could print those out and discuss them with the case manager during supervision. One case manager talks about how this has been helpful to her:

And what I really like about (the supervisor) is in supervision she always brings it up, we go over the shared decisions that they have done in med clinic. And so or she'll remind me, do you get this, because sometimes I'll just skim through them and she'll remind me about it and we'll go over it to see what it is that the client has identified I can help them with. (P19:59)

Another case manager acknowledges the same thing:

A lot of times my supervisor looks at the e-mail thing that they send out, and she'll pick up on stuff sometimes, and when we do supervision, she'll kind of bring it up and we'll talk about the shared decision and stuff. That's another way. It is just one more way for me to get to know consumers. (P42:163)

One case manager did not view the early reports from prescribers as very helpful. Early on in the implementation of Common Ground, many of the tools now embedded in the software were not yet available, so some case managers were unclear about what specifically they should

do to assist the client based on what the prescriber was sending them from the Common Ground report. She says:

There's not a lot of intervention happening yet, I don't think. Some of the tools are still in development. We haven't had a lot of training about the tools, and I think the training of the case managers is a challenge because some things, as a case manager, you can seek out for your client if you know that it's there. But if you don't know that this intervention has been created and is in use, then you can't use it. And really it's not working out so well that way. ...they're not getting suggestions to use interventions from the nursing staff and they're not getting it on the back end side either. I mean they're not getting it from any other sources. So really, we're not getting a lot of benefit yet in the shared decision side. (P33:78-84)

With Common Ground now being an internet-based software, some of the same barriers still occurred that were present when Common Ground reports were sent via e-mail to staff. Because of the nature of case management being primarily a community based service, case managers were rarely in the office to print out the Common Ground report. One case manager discusses this:

For me, personally, I'm always on the go, so me and my clients are hardly ever around the computer. So, unless I have a client here in the office where I can get on the computer and get on the internet, I tend to not get on there. The way my schedule works out, it hasn't been accessible for me really. So, if that would change, and I could just view it anywhere it would be great. (P35:111)

One prescriber is concerned that case managers may not have time to regularly check their e-mail because of the time they spend out in the field. She says:

It's just another place for them to have to check that they don't have time to do. I know I send e-mail messages out now and they are read three or four days later because they just don't (have time), they're not in the building to read them...It's a concern of mine. (P39:49)

Another prescriber views that case managers having access to laptops to be able to view the Common Ground report with their clients would be helpful. He says:

If we could ever get to the point where we have laptops that the case managers could be taking out into the community for people to do their Common Ground report on the way in, or do some of these searches, part of the case management goals, you know, I think that would be helpful. (P40:300)

One prescriber saw a dramatic shift with case management involvement around client's Common Ground reports when it was separated from PowerFace. This particular prescriber has tried to adjust to this by copying and pasting her notes from Common Ground into an e-mail that she sends to the case manager whenever there is an action that she would like to have them follow-up on. This though is not the practice of all the prescribers in medication clinic. She says:

Where I see when things slipped off was when it went to Internet-based as opposed to being in Power Face. When it was in Power Face, the information was e-mailed to the case manager. They were in their e-mail, anyway. Now that it's Web-based it's just an extra step for them to go into the Web, check to see who did what, what the assignment is. Before when it was e-mailed to the case manager, it was easy for them to access and I think that they stayed engaged that way. I think now, a comment that I heard in a team meeting about a month and a half ago was the only way we look at the Common Ground reports now is when you copy and paste them in the Progress Notes. They don't even go into the Web. So from my side, that's when I saw kind of the split out. (P39:21)

Another case manager acknowledges that communication about what occurred in medication clinic changed once Common Ground was moved to an Internet based software. She states:

For my other clients and my other guys, they are sporadic in coming in to med clinic. I only have one or two on my caseload that consistently comes in, and (the prescriber) does a great job by emailing me if there is something. She will, well, she was, until it came on Power Face. She was doing a great job about emailing me if there was anything that involved me helping them with their shared decision. (P35:107)

The supervisor of the case management team views that following-up on all the shared decisions made in medication clinic can be overwhelming for case managers. She views that they do not have enough time to assist clients with all the Common Ground tools clients may leave medication clinic with. She views that peer support might be a better option as a source of support for clients with this. She views that if this responsibility is left to case managers, things are likely not to get done. She says:

I know the answer that has been coming down is to put more pressure on people, as far as staff. One of my suggestions is if there's a form that they need to fill out, something they need to process, that that be sent back through either Decision Support or that they (the client) leave with that form. This is the form, something for you to think about, instead of

saying, this is what you'll do with your case manager the next time you see them. At least, then, they can start thinking about it...I think that peers are going to be able to do a lot more than case managers can do in this system. They (case managers) just don't have the time to do (it). (P34:399-411)

The supervisor does acknowledge that there is still a role for case management in the process, but she views that this is when clients are stuck and cannot proceed any further without the case manager's assistance. She says:

However, when they do recognize, like in Roberta's case, that they're stuck, that's where they can activate around instead of just putting in their treatment plan, use medication as prescribed or something like that. At least you feel like there's something you can do. (P34:411)

The team's supervisor acknowledges the resistance from case managers in doing more paperwork with clients because of their time demands. This could have something to do with case managers view of the benefits of the Common Ground tools in relation to the clients overall well-being. If case managers view that the tools they are helping clients with benefit the client in areas outside of medication clinic, they would not necessarily view these tools as an added burden, but rather something that could contribute to the work they are already doing in case management. The supervisor says:

Actually doing what's supposed to be done is a challenge just because of time... looking up the shared decision, making sure you have the tools and that you know how to use the tools, and then going and finding the person and using them. And, people (case managers) aren't always responsive to worksheets. And, so, sometimes that gets translated into case managers talking to them and then just recording it instead of doing it with them. Talking about it and then, filling it out. Instead of sitting and filling it out side by side. Some people just don't want to do worksheets. I don't know what percentage of people that is, but that's something I hear pretty often about worksheets and case managers actually having to carry worksheets. They don't need another piece of paper stuck to them, honestly. So, there's some big challenges with that.(P34:47-63)

The team's supervisor views that current caseloads are a factor impacting the time that case managers have available to spend with individual clients supporting them around Common

Ground. A pressure that she notes is that the agency has productivity standards that individual case managers must meet each month. She says:

Yes, but they're saying that if you're not making productivity, there's no reason to reduce your case load. I think what's not being considered is that there's a lot of paper involved with the people, so, yeah. If you're bogged down by the paper part, then you're not going to have all due productivity, and there's not a recognition that people need different levels of service. (P34:415-419)

The supervisor does not see this being resolved anytime soon. She says:

That's one of the challenges that I've had with the system. I believe in it, but...If they have to wait for a case manager with case loads, and...case loads are going up, because we can't have a waiting list, so we're just going to keep piling people on. That's the kind of stuff (Common Ground) that's going to get left behind, and it can cause the whole system not to work. (P34:231)

The supervisor admits that if clients have been waiting for case managers to help them with Common Ground tools they are probably still waiting. She says:

The challenge, honestly, I think the challenge for her (Roberta) is if she's had any forms (Common Ground tools) that she needed to follow-up with, if they're waiting for me to do it with her, just because of the way my schedule's been, she's still waiting, and that makes me sad, but, you know, you can only do what you can do. (P34:231)

The supervisor acknowledges that clients not getting support around Common Ground can be discouraging for some clients. She recognizes that staff have been giving clients the message that things have changed in regards to their involvement in decisions in medication clinic. She views that if clients do not have support to help them carry out decisions made in medication clinic they could possibly become disillusioned with the process. She says:

If you make a shared decision to look at a Decisional Balance Sheet and three months later it's still not done, well, that can be, I don't know, what's the word, besides discouraging, just make you feel just as powerless, or even more frustrated because before, no one was listening to you, but that's what you expected when you come and meet with your peers and make your report and feel like something's going to change for me, and then you go in, and you don't have the support to follow-up to make a change, that can be more disappointing. (P34:231)

One case manager admits that it's difficult to balance spending time with people around their Common Ground reports and spending time with people who are in crisis or have other immediate needs. She says:

It's very tedious and a lot of times we work with folks on crisis or helping people meet their every day needs, so sometimes, you might always not have the time to address what they commented on, on their Common Ground reports, or come in to the Decision Support Center, so that they can use the other stuff that are available there. (P35:127)

Conclusion

There seems to be a strong connection between the perception of how staff view Common Ground as a powerful tool that can make a difference in a clients overall recovery and how much of a burden they see Common Ground being on their current workload. All case managers, whether at this agency or another, perceive they have high work demands. It is true that case managers serve people who often have intensive needs. Not only do they work with people who may experience distressing psychotic symptoms or debilitating mania or depression, but the people they work with often live in poverty, lack safe and affordable housing, have difficulties with transportation, etc. Working with up to twenty individuals meeting any combination of these challenges is no easy task. The question that has to be raised is...can Common Ground be of assistance to case managers in the midst of helping clients overcome these life challenges? The answer to this question may serve as a basis for determining whether or not Common Ground is seen as a benefit or burden to staff.

Most case managers were initially very enthusiastic about Common Ground when it was introduced. This suggests that they saw hope for what Common Ground could potentially offer to clients. They also were encouraged by some early results because some clients started using Common Ground and quickly engaged with it. Case managers recognize the difference it has made with some of their clients. The "easy" clients are now in the routine of using Common

Ground and because of some clients' investment in the process; they initiate discussions with their case managers on their own. There are other clients though that will need additional support to fully make use of Common Ground. Here is where case managers seem to struggle. Some seem to find it difficult to take the time to invest in something that the client is not showing an investment in. My hypothesis is that these clients would benefit from Common Ground if their case manager took the time to show them how it can make a difference. Not with words, but with concrete actions that showed they were interested in hearing about their experiences, their goals, and their struggles, and they were willing to help them find ways to overcome their challenges and achieve their goals.

I think that support for case managers around Common Ground was more purposeful in the early part of the process. There was a student assigned to the team who helped case managers learn how to do power statements and personal medicine and these were entered into the computer early on. There was an agency expectation that these things get done. The initial supervisor also took an investment in Common Ground and would bring reports to group supervision to ensure follow-through if needed. Midway through the study, it seems as if not only the expectations have leveled off, but so has the support for individual case managers. One case manager still does not know how to check the website to see if there is a shared decision she needs to follow-up on. If there is not an expectation that she does this nor is there support to learn how to do it, it is not likely to get done. While some case managers are able to overcome many of the perceived barriers to using Common Ground and find ways to incorporate it into their work flow, others struggle to do this. Investment at the agency and supervisor level into training and on-going support for case managers in using Common Ground seems critical. For case managers to become an important auxiliary support in the shared decision making process,

they will need to not only have clear expectations set for their role, but they will need to understand how their role supporting clients in medication clinic is integral to work they do with clients outside of medication clinic and vice versa.

In the last theme, it was mentioned that peer support and case managers had some overlapping and at times duplicate functions. An observation of the totality of the shared decision making process suggests that effective shared decision begins prior to the actual medication consultation with the prescriber and extends after the medication consultation has ended. Auxiliary supports therefore play a significant role in contributing to effective shared decision making. Both peer support and case managers can contribute to helping clients enter medication clinic with a goal the client finds meaningful and important. Both peer support and case managers can also help the client view the Common Ground report as a relevant vehicle for sharing information related to achieving the goal. Lastly, peer support and case managers can assist the client with taking concrete actions based on the decisions made in medication clinic regarding their desired goal.

In ideal circumstances, these efforts would be coordinated and made explicit for each clinic using Common Ground. In the discussion section, a framework will be proposed that allows the prescriber and both auxiliary supports to work in a more cohesive fashion. This framework will draw from the factors mentioned throughout the findings section that allowed for effective decision making to occur. It will also seek to potentially mitigate against those factors that served as barriers to clients for whom the shared decision making process did not work well.

Chapter 5: Discussion

Cautionary Notes

Since the setting of this study focused on one particular mental health center implementing a new intervention, caution must be exercised in generalizing the findings beyond this specific site and corresponding group of professionals and clients. As mentioned earlier, the purpose of a constructivist inquiry is to develop a characteristic body of knowledge that is particular to the participants involved in the study. There are no truth statements that exist independently of time and context. Rather the reader is offered a series of tentative suppositions based on participants' constructions at the subjective, experiential level. While this study does not attempt to make generalizations, it does offer the possibility of transferability. The decision about usefulness of this body of work to other environments rests with the reader.

It should be noted that the prescribers at this agency were collaborative participants in bringing Common Ground to the agency; therefore they were open to the concept of shared decision making prior to the start-up of the intervention. The case management team volunteered to participate in piloting this intervention from among five other case management teams at the agency; therefore they also went into the intervention open to the concept of shared decision making. Broadening the scope of this study beyond this particular agency, professionals, and clients could lead to different data and findings obtained.

The client participants in this study all had a diagnosis of either schizophrenia or schizoaffective disorder. Findings in this study may be relevant only to those diagnosed with a major thought disorder and not applicable to those with other diagnoses. The particular mental health center was also in an urban setting with a high percentage of individuals who were African American compared to other mental health centers in Kansas. While the sample chosen

for the study is reflective of the distribution of clients diagnosed with a major thought disorder being served by this particular team, sampling among different criteria related to race, ethnicity, or gender could lead to different information and results.

Interviews for this study were conducted during the first year of implementation of Common Ground. Beyond this intervention being new to all participants involved, there was no precedent for this intervention at any other mental health center in the United States. Because of this, participants and developers of the software and approach were learning as implementation was unfolding. Adjustments were being made in regards to the software and the process as implementation was occurring. Interviewing participants at a different time frame in implementation could lead to different information and results.

It should also be noted that the inquirer in this study was invested in the success of Common Ground at this particular mental health center as well as the potential for its implementation in future mental health centers. This inquirer holds a belief that people with psychiatric disabilities have a right to participate in decisions regarding their medications and treatment. While steps were taken to ensure the trustworthiness and authenticity of the data (refer to methodology section for more information), the findings do reflect a unique construction of the data written by the inquirer. Another inquirer may construct an alternative view of the finding which could equally be valid.

Discussion of Key Findings

Keeping in mind the limitations above, the following is a discussion of some of the key findings from the preceding sections and their implications for the shared decision making process. The intent here is to provide a construction of the findings that might help improve the shared decision making process in a way that increases the self-determination of people with

psychiatric disabilities. Two new concepts will be introduced here that might offer new insights for how Common Ground can be used more effectively in shared decision making. The first is the concept of Activation Points, which will be explained in more detail later. This concept will allow professionals to better understand the variety of ways clients seem to be activated by Common Ground, allowing them to more fully participate in shared decision making. Understanding activation points might also help professionals avoid missing key opportunities to engage with clients around treatment decisions.

The second concept is a proposed framework for shared decision making that takes into account these activation points and provides more consistency to how Common Ground is used prior to, during, and following the medication consultation. The framework denotes key roles for various treatment team members and assists with creating an integrated approach around decisions made in medication clinic.

The concept of activation points and the proposed framework will be used to formulate implications for both policy and practice regarding shared decision making around the use of psychiatric medications. These implications have the potential to shape implementation of Common Ground at future sites.

This discussion section includes feedback, comments, and recommendations from participants involved in the study. This information was obtained from the two Comprehensive Member Checks conducted at the end of the study. In addition, updates on all clients involved in the study will be interwoven into the discussion section. Their stories a year after the end of the formal interviews continue to shed light on the potentials as well as the challenges of shared decision making.

Comprehensive Member Check

A draft report of all the findings were distributed to all participants involved for their feedback and comments. Two comprehensive member checks were held: 1) one group consisting entirely of all the professionals that were interviewed (prescribers, nurses, case managers, and peer specialists); 2) one group consisting entirely of clients that were interviewed. The decision to hold separate comprehensive member checks for clients and professionals was to allow for more candid responses from all participants involved. There was a fear that clients would be less inclined to speak with professionals in the room, especially clients for whom the shared decision making process did not work well. Of the twelve clients that were interviewed, ten attended the Comprehensive Member Check. The fact that six of out seven clients from the group for whom the shared decision worked well and four out of five clients for whom the shared decision making process did not work well attended, adds credence to the feedback on the overall report. As far as prescribers, all three were able to offer feedback on the final written report, though only one prescriber was able to attend the Comprehensive Member Check. The other two were contacted for a phone interview to obtain their feedback. Both of the nurses attended the Comprehensive Member Check. Four out the six case managers in the study attended the Comprehensive Member Check. The remaining two case managers were no longer on the team at the time of the Comprehensive Member Check and were unavailable to attend.

Inquirer's Constructions

Prior to looking at the new concept of activation points and the proposed framework for improving the shared decision making process around psychiatric medications, it is important for the inquirer to offer his own constructions as it relates to the research questions initially proposed in this study. Pairing this with the constructions embedded throughout each of the themes in the

previous chapter will serve as a foundation for introducing the concept of activation points and the proposed framework.

Research Question 1) What are clients' experiences with shared decision making around medications? How do these experiences evolve over time (at least six visits with the prescriber over approximately a nine month period)?

Client experiences of the shared decision making process varied, but it could be argued that only the clients who were engaged with Common Ground actually experienced shared decision making. One of the foundations of shared decision making is that it is a collaborative partnership between client and prescriber. Therefore both parties must be engaged and have something to contribute to the decision making process. Clients who were engaged with Common Ground had a mechanism to contribute something to the decisions made in medication clinic. This included a goal that established a context for making decisions (Power Statement); an organized self-report of their current well-being and any concerns they had at the present time (HIAD scale), an organized self-report of any decisional uncertainty they had regarding the use of medications (Decisional Uncertainty Profile); and a list of potential options besides pill medicine that might be used to achieve their stated goal or address any concerns they had (Personal Medicine). A foundational premise of shared decision making is that clients contribute to shared decision making by sharing the personal expertise of their values, preferences, and goals (Charles et al., 1997). Common Ground offered a vehicle for client's to do this. The clients who did not engage with Common Ground were therefore not able to make use of this vehicle to contribute to the discussions at medication clinic and participate in shared decision making. As further evidence of this, clients who did not engage with Common Ground were less likely to see a difference in

the way the medication consultation was conducted after the implementation of Common Ground compared to how things were done prior to Common Ground.

Clients who experienced shared decision making found Common Ground relevant to expressing their values, preferences and goals. Because of this relevancy, they responded positively to Common Ground and the shared decision making process. Another factor that contributed to clients positive response to the shared decision making process is that concrete steps were taken using Common Ground to help them achieve something meaningful and important in their lives. On the other hand, clients who were not engaged with Common Ground found it to be an added burden to seeing their prescriber or they were indifferent to the process.

Over time, a positive experience with Common Ground and shared decision making were interrelated. As the Common Ground report became relevant to decisions made in medication clinic, the more clients were engaged and invested in the Common Ground report. The more clients' were engaged in using Common Ground the more they were able to satisfactorily experience shared decision making.

The majority of clients who were not engaged in Common Ground during the first round of interviews never engaged with Common Ground nearly nine months later. The only exception to this was Maria, who found relevancy with the Common Ground report to the decisions made in medication clinic once the prescriber began to focus on what was most meaningful and important to her. Specific actions on the part of treatment team members seem critical to helping people engage in Common Ground and ultimately participate in shared decision making (Will be discussed in more detail in research question number three).

There was evidence to suggest that all clients in the study wanted to be involved in decisions about their medications, even clients who were not engaged with Common Ground. Each of the clients who were not engaged in Common Ground had substantial decisional conflicts related to taking medication and were able to state their preferences for taking or not taking certain medications. Clients who experienced shared decision making seemed satisfied with their active role in medication clinic and seemed to expect it as the new way of conducting medication consultations. Clients who did not engage with Common Ground were more likely to continue experiencing frustration with the decisions made in medication clinic or were resigned to their more passive role.

Research Question 2) What are team members' (i.e. psychiatrist, nurses, case managers, and peer specialist) experiences with the shared decision making process? How do these experiences evolve over time (at least six visits with the client over approximately a nine month period)?

Prescribers

Prescribers were initially enthusiastic about using Common Ground to guide the shared decision making process. Prescribers perceived that Common Ground had the potential to save time in the medication consultation by quickly getting to what clients wanted out of medication clinic (i.e. goals or concerns). This allowed the prescriber to skip over typical clinical assessments used prior to Common Ground and start addressing what the client found important. Eventually, prescribers started to see a split between clients who were engaged with Common Ground and clients who were not. For clients who were engaged in Common Ground, prescribers found it much easier to do shared decision making. This was especially true when

clients had a goal that was meaningful and important (establishing client's values and goals) and personal medicine they were actively using (increased options for making decision).

For clients who were not engaged in Common Ground, prescribers tended to narrowly focus on the HIAD scale. This alone though did not allow for shared decision making to occur since the responses were not placed into a context that the client found meaningful and important. While prescribers were still inclined to begin with a focus on the HIAD scale for the clients who were engaged in Common Ground, the HIAD scale was more relevant to these clients. Over time, prescribers tended to become more engaged in using multiple aspects of Common Ground in a coordinated fashion (e.g. Power Statement, Personal Medicine, HIAD scale, Decisional Uncertainty Profile), when the client was engaged with Common Ground and kept these elements at the forefront of discussions. When clients were not engaged, prescribers did not seem to go much beyond the HIAD scale.

Prescribers perceived that clients who were not engaged in Common Ground were typically not involved in other areas of service or were never engaged in medication clinic prior to Common Ground. This may partially explain why prescribers were less diligent in pursuing shared decision making with clients that were not engaged in Common Ground than with those that were. Prescribers may have perceived that these clients were either not interested in shared decision making or less likely to benefit from it. Prescribers were inclined to respond more favorably to clients who showed some initiative to engage in discussions with them during medication clinic.

Prescribers also generally believed that it took substantial effort to engage some clients in shared decision making. Much of this was attributed to some clients preferring to have the prescriber make the decisions. Since each of the client participants in the study seemed to prefer

being involved in decision making, this may suggest that extending an invitation to be involved in the decision making process is not sufficient. Relevancy for the client needs to be established and this may require some effort on the part of the prescriber to demonstrate how each of the components of Common Ground is used to make decisions. Taking concrete steps towards achieving a goal or addressing a concern that is meaningful and important to the client seems key to establishing relevancy.

Over time, prescribers became frustrated with the lack of involvement by some case managers in the Common Ground process. This usually entailed power statements and personal medicine not being updated, lack of follow-up on shared decisions, etc. This lack of involvement seems most relevant to those clients who were not engaged in Common Ground, since case management involvement was more likely to be present with clients who were engaged. Prescribers generally viewed that time constraints of the medication consultation limited their ability to engage clients who were not sufficiently prepared to enter into shared decision making. In fact, prescribers did not see it as their responsibility to ensure that the information entered on the Common Ground report was updated and accurate. Prescribers did perceive that Common Ground could be more effectively used if case managers were more involved in the process. Prescribers acknowledged successes with the shared decision making process when case managers were more involved.

Over time, prescribers started viewing peer support as an effective means of quickly following up on some shared decisions (e.g. looking up information for the client via the Internet, assisting with explaining and filling out Common Ground tools, etc.). As prescribers became more comfortable with peer support in the clinic, they tended to use case managers less to support client's use of Common Ground.

Case managers

Case managers, like prescribers, were initially enthusiastic about using Common Ground. Case managers quickly saw the time burden involved with various aspects of Common Ground including: initially entering of all client's power statements and personal medicine, orienting clients to the Common Ground process, making sure client's arrived at medication clinic thirty minutes prior to the actual clinic appointment to complete the Common Ground report, accessing the Common Ground report from a website, following through on shared decisions made in medication clinic, and assisting clients with completing Common Ground tools. Case managers weighed these time burdens with other existing responsibilities including: meeting agency productivity standards, timely submission of documentation, balancing caseload demands, responding to crises, etc.

Case managers found that most clients responded positively to Common Ground while a few did not. Case managers also seemed to base their level of support for client's using Common Ground by the client's level of engagement with Common Ground. For clients who were highly engaged with Common Ground or were enthusiastic about using it, case managers seemed to incorporate the aspects of Common Ground to which they were engaged (e.g. achieving a goal on the power statement, using personal medicine, etc.) into their appointments with clients. If clients were not quickly engaged with Common Ground, case managers tended to de-emphasize it during their scheduled appointments.

Over time, case managers recognized the importance of Common Ground to the clients that were engaged with using it and continued to interact with clients around areas they were engaged. For clients who were not engaged, Common Ground ceased to become a part of interactions between clients and case managers. While responses varied, most case managers

saw shared decision making as something between the client and the prescriber, and minimized their role in the process. A common view was that it was up to the prescriber (by notifying them through e-mail) or the client (by verbalizing it to them during appointments) to determine what specific role they needed to play in relation to the process. Over time, case managers viewed that peer support was better able to respond to client's needs around Common Ground in a timely manner than case managers would be. Over time, case manager support for clients around Common Ground tended to be primarily limited to client's who were highly engaged with Common Ground and routinely brought up things related to Common Ground with their case managers.

Peer support

Peer support workers increased in their role around Common Ground over time. Initially the peer support worker's role revolved around welcoming clients into the Decision Support Center and assisting them with using Common Ground. Eventually, their role expanded to assisting clients with using Common Ground tools following the medication consultation. Peer support workers welcomed this expanded role and perceived they were more a part of the shared decision making process than they were in the beginning.

Peer support workers were overall very positive about Common Ground and the shared decision making process. Since most clients in the study spoke highly of the support received from peer support workers, it is likely that their interactions with most clients were positive. Peer support workers seemed enthusiastic about their role in impacting client's lives and considered the work that clients were doing on the Common Ground report as making a difference.

Research Question 3) What contributes to clients' involvement in the shared decision process?

Several factors seem to contribute to client's involvement in the shared decision making process. First, the client's prior motivation for being involved in medication clinic prior to Common Ground was a factor. Clients such as Samuel were already highly involved in decisions made in medication clinic prior to the start-up of Common Ground. This made a natural transition for him being highly involved in the shared decision making process. Clients such as Bernice, Roberta, and Mary were not highly involved in medication clinic prior to Common Ground, but they were motivated to come into medication on a regular basis (usually to get a prescription for a medication they found helpful). Having a self-generated motivation for coming into clinic seemed to precede some client's being highly involved in the shared decision making process. Clients that were not involved in the shared decision making process also tended to be clients that were not very involved in medication clinic and had low levels of motivation for coming into medication clinic. For example David, Jason, and Albert regularly missed medication clinic appointments prior to Common Ground and did not always see a reason to even come into medication clinic.

Second, clients need to feel comfortable using Common Ground so that it can be used as a vehicle to engage in shared decision making. Initially, this was facilitated by case managers and/or peer support workers who explained how to use Common Ground and supported them in their use of it. For clients in the study who were not used to taking an active role in medication clinic prior to Common Ground this was critical. For example, the support that clients such as Roberta and Bernice received from their case manager and peer support helped them overcome fears about using the new technology. Having multiple ways of responding to questions for the

Common Ground report helped to facilitate involvement in the process. Since several clients in the study had limited reading and writing skills, the ability to listen to the questions via headphones overcame a potential barrier for clients being able to engage with Common Ground. This is especially true for clients like William who would not have used Common Ground if the only option was to read the questions.

Third, clients must feel safe sharing information about themselves in order to honestly respond to questions for the Common Ground report. This was facilitated by clients seeing the information they shared as relevant to meeting a particular goal or address a particular concern. It was particularly helpful when case managers assisted the client in developing a power statement that was meaningful and important to them or assisted the client with developing meaningful personal medicine that contributed to the client's well-being.

Clients must also feel that there will be no repercussions from sharing personal information. Clients who perceived information had been used against them in the past were more reluctant to share information via Common Ground. Clients who saw concrete evidence that progress was being made to achieve a stated goal or address a stated concern were more likely to begin or continue disclosing personal information about themselves via Common Ground.

Fourth, the relevancy of Common Ground must be established when engaging with the prescriber during the medication consultation. This was facilitated by the client feeling that Common Ground conveyed something they desired to communicate with the prescriber, the prescriber acknowledging the client's goal for seeking help, the client feeling their concerns as expressed on the HIAD scale were heard, and the client feeling like concrete steps were taken to achieve their goal or address their stated concern.

Fifth, decisions must actually be shared. This entails a context that is meaningful or important to the client has been established in which decisions are made, decisional uncertainty held by the client is addressed, multiple options are available to the client for achieving a stated goal or addressing a stated concern, and the decision is agreeable to the client and supported by the prescriber.

Sixth, the client's relationship with the prescriber seems to be an important factor contributing to client's involvement with shared decision making. Clients who perceived their relationship with their prescriber to be positive tended to be more involved in the shared decision making process.

Seventh, involvement in shared decision making was enhanced when clients received support outside of medication clinic to achieve a stated goal or address a stated concern. Clients who were highly engaged with Common Ground tended to receive support from their case manager outside of medication clinic related to decisions that occurred during the medication consultation.

Research Questions 4) How does a client's level of involvement in the shared decision making process impact various outcomes related to treatment, such as client satisfaction with the medication consultation, follow-through with treatment decisions, and level of well-being?

Clients who were highly involved in the shared decision making process were more satisfied with the medication consultation. This was evidenced by differences in how clients in the two groups spoke about the experience of the medication consultation, their relationship with their prescriber, and satisfaction with the decisions made in medication clinic. Clients who were satisfied with medication clinic were also more likely to keep medication clinic appointments.

Clients who were highly involved in the shared decision making process also had better follow-through with decisions made in medication clinic. The fact that clients who were highly involved with the decision made in clinic actually followed through seems to make intuitive sense, but what is most notable is that most of the clients who were not highly involved did not follow-through with the decision made at clinic. David stopped taking his medications until he was put back into the hospital, Albert was inconsistent in coming in for his injections, and Helen would not accept the anti-psychotic that was prescribed for her. On the other hand, Jason and Andreas both continued to come into medication clinic to receive their medications but both continued to have high decisional conflict regarding medications as stated on the Decisional Uncertainty Profile.

Clients who were highly involved in the shared decision making process tended to have better overall scores on the HIAD scale as the study progressed, but this did vary some. Sometimes even the clients who were highly involved occasionally expressed significant concerns on the HIAD scale, but this was viewed in a positive light since they felt comfortable communicating a concern through the HIAD scale and confident it would be addressed. Also, some clients who did not engage had a tendency to downplay concerns on the HIAD scale in order to avoid a potential hospitalization. For example, Helen was never completely honest about having thoughts of hurting self or others and would always pick a neutral response to this question.

Key Items and New Concepts

From the major findings in the preceding sections we find that:

- 1) Having a goal that is meaningful to the client that guides the shared decision making process helps clients to feel heard and encourages further involvement in the process;

- 2) Having personal medicine brought into the shared decision making process increases the options available to clients to achieve their goals and empowers them to take an active role in their own recovery;
- 3) The Common Ground software has the potential to help clients disclose important information about themselves that was previously not discussed at medication clinic. This new information enhances the shared decision making process because it brings the client's expertise about themselves more fully into discussions at medication clinic;
- 4) Peer support workers are an important auxiliary support to the shared decision making process because they facilitate client's use of the Common Ground software in order to communicate effectively with their prescriber;
- 5) Case managers are an important auxiliary support to the shared decision making process because they can assist clients with preparing to use Common Ground and following through with shared decisions made in medication clinic.

Of the twelve clients that were interviewed as part of the study, seven (Samuel, William, Bernice, Roberta, Mary, and Marcus) were found to be engaged with the Common Ground process and making progress towards goals they have set for themselves in medication clinic. Five clients (Albert, Jason, Helen, David, and Andreas) were not engaged in the Common Ground process. The five major findings listed above are common elements that can be found present in varying degrees among the clients for whom the shared decision making process is working well. It does not appear though that these elements occurred because there was an understood or clear protocol that was being followed. What seemed to occur was that some clients became activated around a certain component of the Common Ground process (e.g. the Power Statement, personal medicine, self-disclosure through the HIAD scale, addressing

decisional uncertainty through the Decisional Uncertainty Profile, recovery videos, etc.) and prescribers in turn responded positively to the client's activation. Since prescribers had accepted the underlying philosophies and principles of Common Ground, they were predisposed to engaging with clients that were positively engaged themselves with Common Ground. But what happens when a client is not engaging in the Common Ground process? For client's like Albert, David, Andreas, Jason, and Helen, we find the prescribers moving away from using the Common Ground process and reverting to practices they were familiar with prior to Common Ground.

There does not seem to be a consistency with how Common Ground is used to make shared decisions either between prescribers or even for the same prescriber working with different clients. This inconsistency, at times, leads to the Common Ground process working for some clients and not others, with the most apparent factor separating the two being the client's level of activation with the Common Ground process.

The findings in this study suggest there are two major factors that need to occur for effective shared decision making:

- 1) A client who is activated to participate in shared decision making.
- 2) A process of shared decision making that supports this activation.

We will first look at client activation and then turn to the processes that support client activation in shared decision making. The following discussion should lead to a greater awareness of how clients are activated and a framework for helping clients engage more fully in decisions about use of psychiatric medications within the medication consultation.

Activation Points

The idea for using the term activation came from one of the prescribers who was noticing that some clients who never engaged in discussions at medication clinic prior to Common

Ground have “somehow been activated.” What is key for those clients for whom the shared decision making process worked well in the study is that they were activated at some point through the use of Common Ground and this allowed them to increase their level of participation in medication clinic. I will refer to these as Activation Points, which I will define as:

A point in the Common Ground process where a person becomes engaged or enhances their current involvement in decisions regarding their mental health treatment or personal well-being.

Table 6 shows the Activation Points that were observed for each of the clients in the study:

Table 6
Clients and their Activation Points

| Client | Activation Points |
|---------|---|
| Samuel | Personal Medicine, Goal for discussing medication (Power Statement, Common Ground videos, Peer-to-Peer Medication Workshop, Using the computers at the Decision Support Center, HIAD scale, Decisional Uncertainty Profile, discussing options with prescriber in medication clinic, coming to a shared decision with prescriber in medication clinic. |
| Mary | Personal Medicine, Goal for discussing medication (Power Statement, Common Ground videos, Peer-to-Peer Medication Workshop, Using the computers at the Decision Support Center, HIAD scale, Decisional Uncertainty Profile, discussing options with prescriber in medication clinic, coming to a shared decision with prescriber in medication clinic. |
| William | Personal Medicine, Goal for discussing medication (Power Statement, Common Ground videos, Using the computers at the Decision Support Center, HIAD scale, Decisional Uncertainty Profile, discussing options with prescriber in medication clinic, coming to a shared decision with prescriber in medication clinic, Common Ground tools following medication clinic. |
| Maria | Personal Medicine, Goal for discussing medication (Power Statement, discussing options with prescriber in medication clinic, coming to a shared |

| | |
|---------|--|
| | decision with prescriber in medication clinic. |
| Marcus | Personal Medicine, Goal for discussing medication (Power Statement, discussing options with prescriber in medication clinic, coming to a shared decision with prescriber in medication clinic. |
| Bernice | Personal Medicine, Goal for discussing medication (Power Statement, Peer-to-Peer Medication Workshop, HIAD scale, Decisional Uncertainty Profile, discussing options with prescriber in medication clinic, coming to a shared decision with prescriber in medication clinic. |
| Roberta | Personal Medicine, Goal for discussing medication (Power Statement, Common Ground videos, Peer-to-Peer Medication Workshop, discussing options with prescriber in medication clinic, coming to a shared decision with prescriber in medication clinic. |

It is not surprising to see that those individuals for whom the shared decision making process worked well were activated at multiple points. While certain activation points may have contributed more than others to their initial engagement with Common Ground, the fact that they were activated at multiple points may have contributed to each of them remaining engaged in the overall process over time.

Activation Points – the example of Samuel

Samuel was initially activated by the concept of personal medicine. While Samuel was always amenable to coming in to medication clinic prior to Common Ground and engaged in discussions with his prescriber around his use of medication, the concept of personal medicine took these discussions to a new level. The concept of personal medicine gave him a language to discuss his recovery and well-being with his prescriber. Eventually, being able to use his personal medicine so he could enjoy life to the fullest became his power statement, even though this power statement was actually what he communicated to his prescriber rather than being written officially on the Common Ground Report.

As Samuel became engaged with his prescriber around a goal for treatment, he started to expand his personal medicines exponentially. He also became more active in using the HIAD scale to evaluate his progress towards his goal. He started to view his personal medicine as increasing the options that were available to him to stay well. A crucial point in the shared decision making process occurred when he added having a sexual relationship to his list of personal medicine. He was able to use the Decisional Uncertainty Profile to discuss concerns with his prescriber about the effect his pill medicine had on his ability to engage in sexual activity. His prescriber explored options with him and together they arrived at a decision that Samuel was happy with.

Being activated at multiple points helped Samuel engage more fully in his treatment. The key though seemed to be his activation around the concept of personal medicine. Once activated by this concept, this led to the formation of a goal around his use of medications, answering questions on the HIAD scale to gauge his progress in staying well, and using the Decisional

Uncertainty Profile to make decisions when pill medicine interfered with his use of personal medicine.

Samuel is an example of everything going right with the shared decision making process. Samuel was already activated around the concept of recovery prior to Common Ground and was taking steps to promote his own wellness. It was natural for Samuel to become activated by various elements of Common Ground (i.e. Personal Medicine, Power Statement, Recovery Videos, HIAD scale, etc.) because they fit well within the framework he already held regarding recovery. What made shared decision making effective is that his prescriber kept these elements at the forefront of discussions during the medication consultation. The prescriber used Common Ground to bring in Samuel's own expertise about his lived experience, preferences, and values and complimented these with her own expertise of the medications that Samuel was considering and options he might not have considered. This allowed Samuel to feel fully involved in the discussions at medication clinic and left him feeling satisfied with his overall experience.

Two years after his initial exposure to Common Ground, Samuel is still highly engaged with the process. Samuel reported at the Comprehensive Member Check that he is not only highly satisfied with Common Ground, but satisfied with his relationship with his prescriber and the gains he has made in his life since first using Common Ground. In continuing his goal to live life to the fullest, he has recently married which he considers an addition to his personal medicine.

An important point to consider is that Samuel had a change in prescriber after the study was completed. A few other clients reported that this new prescriber did not use Common Ground as regularly in the medication consultation as the original prescribers in the study did. Samuel though did not feel this change in prescribers lessened his involvement in medication clinic.

This may suggest that some clients who are highly activated by Common Ground can find success in the shared decision making process even when presented with a prescriber who is not fully activated by the process. This will be discussed further later.

Activation Points – the example of Roberta

Roberta was another client for whom the shared decision making process worked well in the study. Roberta, unlike Samuel, was not highly involved in discussions at medication clinic prior to Common Ground. In fact, Roberta struggled with decisional uncertainty related to the medications that she was being prescribed but could never communicate this to her prescriber. She continued to take the medications that she was prescribed, but would regularly go back into the hospital on a yearly basis. Her medications would be changed and the same pattern would occur again.

The important activation point for Roberta was the presence of a goal that she found important and meaningful. Roberta's case manager was key to helping Roberta identify this goal and elevate it to the forefront when discussing the possible benefits of Common Ground. With Roberta activated around a goal for medication clinic, she then became activated around the concept of personal medicine. This concept particularly excited Roberta because it expanded the options for her to stay well and achieve her goal, especially considering that the medications she was being prescribed were not working well for her. Armed with a goal and personal medicines at her disposal, she had more confidence going into medication clinic. With encouragement from her case manager, she was able to use Common Ground to communicate how she was doing through the HIAD scale and express her concerns with the medications through the Decisional Uncertainty Profile. As with Samuel, the prescriber noticed these things through the Common Ground report and made Roberta's goal and her primary concerns the focal point of

medication clinic. Roberta was able to make progress towards her goal throughout the study and this kept her engaged with the process. Roberta communicated to her prescriber that an older antipsychotic medication worked best for her and that she did not want any of the newer antipsychotics that her prescriber had been suggesting to her over the past several years. Her prescriber was willing to go along with Roberta's request. Roberta then turned to working with her case manager to increase the personal medicine that she had available to her.

From the examples of both Samuel and Roberta we see some important elements taking shape. For starters, we see a client who becomes activated and a prescriber who equally becomes activated around what is important to the client. This seems to set the stage for effective decision making. Second, decisions are arrived at during the medication consultation that meet the client's desires, and are aligned with the goal they are trying to achieve. Third, concrete steps are taken, either inside medication clinic or outside of clinic to assist the client in making progress towards that goal.

As mentioned in the example of Samuel, Roberta also had a change in prescriber following the end of the study. This did not work well for Roberta. During the Comprehensive Member Check, Roberta mentioned that she didn't use Common Ground the last time she came in and her prescriber said, "Ah that's nothing anyway." Roberta feels that her current prescriber is not as involved in using her Common Ground report as her previous prescriber. She says her previous prescriber "looked at all the angles". Her prescriber discussed her goals with her and used the report to see how she was doing the last time she came in compared to the present time. Roberta describes her new prescriber as "distant". She said she reported on the Common Ground report that she was crying more than usual. When he didn't bring this up during the medication

consultation, she verbally mentioned it. She says that her new prescriber said he cries a lot too and that was normal. Roberta felt she was “being dismissed”.

Roberta’s example sheds some light on the importance of the prescriber’s level of activation in addition to the clients. Samuel shared the same prescriber, but was still able to stay highly involved even after the change. Samuel though was highly activated prior to Common Ground, so he already viewed his role as being active in medication clinic and being vocal about what he wanted. Roberta on the other hand was quiet in medication clinic prior to Common Ground and it took the efforts of her case manager and the positive response from her prescriber to bring her into a more prominent role. When the response to Common Ground changed, Roberta began to revert to her previous role. It is possible she is slowly becoming de-activated. While Roberta is still activated by her goal and the concept of personal medicine one year after the end of the study, its relevance to discussions at medication clinic is now being questioned. Since Roberta still has fears about how the information reported on Common Ground might be used, it is a likely scenario that Roberta will stop using Common Ground in the future if it is not being used to help her achieve her goals and stay well.

Activation Points – Example of Bernice

Bernice shares a lot in common with Roberta in that she did not speak much during the medication consultation prior to Common Ground. Also like Roberta her primary activation point was around a goal that was important to her (keeping herself well so she could care for her son). Upon being activated around a goal, Bernice embraced the concept of personal medicine and started communicating more in medication clinic via the HIAD scale in order to achieve her goal.

A year after the end of the study, Bernice reported during the Comprehensive Member check that she is still highly engaged in using Common Ground, feels that she is being heard by her prescriber, and is in control of making decisions during the medication consultation. Like Samuel and Roberta, Bernice is now working with the same new prescriber. Her favorable response to the new prescriber was similar to Samuel, and this change in prescriber did not seem to impact her investment in or use of Common Ground.

So why did Bernice remain activated around Common Ground with the change to a new prescriber, whereas Roberta became less activated around Common Ground? One consideration is that Bernice did not have the fear that Roberta had around how information collected in Common Ground would be used. Bernice viewed Common Ground as an opportunity to finally communicate what she wanted to her prescriber. With a goal leading the discussions at medication clinic, she was open to revealing more about herself in order to achieve this goal. Her prescriber was actively using the information in Common Ground to help her improve her well-being and she was seeing positive results. Roberta on the other hand was more selective in what she revealed about herself. While her goal was leading the discussion in medication clinic, as Bernice's was, Roberta was also navigating relationship dynamics with her prescriber. Could she tell her prescriber everything she was experiencing? What if she said something that put her back in the hospital, which would negatively impact the goal she was trying to achieve (care for her small child)? What if she said something that resulted in the prescriber putting her on a medication she didn't want? When Roberta received a new prescriber, she had to re-navigate the relationship. This was not the case with Bernice.

Another consideration is that Bernice had reached a point of stability and her confidence in her own decision making was elevated by the time the change in prescribers occurred. Roberta

was still struggling with side effects from the current medication she was taking. She had decided on this medication because she found it was better than other medications she had previously tried in allowing her to care for her child. Even so, she found the side effects difficult to tolerate. Roberta still had considerable decisional uncertainty about taking her current medication at the time of the Comprehensive Member Check.

What this may suggest is that activation points remain tentative for some people. While a particular activation point might allow the opportunity for a client to become more involved in their care, a corresponding action is still required on the part of the treatment team in order for the client to remain involved. Roberta was initially activated by a goal to stay well so she could care for her small child. While this goal was understood by her previous prescriber and shared decisions were occurring around this goal throughout the course of the study, this goal was never formalized in the Power Statement on the actual Common Ground Report. When Roberta changed prescribers, the goal was lost because the new prescriber did not work with Roberta to understand and re-establish the context for how their decisions in medication clinic would be made together. Roberta continued to mark areas of decisional uncertainty on the Common Ground Report even after the change to a new prescriber, but since the prescriber did not explore these areas with Roberta, the information could not be used in the decision making process.

Bernice and Samuel represent a unique subset of clients who have reached a point of stability in their life, have found a medication that works well for them, gained confidence with an active role in medication clinic, and have a positive relationship with their prescribers. While key actions by members of the treatment team (i.e. prescribers, nurses, case managers, and peer specialists) were instrumental to initially increasing their involvement in medication clinic, Bernice and Samuel are currently at a point in life where they are less at risk of becoming

deactivated. A change in life circumstances though, could put them in the same position as Roberta.

A strength of Common Ground is its flexibility in providing multiple avenues to engage clients in discussions and decisions at medication clinic. Prescribers need to be conscious of where clients are becoming activated and exploit these areas to maximize the client's involvement in the decisions being made about their care. Use of Common Ground also needs to be consistently relevant to the client during each medication consultation. Is the current Power Statement relevant to the goal the client wants to achieve by coming into medication clinic today? What is the relevance of what the client is communicating on HIAD scale to what the client wants to achieve today? What is the relevance of what the client is reporting on the Decisional Uncertainty Profile to what the client wants to achieve? Is the decision arrived at today relevant to what the client wants to achieve and is the plan relevant to the client's preferences and values? Common Ground has the ability to open up these avenues of relevance, since the report is generated by the client's responses, but the prescriber's response to this information can make the difference between increased involvement on the part of the client or a missed opportunity.

Activation Points – Example of Maria

In the initial sample of client participants, staff identified six clients they perceived as being engaged with Common Ground and six who were not engaged. Maria provides a unique example among the client participants because she was the only client to switch groups by the end of the study. Initially, Maria was identified as a client who was not engaged, but over the course of the study she became more involved and at the time of the Comprehensive Member

Check her responses indicated that her involvement level had increased to similar levels as Samuel and Bernice.

Maria was initially activated by the concept of personal medicine. Prior to Common Ground she experienced some tension with her prescriber around the medications she was prescribed. The prescriber perceived that the medication Maria had been taking for years was not working and wanted Maria to try different medications. Maria insisted that the medication worked fine for what she wanted it to do (keep her from crying all the time) and did not want too much pill medication in her system. Still, Maria continued to mark areas of concern each time she came into medication clinic on the HIAD scale. The prescriber finally stopped pushing for a medication change and instead explored with Maria the concept of personal medicine to help her with her concerns. This concept fit well with Maria's preferences and values and helped activate her in the discussions at medication clinic. A second activation point was achieved when the prescriber explored the context for how they would make decisions together. Maria's goal of being able to spend more time with her granddaughter became a focal point of discussions at medication clinic and an evaluative measure of Maria's progress. At the time of the Comprehensive Member Check, Maria reported that she had now set a new goal to go back to school and she had been working with her case manager to increase the personal medicine available to her. Particularly noteworthy is that Maria is now using the term "personal medicine," whereas during the study she identified with the concept but was unfamiliar with the actual term. Maria reported that she is now using Common Ground every time she comes into see the prescriber, whereas initially she didn't see the value of using Common Ground every time.

At the time of the Comprehensive Member check, Maria was still seeing the same prescriber she had during the study. This may suggest the importance of continuity in care when using Common Ground, especially for clients who were not engaged in medication clinic previously. It took almost a year of using Common Ground, and a prescriber who used the information to keep the focus relevant to the client, to fully activate Maria in the process. This speaks volumes to the role of the prescriber in engaging clients who might not initially see the value of Common Ground. A key in the example of Maria is the prescriber using Common Ground to shift decision making discussion from the vantage point of the prescriber to the client. Once the prescriber shifted discussions from ‘what medication do I think you should take’ to ‘what is the goal you are trying to achieve (spending time with my granddaughter) and what are the options (pill medication and personal medicine) to get there’, Maria responded by becoming more involved in the decision making process. Maria’s perception of coming to medication clinic changed from only coming in to get her prescription refilled to now coming in to work on her goals.

Activation Point – Example of Helen

Helen is still not engaged with Common Ground over a year after the end of the study. At the Comprehensive Member Check Helen groaned that the system was still in operation. Helen was never activated at any of the points mentioned in Table 6 above. Helen is an example of missed activation points that could have been opportunities to involve her more in her own care. At the Comprehensive Member Check, Helen continued to speak of her desire to get better but also mentioned that she still does not feel heard by her prescriber.

Let’s break down Helen’s journey through the Common Ground process and see what implications this has for improving the process to target key activation points. First, it did not

appear that her case manager was highly involved in helping her prepare for using Common Ground. She switched case managers in the middle of the study and neither had helped her develop a meaningful power statement nor personal medicine that matched with what she was actually using to stay well. During the interviews, Helen did mention that being able to spend time with her grandchildren was important to her and this is what kept her going in life. This did not occur as often as Helen would like though because her sons would sometimes not bring them over if they felt Helen was talking too much about the “ghosts” she experienced. It’s unfortunate that Helen being able to spend more time with her grandchildren was not made into a Power Statement because this might have established relevancy to making shared decisions in medication clinic.

Helen also had some great personal medicine that was helping her stay well (e.g. specific activities that she did with her grandchildren, collecting antiques, keeping her apartment in immaculate shape, watching movies, etc.) that was never recorded on the Common Ground Report. Helen was never offered assistance in seeing the value that personal medicine could play in her life. Even at the time of the Comprehensive Member Check, Helen was still unfamiliar with the term. This is also unfortunate because Helen did not seem to think she had any power to change what she was experiencing in life. She stated that prescribers were trying to find a pill that would work, but she did not have any confidence that this would ever be found.

Second, Helen was never activated around answering questions on the HIAD scale or the Decisional Uncertainty Profile. Neither of the two case managers during the study went with her to use Common Ground or assisted her during medication consultations. Helen never understood how answering these questions could help her, so she went through the motions of filling out the report so she could get in to see her prescriber, which was primarily so she could get her

antidepressant refilled. This activation point could have been pivotal for Helen if a few elements would have been met:

- 1) A meaningful Power Statement (spending more time with my grandchildren) would have been placed at the top of the report;
- 2) The case manager and/or the peer support specialist would have recognized that Helen was struggling to understand how the report could help her and walked her through how responses to each of the questions would help the prescriber assist her with her goal.
- 3) Helen felt safe to report her concerns without retribution of going back into the hospital.

Helen was not able to communicate how she was truly feeling on the HIAD scale, because like Roberta, she was suspicious about how the information reported on Common Ground would be used. Helen would also choose the middle option for each question, because that was the safest for her. She feared that reporting concerns in any particular area might lead to a hospitalization she did not want. Without a goal to set the context for why she was answering questions on the HIAD scale and Decisional Uncertainty Profile and support while answering the questions, Helen was left to her own fears as she filled out the report. Helen also had difficulty answering the questions because she felt that what she was experiencing might change from the time she was sitting at the computer to the time she went home. This would have been an opportune time for her case manager to validate this concern for Helen if they were present with her during the visit. They could have revisited the questions from the Common Ground report at a later point when they met at Helen's home to see how the responses had changed. This could have led to discussions around strategies for helping Helen around specific times and situations when she wasn't doing well, even possibly incorporating Helen's personal medicine.

A third missed activation point was during the actual medication consultation. Once again the lack of a meaningful goal to Helen guiding discussions was a key missing element. Equally important was that the decisional uncertainty Helen was trying to report through Common Ground during her early visits was never addressed adequately. Helen was being prescribed two medications; an antidepressant (which she found helpful) and an antipsychotic (which she did not find helpful). The fact that Helen found value in the antidepressant kept her engaged on some level in continuing to return to medication clinic, but during each visit she experienced a struggle with her prescriber about the antipsychotic. This is very similar to Maria's situation. Where Maria and Helen's situations begin to distinguish themselves is that Maria's prescriber acknowledged her goal, stopped pushing the medication she didn't want and replaced it with an exploration of personal medicine, and then Maria's case manager followed up to help her increase her use of personal medicine outside of medication clinic. On the other hand, Helen's goal was never acknowledged, the prescriber continued to prescribe the medication she didn't want, and there was no follow-up by the case manager. What we see with Maria, a person who like Helen initially did not see the value of Common Ground, is someone who increasingly became more engaged in medication clinic and use of Common Ground. Helen hoped that Common Ground would just go away.

Activation Points – Example of Marcus

Marcus is a person for whom the shared decision making process worked well, but a year after the end of the study, we find that little progress had been made with Marcus following some substantial gains made initially in the process. Marcus was activated by the concept of personal medicine. This was critical for Marcus, since he did not communicate much in medication clinic prior to the start of Common Ground. Most of the decisions that were made regarding Marcus's

medications were made between his prescriber and his mother. Personal medicine opened a pathway for Marcus to start contributing in discussions. This also led to the formulation of a goal of Marcus staying well so he could enjoy using his personal medicine. While this goal was never formalized into an official Power Statement, it was verbally recognized by his prescriber and decisions were framed around the context of this goal. Throughout the study, Marcus increased his use of personal medicine and even advocated for his own medication change without his mother being present. Marcus perceived that he had more control over the decisions made in medication clinic than prior to Common Ground.

There is reason to believe that the treatment team could go further with Marcus. The concept of personal medicine has opened up dialogue between Marcus and his prescriber, which signifies a foundational element of the shared decision process has been achieved. But the treatment team should be cautious that they are not satisfied with mere stabilization of the person. This really is only a continuation of the old way of thinking. We have merely added a new tool to achieve this. The treatment team should now start to help Marcus craft goals to press even further into his recovery. Now that Marcus is starting to feel well, what does he want to achieve in his life with his newfound wellness?

Marcus declined to participate in the Comprehensive Member Check, as he did a second interview during the study. His case manager reported Marcus's reason being that he had nothing more to add than what he previously reported about Common Ground. Marcus's case manager reported during the Comprehensive Member Check that while Marcus continues to use Common Ground, he doesn't feel that he is getting as much out of it as he could. Marcus's original goal (staying well in order to use personal medicine to enjoy life) was never recorded as a Power Statement. Marcus now has a new prescriber, so it's possible this information is not being

discussed during the medication consultation, especially considering that Marcus was not a vocal person in medication clinic prior to Common Ground.

Marcus seems to be at risk of following a similar pattern as Roberta, who like Marcus was engaged with Common Ground during the study. Both of these individuals were not vocal in appointments prior to Common Ground, and now without a goal to guide the context of medication consultation discussions and information from Common Ground not being incorporated into these discussions, the possibility of de-activation remains high.

Activation Points – Example of William

William probably made some of the greatest gains during the course of the study. William was not highly engaged in medication clinic prior to Common Ground and reluctantly came in each week to get an injection he didn't like receiving. William was activated by a goal that his case manager helped him develop into a Power Statement, which was to spend more time with his family. Equally important, William was activated by the concept of personal medicine. Not wanting to take injections anymore, William saw personal medicine as increasing the options available to him for keeping well. Armed with a meaningful goal and an array of personal medicine, William advocated for his injection to be replaced with a pill. William's prescriber responded positively to this, and despite reservations agreed to begin helping William take steps towards the medication change. William's activation around personal medicine contributed greatly towards the prescriber's willingness to agree with William's decision. William, in turn, became activated by answering questions on the HIAD scale. These responses to these questions became important to both William and his prescriber because they could monitor how well he was doing each week with the transition. William also became activated by using the Common Ground tools, because they gave him and his prescriber additional information on how he was

doing with side effects and moods that might be impacted by the medication change. As the study concluded, William was able to successfully make the transition to a pill medication as he requested. Unfortunately, William's prescriber during the study left the agency and William started doing poorly once again. With William's new prescriber, the Common Ground report was not the focal point as it had been with his prescriber during the study. William reported at the Comprehensive Member Check that he was eventually hospitalized and put back on the injection. While William reported that he was saddened by this happening, he said he understood the doctor's decision. He still holds out hope that he will be able to go off the injection again in the future.

William and Roberta both represent clients who were highly activated by Common Ground and made substantial progress towards their goal while Common Ground was a focal point of the discussions during medication consultations. Once Common Ground was no longer the focal point, each was faced with a struggle to define their role in medication clinic. Roberta was more vocal about her frustrations with the current lack of emphasis on the Common Ground report during the Comprehensive Member Check. Roberta expressed that she no longer felt heard in medication clinic. William seemed more resigned to the change and was willing to go along with what the doctor thought was best, which was similar to how William engaged in medication clinic prior to Common Ground.

Activation Points – Example of Mary

Mary represents a special subset of the clients for whom the shared decision making process worked well, since she had more internal knowledge of the Common Ground process prior to the study, having worked as a peer specialist. Mary had difficulty communicating with her prescriber prior to Common Ground, much of this due to the fact that she had difficulty finding

the words to express what she was experiencing and what she wanted in terms of medications. Mary felt intimidated in the presence of prescribers and often would just accept their recommendations. Common Ground provided a template for Mary to organize her thoughts and communicate more effectively with her prescriber. Mary was activated at multiple points including: having a meaningful goal (keep working) that guided discussions at medication clinic, the concept of personal medicine, and answering questions on the HIAD scale and Decisional Uncertainty Profile. Mary gained confidence in herself over the course of the study because she felt like she had the Common Ground report to back up anything she said in medication clinic.

Mary was still working at the time of the Comprehensive Member Check, though she had been experiencing some significant side effects from her medications. Mary is still working with her prescriber to find a dosage of current medication that works for her as well as non-pharmacological alternatives to deal with symptoms. Mary also had a change in prescriber from the initial study. She is now seeing the same prescriber as Samuel, Roberta, Bernice, Helen, Marcus and William. Like Samuel and Bernice, Mary is satisfied with the relationship she has with her current prescriber and is using Common Ground during the medication consultation. What this suggests is that clients such as Samuel, Bernice, and Mary, who were activated by the Common Ground report can continue to make good use of this report during the medication consultation, even with a prescriber who is not routinely emphasizing the use of the report, if the client takes the initiative to keep the report at the forefront of discussions.

Activation Points – Example of David

David reported that he was now on a medication that was acceptable to him and that he was now coming in to medication clinic regularly. He also reported using Common Ground now occasionally. Caution must be exercised with associating this activation though. David

expressed during his interviews that his main reason for taking medications, when he did so, was to avoid the hospital. David was hospitalized again after the end of the study and is now on an outpatient court order to take medications. He did feel he was given some input into which medication he took. David did not seem like the same person I interviewed during the study. Rather than the articulate person who clearly expressed what he liked and did not like about the process, he appeared heavily medicated and did not mention anything negative towards his providers or Common Ground. He appeared similar to William in being resigned to the way things were.

The fact that David is now coming to medication clinic again presents another opportunity to engage him around Common Ground. From what we have learned from this study, finding a goal that is meaningful to David to guide future discussions in the medication clinic would seem to be a high priority. David still has considerable decisional uncertainty around taking medications, and he takes them to avoid hospitalization, not to achieve something that is important to him. Since David previously revealed that the medications don't seem to have much of a positive effect for him and the side effects are sometime unbearable, the concept of personal medicine might be appealing to him. Having multiple options available to David when discussing how to achieve his goals for life could be a significant activation point. David seems like an intelligent person who would be able to contribute a lot to the discussions at medication clinic if an avenue was created for him to take a more active role. While David has considerable decisional uncertainty around the medications, this previously has not been adequately addressed at medication clinic. Like Roberta, a safe environment, created by a trusting relationship with his prescriber, would need to be present for him to honestly communicate his concerns through the HIAD scale and the Decisional Uncertainty Profile.

Activation Points – Example of Jason

Jason, likewise did not report anything negative about his providers or Common Ground. He reported that he would use Common Ground if he ever needed it, but would prefer just to come in and get his injection and leave. Jason might represent a type of client for whom having Common Ground completed at the mental health clinic might not work well. Jason does not like being around a lot of people and being at the center increases his symptoms of paranoia and anxiety. Since Jason is not closed to the idea of using Common Ground, being able to complete the report offsite, possibly with his case manager or online might provide him an avenue to become more activated using features of Common Ground. From Jason's interviews during the study, he seems to have decisional uncertainty with his current medication and does not feel as if he is doing as well as he could. With Jason's brief visits to medication clinic, this information was not made available on the Common Ground report for his prescriber to discuss with him.

Activation Points - Example of Andreas

Andreas is the one person from the group of clients that the shared decision making process did not work well during the study that may be beginning to become activated around certain parts of Common Ground. Andreas is a difficult person to understand through regular conversation. His thoughts seem disorganized and his words are all over the place. His prescribers had difficulty understanding him when he came in for the medication consultation. He was typically prescribed the same medications each week, which Andreas did not always take. He had considerable decisional uncertainty over taking these medications. Towards the end of the study, Andreas's prescriber started noting his decisional uncertainty from the Common Ground report and used this to open up discussions about how he was currently taking his medications. Andreas finally communicated to his prescriber that breaking up one of his

medications into three pieces and taking it throughout the day was helpful to him. While his prescriber did not dissuade Andreas from taking the medication in this manner, it was not until after the study ended that this was finally made into an official shared decision that was recorded on the Common Ground report. Also after the study ended, the prescriber started exploring with Andreas the option of using personal medicine to help him in areas of concern that he marked on the HIAD scale. Andreas's personal medicine was eventually changed on the Common Ground report to better reflect what he was actually using. This included painting, reading, and doing crafts, which he reported provided a calming effect to him and improved his mood.

Andreas continued to express decisional uncertainty about his current medications at the Comprehensive Member Check, but acknowledged that he was now periodically using Common Ground. While it is difficult to assess Andreas's level of activation post-study, there are encouraging signs that the information he is reporting on the Common Ground report is being used in the medication consultation to help him and his prescriber make decisions about the medications (both pill and personal) that he is taking.

Andreas's example may offer insight into the importance of using Common Ground with client's who are disorganized in thought and have difficulty verbally communicating information to their prescriber. In Andreas's case, we see Common Ground serving as an assistive technology to help him make visible what was previously invisible within the medication consultation. The activation points which seemed to be exploited in Andreas's case was a meaningful goal (being able to use his personal medicine, specially noted as painting and reading on his Power Statement), a positive response by his prescriber towards the decisional uncertainty he was experiencing, explorations via personal medicine to increase the options for addressing concerns on the HIAD scale, and coming to a shared decision, even despite decisional

uncertainty, that was satisfactory to Andreas. Without Common Ground, it is difficult to imagine the prescriber and Andreas making a connection through these activation points.

Activation Points – Example of Albert

Albert did not attend the Comprehensive Member Check, but reports from his case manager suggest that Albert is being introduced to the concept of personal medicine now, both by his case manager and his prescriber. His most recent Common Ground report showed that Albert was listening to music now as a strategy to help when he experienced distressing voices. It also appears that Albert's goal of going back to work is being discussed again. It will be interesting to see if the concept of personal medicine and a meaningful goal prove to be activation points that increase Albert's involvement in discussions at medication clinic.

Application of Activation Points to Practice

The concept of activation points could serve an important role in engaging clients more fully, not only in the shared decision making process, but in treatment in general. Krenyenbuhl, Nossel, & Dixon (2009) in their review of the literature noted that keeping individuals diagnosed with schizophrenia involved in treatment has long been a struggle in the field of mental health. Factors such as poor therapeutic alliance (Lecomte et al., 2008; Priebe, Watts, Chase, & Matanov, 2005; Young, Grusky, Jordan, & Belin, 2000), lack of active participation in treatment on the part of the client (Priebe et al., 2005), dissatisfaction with treatment (Rossi et al., 2008; Ruggeri et al., 2007; Young et al., 2000), and the perception that treatment would be unlikely to help (Rossi et al., 2008) have all been cited as reasons why individuals with schizophrenia disengage with treatment. In another review of the literature, O'Brien, Fahmy, & Singh (2009) found that clients often cited unsympathetic providers, not being listened to, not being able to

actively participate in decision making, and being dissatisfied with services as reasons for disengaging from psychiatric services.

The concept of activation points reveals that there are multiple avenues for potentially engaging clients. Common Ground creates a pathway for these activation points to be explored. Awareness of potential activation points for clients would allow treatment team members the ability to pinpoint where engagement is occurring and where strategies might need to be developed to engage a person who is not involved in treatment.

The Centrality of the Goal

While activation points are an important concept to consider in terms of engaging clients in the process, it is not sufficient in and of itself for effective shared decision making to occur. A major finding of the study was the centrality of the client and prescriber agreeing on a goal that framed the context for making decisions. The presence of a meaningful and important goal for the client that was acknowledged by the prescriber was a common element for all of the clients for whom the shared decision making process worked well. It was also a pivotal element for the one client who changed from being peripherally involved with Common Ground to being highly involved in the process. Activation points should therefore be viewed as pathways that can lead to the formulation of a goal that defines the context for shared decision making.

The following diagram illustrates this:



Figure 1: Relationship of Activation Points to the Goal

Ultimately, what allowed shared decision making to occur was the presence of a goal that framed the discussion within medication clinic. The goal is what made the other aspects of Common Ground relevant to the discussion. When a goal was established, the other elements of Common Ground could be used to fully involve the client. Roberta is an excellent example of how this plays out in practice, since she was a client who went from being passively involved in medication clinic prior to Common Ground to a person who was actively involved who never spoke much at all within medication clinic. Shared decision making began to occur for Roberta when the goal of her being able to care for her small child was made the focal point of medication clinic discussions. Answering questions on the HIAD scale now had relevancy because it let her and the prescriber know how she was doing at each clinic visit pertaining to being able to care for her child. Remember that Roberta initially had significant reservations

about answering questions on the HIAD scale. Once the goal was established, she became much more candid in her responses, especially related to how she was doing on the medications she was taking. The questions for the Decisional Uncertainty Profile also became relevant to Roberta, because now she could communicate the importance of factoring in side effects when considering medication choices. Personal medicine now had relevancy because they increased her options for staying well to care for her child. The videos had more relevancy because they gave her ideas of how to stay well in order to care for her child. More relevancy was also brought to the work she did with her case manager outside of medication clinic, because together they were now working on increasing her personal medicine so that she could stay well to care for her child.

We could do the same with other clients for whom the shared decision making process worked well. Various activation points may have engaged the client and started them thinking about the opportunities afforded them, but it was the arrival at a meaningful and important goal that laid the foundation for shared decision making to begin. For clients who never arrived at a goal within medication clinic, shared decision making did not occur.

Proposed Framework for the Shared Decision Making Process

In order to conceptualize how the concept of activation points could be incorporated into practice, the following framework could be considered for guiding the shared decision making process. This framework takes into account the findings from this study where shared decision making was successful and also where shared decision making broke down. The framework also takes into account that involvement in shared decision making was often preceded by clients becoming activated in key areas before seeing the prescriber and then being further explored within the actual medication consultation.

It is believed that a framework for shared decision making needs to be developed for the following purposes:

- 1) Establish a consistent protocol for prescribers when engaging clients in the shared decision making process;
- 2) Establish roles for auxiliary supports (peer specialists and case managers) for supporting clients using Common Ground and the shared decision making process;
- 3) Establish a series of engagement points to assess areas of breakdown in the shared decision making process and prompt for interventions to re-engage clients.

I do not believe that having a consistent protocol detracts from the flexibility of Common Ground to be used differently to account for the diversity of client's needs and situations. Rather it serves as a guide for all members of the treatment team to assess various points in the process to evaluate whether or not a client is effectively engaged. For clients who are not engaged, like Albert, David, Andreas, Helen, and Jason, it offers the opportunity to evaluate areas where the client might be re-engaged. For clients in the study such as Samuel, Bernice, and Mary, who were highly engaged in the shared decision making process, it may not seem like a framework is needed, but it should be noted that client's such as Roberta and William were also highly engaged in the shared decision making process at one point in the study but quickly became disengaged once the process lost its relevancy to their stated goals and concerns.

An important finding from the study was that clients assumed a disproportionate burden for keeping their goals and concerns at the forefront of the shared decision making process. This framework calls for the prescriber and the other members of the treatment team to remain aware of exactly where the client is engaging or not engaging through Common Ground and eliciting

proactive responses that either validate the clients point of engagement or explores areas where a client might increase their involvement in the process.

While this proposed framework follows some of the protocols that were initially outlined for the use of Common Ground to support shared decision making, it has been refined and made more explicit based upon factors that contributed to the shared decision making process working well for some clients and not for others.

Framework for Shared Decision Making

Interaction with the Case Manager

- 1) What is it that you want to achieve in your recovery? (Long Term Goal)
- 2) What are your goal(s) for considering the use of psychiatric medications? (Power Statement)

It is possible that #1 and #2 could be the same thing. For example, a person's Power Statement might read something like "raising my child is the most important thing in my life. I am not willing to sacrifice being able to raise my child to symptoms of schizophrenia or to side effects of medications. You and I must work together to find a medication that supports me in my efforts to raise my child." Here the person's goal for recovery might be the same as their goal for deciding whether or not to use pill medicine.

A person's goal for considering medication though might be a subset of their goals for recovery. For example a person might have a goal to raise their child, but they have also identified that attending church on Sunday and singing in the choir helps them to stay well in order for them to be the parent they want to be. A person might like their Power Statement to read "Attending church on Sunday and singing in the choir is powerful personal medicine to me.

This helps me to stay well so I can be a better parent to my child. You and I need to find a medication that supports me being able to worship at church on Sunday and sing in the choir.”

- 3) What things are you currently doing besides medication that supports you in the above goal (Personal Medicine)?
- 4) What current things are getting in the way of you being able to achieve the above goal (set up for HIAD scale)?
- 5) Do you have any uncertainties about taking pill medication (set up for Decisional Uncertainty Profile)?

Once a goal for medication clinic has been established, case managers can help clients enter into effective decision making by helping them to think through what’s currently working, what’s getting in the way, and any potential decisional uncertainty or conflict with pill medication. Case managers can use this information to prompt clients on how to communicate this information when answering questions for the Common Ground Report. Case managers can also be proactive in planning to address any barriers that are getting in the way of the person achieving their goal that falls under the scope of case management.

- 6) Do you need any assistance in communicating this information to your prescriber?

Case managers can assist clients with writing down any specific concerns or questions that they want to address in medication clinic. Case managers can also volunteer to attend the medication consultation with the client if they feel more comfortable with this.

Interaction with the Peer Specialist at the Decision Support Center

- 1) Verification of the Power Statement. Is this the goal you have for considering the use of psychiatric medication? Do you have any changes that need to be made to this statement?

- 2) Verification of Personal Medicine. Are these all the things that you are doing in addition or apart from pill medicine that help you with achieving this goal or to stay well? Would you like to add anything here or make any changes to the personal medicine you have listed?
- 3) Summary of the responses on the HIAD scale. Your report shows that you are concerned about the following things. Is this correct? Are these the important areas that you wish to discuss with your prescriber during this visit? If not, would you like to re-visit some of the questions on the HIAD scale?
- 4) Summary of the Decisional Uncertainty Profile. Your report shows that these are areas that you have some uncertainties around the use of psychiatric medication. Are these correct? Are these things you would like to discuss with your prescriber when deciding whether or not to use psychiatric medication or to continue using psychiatric medication? If not, would you like to re-visit some of the questions on the Decisional Uncertainty Profile?
- 5) Are there any other specific concerns or questions that you want me to make note of when you see your prescriber?
- 6) Would you like any assistance looking up any information that would help you make better decisions with your prescriber? (i.e information about a particular medication, information about potential side effects, information about a particular diagnosis, information about alternative strategies to assist with particular symptoms, etc.).

Interactions with the prescriber during medication consultation

- 1) Clarification of Power Statement (read aloud). Is this what you want to achieve by coming into medication clinic today?

If the person does not have a specific Power Statement, but they do have specific concerns, then the prescriber could start with #2 and #3, but continual efforts should be made to help them shape this into a Power Statement. This does not have to be done by the prescriber, but at minimum the prescriber should notify the case manager and/or the peer support worker that the client might need some help with this.

- 2) Clarification of Personal Medicine (read aloud). Is this what is currently helping you to stay well so that you can achieve this goal?
- 3) Review of responses on the HIAD scale. This shows how you currently see yourself as doing as you work towards this goal. I see that the following areas are going well (comment on changes from last visits if there is a history). I also see that you still or now have some concerns in the following areas (responses in red). Tell me how these things are interfering with your ability to achieve the goal you desire or being able to access your personal medicine to stay well.
- 4) Review of responses on the Decisional Uncertainty Profile. Your report shows that if you are to consider using pill medication to help you with this goal, you have some uncertainty in the following areas. Can you tell me more about this?
- 5) Presentation of Options. Based on the information you have presented through the Common Ground report, as well as what you have just shared with me, here are some possible options for us to consider. I'd like to use these as a starting point to begin the shared decision making process. Do any of these options appeal to you? (explore pros and cons of each option).
- 6) Creating a shared decision. It sounds like you would like to do the following (written down and read aloud to the client). Is this correct?

- 7) What supports do you think you might need to carry out the decision we have made together? Here are some options you might consider.
- 8) Notification sent to any supports (i.e. case manager or peer specialist) involved in the shared decision. “I’m going to let your case manager know this is what we have decided to do between this visit and next and how he or she can support you with this decision.” or “I’m going to send you back out to meet with the peer specialist so he or she can assist you with the decision we just made.”
- 9) Plan for follow-up. I want to meet with you again on _____. During that visit, we will look to see how the decision we made is helping you to achieve your goal (refer back to Power Statement again). We can further evaluate if we are on the right track or if we need to explore further options to assist you with achieving your goal.

Follow-up with Case Manager

- 1) Case managers need to know the shared decision that was made at each medication consultation. It would be helpful if they knew what the shared decision was within 24 hours of the medication consultation so they can make plans for follow-up if needed. They can find this out through a variety of sources:
 - a) E-mail from prescriber noting the shared decision
 - b) Looking it up directly on the Common Ground website
 - c) Asking the client

It might be important at times for the case manager to verify the shared decision from both the prescribers perspective (a and b) and the client’s perspective (c). This can be helpful when a client is new to the shared decision making process or a strong relationship has not been established yet between the client and the prescriber.

- 2) Case managers need to follow-up with the client on the shared decision within one week on the medication consultation. This may be just a simple phone call if the client is highly engaged with the process and has been making progress on their own without the assistance of the case manager. If the case manager has a specific role in the shared decision or if the client is requesting assistance, it's best to begin making steps quickly so that the client has something to report during their next medication consultation.

Key Areas to Flag for Intervention in the Shared Decision Making Process

- 1) Does the Client have a Power Statement? If no Power Statement exists or the current Power Statement doesn't seem to reflect something the client is truly passionate about, then all efforts need to be focused on engaging the client in developing one. Developing a Power Statement could be part of a shared decision at the end of a medication consultation. If a prescriber does not have a Power Statement to work with, the case manager or peer specialist needs to be notified for follow-up.

If a client is having difficulty coming up with a Power Statement, then here are a few areas that can be explored:

- a) Extracting a Power Statement from the personal medicine the person is using. For example, a client might consider exercising to be a part of their personal medicine. A beginning Power Statement might be just to be able to continue using this personal medicine without interference from symptoms or side effects of medications. One could also find out what the client is trying to achieve by using a particular personal medicine. The answer to this might lead to a Power Statement.

- b) Extracting a Power Statement from responses on the HIAD scale. For example, if a person marks that they are having difficulty with sleep or anxiety, discussion could revolve around what is lack of sleep or anxiety keeping you from doing in your life?
- 2) Does the client have personal medicine listed? If no personal medicine is listed or the personal medicine is outdated from what the client is currently using, the prescriber needs to notify the case manager and/or peer specialist to follow-up. This again could be a shared decision from the medication consultation.
 - 3) Is the client having any difficulty accessing current personal medicine or desires to explore new personal medicine? This could be a shared decision at the medication consultation.
 - 4) Are there items marked on the HIAD scale that are particularly distressing for the client or have been continually flagged by the client for over two sessions. This could be flagged by the prescriber to be brought up in case manager group supervision, a team meeting involving the prescriber, or a staffing specifically called to address a client's concern. It's important for the client to know that any distressing concerns or on-going concerns are taken seriously and there is a plan to help the client and the treatment team address these.
 - 5) Are there items marked on the Decisional Uncertainty Profile that the client is particularly struggling with in the decision to take medications? This could follow the same process as #4.
 - 6) Has a medication been started or changed in medication clinic? The prescriber should notify the case manager of these changes. While this should show up in the shared decision documented on the website, in certain cases this may require a specific e-mail to

the case manager, especially if the client requests support or has some decisional uncertainty with taking a pill medicine. The case manager should contact the client as soon as possible to put together a plan for supporting the client until their next medication consultation.

While the above framework has not been used yet practice, it should at least serve as a guide for agencies implementing Common Ground and the shared decision making process.

Implications for Policy

The findings in this study have several implications for policy at the program, state and national levels. At the program level, expectations need to be established for the use of shared decision within the medication consultation. This study revealed that there was variation among prescribers in how decision making was conducted. This variation was seen not only between prescribers, but for the same prescriber with different clients. A framework such as the one proposed above could be used to standardize particular elements of effective shared decision making.

Expectations also need to be established for the roles of prescribers, nurses, case managers and peer specialists in shared decision making. Once again variation was found in roles for the various members of the treatment team. Expectations are needed to ensure continuity between various professionals working with the client. Roles around shared decision making should be included in treatment team member's job descriptions and reinforced through performance evaluations.

In addition to expectations, sufficient resources devoted to training are required. Since shared decision making is often a dramatic departure from traditional medication consultations, agencies should allow sufficient time for new skills to be developed by all professionals involved

in shared decision making. Training should occur not only at the beginning of implementation but become an ongoing professional development endeavor.

Agencies should also consider building quality assurance measures into agency protocols. Since the study revealed variation in staff practice and prescribers acknowledged that at times they would slip back into previous methods of decision making, the agency should routinely monitor shared decisions.

On the state and national level, there are also multiple implications. For one, Medicaid reimbursement for medication consultation time would need to be reconsidered when using shared decision making. Current Medicaid reimbursement only allows for centers to bill fifteen minutes for the medication consultation regardless of actual time spent with the client. With current productivity demands placed upon prescribers, there is little incentive for centers to allow prescribers to see clients beyond the reimbursable time. While prescribers noted that Common Ground helped them save time within the medication clinic with clients who were highly engaged, fifteen minutes was not sufficient to allow for shared decision making with clients who were not yet engaged.

Standards should also be developed for what is considered shared decision making. Specific criteria that constitutes the elements of shared decision making, such as those developed by Braddock et al. (1999), could be adopted for state quality assurance purposes to evaluate the fidelity with which shared decision making is occurring. The development of a fidelity scale for shared decision making would also be important to this process.

If shared decision making is to enter the realm of standard practice, there should be clear standards of what information prescribers are required to share about various medications that are considered. This would include potential benefits and risks established through research as

well as side effect profiles associated with each medication. This is important considering that this study revealed that there was wide disparity in the types of information client's received regarding the medications they were prescribed.

State and national edicts promulgating the expansion of shared decision making within mental health centers could encourage the dissemination of this practice. These edicts could build upon language contained in the President's New Freedom Commission on Mental Health (2003) as well as the U.S. Surgeon General's Report (U.S. Department of Health and Human Services, 1999), which both elaborated on the importance of people with psychiatric disabilities being more involved with decisions regarding their care.

Implications for Research

While this study suggests that Common Ground has significant potential as a tool to facilitate shared decision making, future studies are warranted at sites where Common Ground will be replicated. Future research should continue to explore factors that promote shared decision making as well as factors that impede shared decision making. Methodologies that evaluate how decision making actually takes place within the medication consultation are advised. This study used client and prescriber recall of what occurred in the medication clinic. Since the purpose of this study was to explore client and prescriber's experience of shared decision making, this method was deemed sufficient. By the end of the present study though, there was evidence to believe that for those clients for whom the process did not work well that shared decision making did not actually occur. Future studies should consider operationalizing the distinct elements of shared decision making and measure the degree to which shared decision making is occurring within the medication consultation. Braddock et al.(1999) conducted a study using this approach observing client-physician interactions occurring in offices of various

outpatient medical specialties. A study of this nature specific to mental health is warranted. The categorized elements of shared decision making developed by Braddock might be a useful tool in measuring this.

This study also suggests that the relationship between the prescriber and the client is an essential element of shared decision making. A future study might explore the degree to which the prescriber-client relationship affects shared decision making and to what degree shared decision making affects the client-prescriber relationship.

In this study, the centrality of a goal that is meaningful and important to the client was found to be essential to the shared decision making process. Future studies might explore what types of goals lend themselves best to the shared decision making process. Another area of exploration could be around what goals are prescribers most likely to agree with and what conditions predict prescriber agreement with client goals. In this study, there was evidence to suggest that prescriber confidence in the client stating the goal and available supports outside of medication clinic to support the client in the stated goal were important factors. This study also showed that case manager and prescriber alignment around a client's goal in medication clinic was an important factor. Future research should explore how this alignment occurs and the communication methods that are used.

This study also raises questions about staff attitudes towards clients and the impact this has on the shared decision making process. It is possible that staff attitudes toward clients can affect the therapeutic relationship and the willingness of the staff person to engage with the client around shared decision making. Areas to consider would be effects of race, gender, symptom acuity, perceived risk of danger to self or others, past hospitalization history, past compliance with medication, criminal history, and the presence of court order.

Conclusion

Social work should take interest in continuing to build a knowledge base around shared decision making. As the largest professional group employed by mental health centers, social workers are often engaged with clients around decisions related to medication use. While the focus of this study revolved around the medication consultation occurring between the prescriber and client, the study also revealed the importance of key interactions that occur prior to and following the medication consultation that impact decisions being made in medication clinic. Decision facilitating software, such as Common Ground, afford a substantive opportunity for social workers to become more involved in assisting clients with the decision making process around medications as called for by both Bentley and Walsh (2001) and Gerhart (1990).

Because of social work's expansive presence within the field of mental health, social workers involved in the policy and research domains, are positioned to answer the calls by various government bodies for increased client involvement in determining their own care including: The U.S. Surgeon General's Report on Mental Health (1999); The President's New Freedom Commission on Mental Health (2003); and The Institute of Medicine's Committee on Crossing the Quality Chasm (2006). The Institute of Medicine's Committee specifically recommended a client-centered focus on mental health services to improve the quality of mental health care through research in traditional mental health settings and suggested that shared decision-making should be included in client-centered care.

Social work should not fail to see the connection between shared decision making and recovery for persons with psychiatric disabilities. The Substance Abuse and Mental Health Services Administration (SAMHSA)(2005) sponsored a conference to develop a definition of recovery that would be used within mental health systems and practice. SAMHSA identified the

following ten elements of recovery: (1) Self-direction: consumers lead, control, exercise choice over, and determine their own path of recovery; (2) Individualized and Person-centered: there are multiple pathways to recovery based on the individual person's unique needs, preferences, and experiences; (3) Empowerment: consumers have the authority to exercise choices and make decisions that impact their lives and are educated and supported in so doing; (4) Holistic: recovery encompasses the varied aspects of an individual's life including mind, body, spirit, and community; (5) Nonlinear: recovery is not a step-by-step process but one based on continual growth with occasional setbacks; (6) Strengths-based: recovery focuses on valuing and building on the multiple strengths, resiliency, coping abilities, inherent worth, and capabilities of the individual; (7) Peer support: the invaluable role of mutual support in which consumers encourage one another in recovery is recognized and promoted; (8) Respect: community, systems, and societal acceptance and appreciation of consumers, including the protection of consumer rights and the elimination of discrimination and stigma, are crucial in achieving recovery; (9) Responsibility: consumers have personal responsibility for their own self-care and journeys of recovery; and (10) Hope: recovery provides the essential and motivating message that people can and do overcome the barriers and obstacles that confront them (Bellack, 2006) (p.436).

These ten elements of recovery can be associated with various elements of the Common Ground software and its potential for facilitating shared decision making. For those participants in the study for whom the shared decision making process worked well, we see an illumination of the recovery journey that was traversing in the midst of Common Ground being implemented. This should spark the interest of all social work practitioners who strive to enhance the self-determination of clients with whom they work. For those for whom the process did not work

well, a corresponding curiosity should be awakened to improve a process that might allow these individuals to benefit as well.

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Appendix A

Slides of Common Ground Questions



Pat



CommonGround™© 2006 patent pending
Created by Pat Deegan PhD & Associates, LLC
Developed by Clientserv Corporation, makers of Powerface Behavioral Healthcare software



Do you want to **READ** or **LISTEN**?



READ



LISTEN



Hi. Many of us who are diagnosed with mental illness recover.

Recovery means we:

- Feel better and can get on with our lives
- Enjoy friends
- Raise our children

Recovery can also mean:

- We get a job
- Or buy a car
- Or go back to school

And recovery can mean:

- We learn a trade
- Fulfill our potential
- Live in our own home
- Or help take care of our aging parents

 **BACK**  **NEXT** 

Learning to work effectively with our doctors and nurses helps many of us in our recovery.

We need to tell them our concerns about medicine, and we need to work with them to find treatments to help us get well.

When you fill out the questions that come next, your answers will be turned into a report.

You and your doctor or nurse will review this report during your appointment today.

Together you will decide on what treatment is right for you and your recovery.

Your answers are confidential and may only be read by you and your treatment team.

 **BACK**  **NEXT** 

Would you like to watch a 3 minute video of a person describing their recovery?



Touch the picture of the person whose recovery story you want to hear today.

You can stop the video and return to the questions at any time by pressing the stop button 



Jean



Carmen



Aramis



Napoleon



Trixy



Vernon



Jean's Recovery Story



EXIT

Your Power Statement

This is your power statement. Your power statement is your goal for using medication to support your recovery.

"Being able to work is powerful personal medicine for me. My work gives my life meaning and purpose. Work keeps my mind off my troubles. I need to work to recover. I don't want mental illness or medication side effects to interfere with my ability to work. I want you and I to work together to find medication that supports my ability to work."



BACK

EXIT

Your Personal Medicine

This is your list of personal medicine. Have you been using your personal medicine since your last appointment?

| | | | |
|---------------|-----------------------|-----------------------|-----------------------|
| <i>Work</i> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | YES | NO | SOMETIMES |
| <i>Walk</i> | YES | NO | SOMETIMES |
| <i>Family</i> | YES | NO | SOMETIMES |

 **BACK**



Would you like to watch a 3 minute video of a person describing their personal medicine and how it supported their recovery?

YES NO

 **BACK**



Touch the picture of the person you want to hear talking about their personal medicine and how it supported their recovery.

You can stop the video and return to the questions at any time by pressing the stop button 

| | | |
|---|---|--|
|  Jean |  Carmen |  Phil |
|  Leon |  Trixy |  Vernon |

 BACK  EXIT

How Vernon Uses Personal Medicine in His Recovery




 EXIT

Shared Decision

At your last appointment, you and your doctor or nurse made a plan about how to move forward with your treatment. The plan was:

Did you follow through with that plan?

YES NO Somewhat

You have now completed 20% of the report



EXIT

Now you will have a chance to tell your doctor or nurse how you have been doing since your last appointment. There are 17 questions. Answer each question as honestly as you can.

How I Am Doing

1. Since my last appointment, my ability to keep up with my **responsibilities** and do the things I need to do has been:

Excellent

Good

Fair

Not so good

Poor



EXIT

How I Am Doing

2. Since my last appointment my **physical health** has been:

Excellent

Good

Fair

Not so good

Poor



EXIT

How I Am Doing

3. Since my last appointment my overall **mental health** has been:

Excellent

Good

Fair

Not so good

Poor

 

How I Am Doing

4. Since my last appointment my **living situation has been:**

Excellent

Good

Fair

Not so good

Poor

 

How I Am Doing

5. Since my last appointment I spent time in a **hospital, nursing home, shelter, jail or other treatment center:**

Yes

No

 

How I Am Doing

6. Since my last appointment I **used alcohol or street drugs:**

0 days

Between 1 – 7 days

Between 8 – 15 days

Between 16 – 23 days

24 or more days

 

How I Am Doing

7. Since my last appointment I heard voices or saw things that others didn't:

None of the time

A little of the time

Some of the time

Most of the time

All of the time



EXIT

How I Am Doing

8. Since my last appointment my energy level was too low:

None of the time

A little of the time

Some of the time

Most of the time

All of the time



EXIT

How I Am Doing

9. Since my last appointment my **energy level was too high:**

None of the time

A little of the time

Some of the time

Most of the time

All of the time

 

How I Am Doing

10. Since my last appointment I have experienced **thoughts, beliefs or fears that bothered me:**

None of the time

A little of the time

Some of the time

Most of the time

All of the time

 

How I Am Doing

11. Since my last appointment I was **able to concentrate and pay attention to the things I need to do:**

All of the time

Most of the time

Some of the time

A little of the time

None of the time

 

How I Am Doing

12. Since my last appointment my **thoughts were racing through my mind and going too fast:**

None of the time

A little of the time

Some of the time

Most of the time

All of the time

 

How I Am Doing

13. Since my last appointment I felt nervous or anxious:

None of the time

A little of the time

Some of the time

Most of the time

All of the time

 

How I Am Doing

14. Since my last appointment my sleep was just right:

All of the time

Most of the time

Some of the time

A little of the time

None of the time

 

How I Am Doing

15. Since my last appointment I have had thoughts about hurting others:

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

 

How I Am Doing

16. Since my last appointment I have had thoughts about hurting myself:

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

 

How I Am Doing

17. In general, **the phrase which describes my recovery** from mental illness at this time is:

- I have recovered
- I am getting better
- I am the same
- I am getting worse
- I am the worst I have ever been

 

You have now completed 40% of the report



 

BACK



Now you will have a chance to tell your doctor or nurse about how you have been **using or not using the medications** they prescribed.

Next you will see the name of each medication your doctor or nurse have prescribed for you. Indicate how you have been using each type of medication:

Abilify

Yes, I am using this medicine as prescribed

I did not start this medicine

I am taking less

I am taking more

I quit taking this medicine



EXIT

How I am using or not using the medicine

Seroquel

Yes, I am using this medicine as prescribed

I did not start this medicine

I am taking less

I am taking more

I quit taking this medicine

You are now done with over half of the report.



BACK



Common Concerns About Medicine

If you are like most people, you may have some concerns about taking medications.

Your concerns or uncertainty about taking medications are important and should be shared with your doctor or nurse.

Here are 11 common concerns that many people have about using medication. Indicate if you have any of these concerns at this time in your life. If you would like to say more about a concern, press the SAY MORE button



BACK



Common Concerns About Using Medicine

1. Since my last appointment I have been concerned about side effects.

YES NO

Do You Want To Say More?

NO 

 BACK 

Say More About Side Effects

The medicine is:

| | | |
|---|-----|----|
| • Interfering with my responsibilities, such as work. | YES | NO |
| • Making me too sleepy. | YES | NO |
| • Making me gain weight. | YES | NO |
| • Making me feel like a zombie. | YES | NO |
| • Interfering with my sex life. | YES | NO |
| • Making my hands shake. | YES | NO |
| • Making it hard to think or remember. | YES | NO |
| • I have other side effects. | YES | NO |

 BACK 

Common Concerns About Using Medicine

2. At this time, I don't think the medicine is working for me.

True False

Common Concerns About Using Medicine

3. I have some concerns about medication and the alcohol or drugs I use.

YES NO

Would you like to say more?

NO 

Say More

- I'm concerned about getting addicted to the medicine.
YES NO
- I'm concerned about how alcohol or drugs will interact with the medicine.
YES NO
- If I know I am going to party, then I skip the medicine.
YES NO
- I think drugs or alcohol work better for me than the medicine.
YES NO
- When I am drinking or using drugs I forget to take the medicine.
YES NO
- I have other concerns about the medicine and the drugs or alcohol I use.
YES NO

Common Concerns About Using Medicine

4. I'm concerned about how the medicine is affecting my health.

YES NO

Do you want to say more?

NO



Say More About My Health Concerns

- I'm concerned about getting diabetes on this medicine.
YES NO
- I'm concerned about gaining weight on this medicine.
YES NO
- I'm trying to get pregnant, or I am pregnant, and I'm concerned about how this medicine will affect me and my baby.
YES NO
- I have concerns about getting tics or other movement disorders from this medicine.
YES NO
- I have other concerns about how the medicine is affecting my health.
YES NO

Common Concerns About Using Medicine

5. I'm not really interested in using medicine at this time in my life.

True False

Do you want to say more?

NO



Say More About My Motivation To Use Medicine

- I haven't found a good reason to take medicine.
YES NO
- I only take medicine because the judge or my family says I should.
YES NO
- The pills remind me of mental illness, so I don't take them.
YES NO
- I'm tired of taking pills.
YES NO
- My symptoms don't bother me so why should I use the pills?
YES NO
- I'm feeling well so why take the pills?
YES NO
- I'd rather go back to the hospital, so I don't bother with the pills.
YES NO

Common Concerns About Medicine

6. Lately I haven't been able to afford the co-pays for medicine or I've had trouble getting transportation to the pharmacy.

YES NO

Common Concerns About Medicine

7. Since my last appointment, I sometimes got confused about when to take the medications.

YES NO

Common Concerns About Medicine

8. At this time I have some fears about the medicine.

YES NO

Do you want to say more?

NO



Common Concerns About Medicine

- I'm afraid I might get addicted to the medicine.

YES NO

- I'm afraid people will find out I have a mental illness if they see me taking the pills.

YES NO

- I had a bad reaction once and am afraid it will happen again.

YES NO

- I'm concerned about the negative things I am hearing about this medicine.

YES NO

- I have other fears or concerns about medicine.

Common Concerns About Medicine

9. Recently, I find it hard to believe that taking medicine is the right thing to do.

YES NO

Do you want to say more?

NO



Say More

- I think medicine is a crutch and a sign of weakness.
YES NO
- I think I should be able to get well on my own.
YES NO
- I don't believe I am mentally ill.
YES NO
- My religious beliefs say I should not rely on medicine.
YES NO
- People who are important to me say I should not use the medicine.
YES NO
- I have other beliefs that make me unsure about using the medicine.
YES NO

Common Concerns About Medicine

10. At this time, I am trying to figure out if I really need to take the medicine or if other things will help me.

YES NO

Would you like to say more?

NO

Say
More

Say More

- I'm wondering what will happen if I stop the medicine.

YES NO

- I'm feeling good now, so why take medicine?

YES NO

- I'm exploring natural, cultural or spiritual healing methods.

YES NO

- I'm exploring what happens if I only take the pills when I'm having a hard time.

YES NO

- There are other ways I am trying to figure out whether I need the medicine or not.

YES NO

Common Concerns About Medicine

11. At this time I feel I am not getting the support or information I need to make my own decisions about medicine.

YES NO

Do you want to say more?

NO



Say More

• I need more information to help me make my decision about taking or not taking medicine.

YES NO

• I need more information about my legal rights.

YES NO

• I need more support from my doctor or nurse to make my decision about using this medicine.

YES NO

• I need more support from my family to make my decision about using this medicine.

YES NO

• I need someone to spend more time with me to help me make my decision about using medicine.

YES NO

You are now done with 90% of the report.



BACK



EXIT

This is the last part of the report.

A clear goal of what *you* want to accomplish today, in your meeting with your doctor or nurse, can be helpful.

On the next page you will find a list of goals. Choose the goals you have for today. It's okay to have more than one goal.



My Goals

Today my goal for meeting with my doctor or nurse is to:

- Get information YES NO
- Ask my question YES NO
- Get my meds changed YES NO
- Share my progress YES NO
- Get information about my rights YES NO
- Discuss my concerns YES NO

Congratulations!

You have completed all the questions

Press the print button  to print out your report. Bring it to your appointment today.

The report will help you and your doctor or nurse work together to find the best treatments to support you in your recovery.

Remember – A majority of people diagnosed with mental illness recover and lead productive lives. You can be one of ones who recovers!

Print my report



Appendix B

How I Am Doing Scale

1. Since my last appointment my ability to keep up with my responsibilities and do the things I need to do has been:

Excellent Good Fair Not so good Poor

2. Since my last appointment my physical health has been:

Excellent Good Fair Not so good Poor

3. Since my last appointment my overall mental health has been:

Excellent Good Fair Not so good Poor

4. Since my last appointment my living situation has been:

Excellent Good Fair Not so good Poor

5. Since my last appointment I spent time in a hospital, nursing home, shelter, jail or other treatment center.

Yes No

6. Since my last appointment I used alcohol or street drugs:

0 days 1-7 days 8-15 days 16-23 days more than 24 days

7. Since my last appointment I heard voices or saw things that others could not:

None of the time A little of the time Some of the time Most of the time All of the time

8. Since my last appointment my energy level was too low:

None of the time A little of the time Some of the time Most of the time All of the time

9. Since my last appointment my energy level was too high:

None of the time A little of the time Some of the time Most of the time All of the time

10. Since my last appointment I have experienced some thoughts, beliefs or fears that bothered me:

- None of the time A little of the time Some of the time Most of the time All of the time

11. Since my last appointment I was able to concentrate and pay attention to the things I need to do:

- All of the time Most of the time Some of the time A little of the time None of the time

12. Since my last appointment my thoughts were racing through my mind and going too fast:

- None of the time A little of the time Some of the time Most of the time All of the time

13. Since my last appointment I felt nervous or anxious:

- None of the time A little of the time Some of the time Most of the time All of the time

14. Since my last appointment my sleep was just right:

- All of the time Most of the time Some of the time A little of the time None of the time

15. Since my last appointment I have had thoughts about hurting others:

- None of the time A little of the time Some of the time Most of the time All of the time

16. Since my last appointment I have had thoughts about hurting myself:

- None of the time A little of the time Some of the time Most of the time All of the time

17. In general, which term best describes my recovery from mental illness at this time:

- I have recovered I am getting better I am the same I am getting worse I am the worst I have ever been

Appendix C

Decisional Uncertainty Profile

18. Since my last appointment I have been concerned about side effects of my medications.

Yes No

19. I have some concerns of whether the medications are working or not.

Yes No

20. I have some concerns about the medication I use and their interaction with drugs or alcohol.

Yes No

21. I'm concerned about how the medication is affecting my health.

Yes No

22. I'm trying to decide if I want to use medications at this time in my life.

Yes No

23. I have been having difficulty paying for my medication or have had trouble getting transportation to pick up my medications.

Yes No

24. I sometime get confused about when to take my medications or how much to take.

Yes No

25. I have some fears about taking my medications.

Yes No

Decisional Uncertainty Scale

26. I find it hard to believe that taking medicine is the right things to do.

Yes No

27. I am trying to figure out if I really need to take the medicine or if other things will help me.

Yes No

28. I feel I am not getting the support or information I need to make my own decisions about my medications

Yes No

Appendix E

Participant Interviews

| Participant Interview Number | Participant |
|---|-------------|
| Bernice's first interview (client) | 1 |
| Samuel's first interview (client) | 2 |
| Liz's first interview (case manager) | 3 |
| Perry's first interview (case manager) | 4 |
| Andreas's first interview (client) | 5 |
| Prescriber 1's first interview | 6 |
| Maria's first interview (client) | 7 |
| Prescriber 2's first interview | 8 |
| Roberta's first interview (client) | 9 |
| Marcus's first interview (client) | 10 |
| William's first interview (client) | 11 |
| Nurse 1's first interview | 12 |
| Prescriber 3's first interview | 13 |
| Mary's first interview (client) | 14 |
| Peer Specialist 1's first interview | 15 |
| Albert's first interview (client) | 16 |
| Peer Specialist Supervisor's first interview | 17 |
| Nurse 2's first interview | 18 |
| Monica's first interview (case manager) | 19 |
| Rose's first interview (case manager) | 20 |
| David's first interview (client) | 21 |
| Helen's first interview (client) | 22 |
| Samuel's second interview (client) | 23 |
| Helen's second interview (client) | 24 |
| William's second interview (client) | 25 |
| Roberta's second interview (client) | 26 |
| Mary's second interview (client) | 27 |
| Bernice's second interview (client) | 28 |
| Maria's second interview (client) | 29 |
| Albert's second interview (client) | 30 |
| Liz's second interview (case manager) | 31 |
| Perry's second interview (case manager) | 32 |
| Kim's first interview (case manager) | 33 |
| Kim's second interview (case manager) | 34 |
| Monica's second interview (case manager) | 35 |
| Rose's second interview (case manager) | 36 |
| Peer Specialist's 2's first interview | 37 |
| Peer Specialist Supervisor's second interview | 38 |
| Prescriber 1's second interview | 39 |

| | |
|---------------------------------------|----|
| Prescriber 2's second interview | 40 |
| Prescriber 3's second interview | 41 |
| Paul's first interview (case manager) | 42 |
| Jason's first interview (client) | 43 |

Appendix F

Sample from Methodological Log

Tentative Themes (October 2008)

Theme 1: CG redefines the expectations, roles, and rules of engagement of med clinic.

Sub Theme A: New expectations are being developed about what you can share in med clinic. Old categories are breaking down that challenge staff and clients to re-negotiate their roles in med clinic.

Sub Theme B: Clients choose how to present themselves based on:

- 1) Prior experience with how information has been in the past;
- 2) The relevance of how that information can contribute to their personal well-being or goals.
- 3) How they wish to be viewed by staff, comfort level with sharing information, and/or prior expectations for interacting in med clinic;
- 4) Other factors that influence presentation (e.g. use of drugs/alcohol, relationship with prescriber/nurse)

Sub Theme C: Prescribers/nurses choose how to present themselves based on:

- 1) Perceived goals of med clinic
- 2) Perceived investment/motivation of clients in med clinic
- 3) Perceived roles played by clients and prescriber in med clinic
- 4) Presence of court order
- 5) Concern for safety/public responsibility
- 6) Relationship with client
- 7) Time and productivity pressures
- 8) Interaction with previous mode of operation – information that needs to be collected.

Sub Theme D: The degree to which the DSC is integrated within med clinic shapes the dynamics of interactions within med clinic.

Theme 2: CG creates an opportunity for the invisible to become visible

Sub Theme A: The computer serves as a safe means for some clients to reveal things about themselves they have not revealed before

Sub Theme B: CG serves as an evaluative mechanism that allows the client to reveal themselves over time.

~~Sub Theme C: The videos become a powerful source of self reflection for some clients that helps them to reveal and formulate their own recovery journey. Moved to Peer Support Theme since the dynamics revealed an alternative way peers can support clients in conceptualizing their recovery and taking control of the decisions they make.~~

Sub Theme D: The paper becomes proof and allows the client to reveal themselves to others.

Sub Theme E: CG allows the opportunity for the personal to enter into the realm of treatment.

Sub Theme F: CG helps clients to remember things and focus in on what they want to communicate to the prescriber.

Sub Theme G: The invisible remains hidden when an activation point is missed

- 1) Interactions with CM prior to med consult fail to focus on viewpoint of client
- 2) Failure to understand client's experience between answering questions on HIAD scale and discussing CG with prescriber,
- 3) Failure to explore use of Personal medicine in relation to wellbeing,
- 4) Failure to pursue decisional uncertainty around medications

~~**Theme 3: When client's concerns as expressed on the CG report are addressed, client's feel heard and are engaged in med clinic.**~~

~~Sub Theme A: CG assists prescribers and nurses to focus in what concerns client's the most.~~

~~Sub Theme B: Clients feel most heard when options are explored beyond the use of medications.~~

This theme has been combined now with Theme 4. They are actually two parts of the same dynamic. When a client's goal for considering medication is expressed in medication clinic AND the prescriber acknowledges that goal AND concrete steps are taken to make progress towards that goal, client feel heard and are more involved in the decision made about their care.

~~**Theme 4: CG assists clients to have more control in making decisions around their medications. The Centrality of a goal that is meaningful and important to the client is essential for shared decision making.**~~

Sub Theme A: ~~Gaining control in med clinic can coincide with feeling control in other areas of life~~ When a goal that is meaningful and important to the client becomes the focal point of shared decision making, clients are more engaged in Common Ground and involved in decisions made at medication clinic.

Sub theme A: ~~Certain factors can hinder clients from having more control in making decisions around medications:~~
 1) ~~decisions made at state hospital can undo SD made at clinic~~
 ▪ ~~Fear of consequences if med change doesn't work~~

Sub Theme B: Clients make decisions based on how it impacts other areas of their life:
 7)1) ability to care for child
 8)2) ability to improve relationship with family
 9)3) ability to keep job
 10)4) feeling of self-worth ability to do other things that are important to them
 5) ability to stay out of hospital
 11)6) ability to maintain some amount of control

SubTheme C: When concrete steps are taken to make progress towards a goal that is meaningful and important to the client, clients are more likely to follow through with decisions made in medication clinic.

Theme 5: The concept of personal medicine shines a new light on ordinary activities and causes a transformation in philosophy and practice that empowers clients in a new way.

Sub Theme A: Personal medicine increases the options for client's to stay well in addition to medications

Sub Theme B: Personal medicine can be a powerful aspect of treatment when reinforced and enhanced by service providers.

Sub Theme C: Focus on personal medicine can be an engagement strategy for client's who were previously not engaged in med clinic.

Theme 6: Peer Support The Peer Specialist serves a vital role in the Common Ground process

- 4)1. helping people feel comfortable with using the computers
- 5)2. understanding the meaning of questions
- 6)3. -serving as a visible marker of recovery
- 7)4. helping people with CG tools

- 8)5. encouraging watching of videos
- 9)6. Assisting those who have difficulty reading
- 10)7. Assisting with the creation of personal medicine and power statements

Theme 7: Common Ground redefines the role of the case managers surrounding med clinic, and can enhance the shared decision making process when fully integrated within the process.

Sub Theme A: Case managers vary in the extent that they support client's use of CG.

- 1) Point of discussion for planning services
- 2) Indicator of Progress
- 3) Ways of knowing what's going on with the client
- 4) Follow-up with SD
- 5) Coach for self-advocacy/Preparing for med clinic visits

Sub Theme B: Time pressures and focus on productivity contribute to the varied involvement of CMs with CG.

Sub Theme C: Comfort level and motivation level with using the Website contribute to the varied involvement of CMs with CG.

Sub Theme D: The level of involvement the client has with CG contributes to the varied involvement of CMs with CG.

Sub Theme E. The way prescribers and nurses involve CMs around CG contributes to the varied involvement of CM's with CG.

Final Themes (July 2009)

Theme 1: CG redefines the expectations, roles, and rules of engagement of med clinic.

Sub Theme A: New expectations are being developed about what you can share in med clinic. Old categories are breaking down that challenge staff and clients to re-negotiate their roles in med clinic.

Sub Theme B: Clients choose how to present themselves based on:

- 1) Prior experience with how information has been in the past;

- 2) The relevance of how that information can contribute to their personal well-being or goals.
- 3) How they wish to be viewed by staff, comfort level with sharing information, and/or prior expectations for interacting in med clinic;
- 4) Other factors that influence presentation (e.g. use of drugs/alcohol, relationship with prescriber/nurse)

Sub Theme C: Prescribers/nurses choose how to present themselves based on:

- 1) Perceived goals of med clinic
- 2) Perceived investment/motivation of clients in med clinic
- 3) Perceived roles played by clients and prescriber in med clinic
- 4) Presence of court order
- 5) Concern for safety/public responsibility
- 6) Relationship with client
- 7) Time and productivity pressures
- 8) Interaction with previous mode of operation – information that needs to be collected.

Sub Theme D: The degree to which the DSC is integrated within med clinic shapes the dynamics of interactions within med clinic.

Theme 2: CG creates an opportunity for the invisible to become visible

Sub Theme A: The computer serves as a safe means for some clients to reveal things about themselves they have not revealed before

Sub Theme B: CG serves as an evaluative mechanism that allows the client to reveal themselves over time.

Sub Theme C: The paper becomes proof and allows the client to reveal themselves to others.

Sub Theme D: CG allows the opportunity for the personal to enter into the realm of treatment.

Sub Theme E: CG helps clients to remember things and focus in on what they want to communicate to the prescriber.

Sub Theme F: The invisible remains hidden when an activation point is missed

- 1) Interactions with CM prior to med consult fail to focus on viewpoint of client
- 2) Failure to understand client's experience between answering questions on HIAD scale and discussing CG with prescriber,
- 3) Failure to explore use of Personal medicine in relation to wellbeing,
- 4) Failure to pursue decisional uncertainty around medications

Theme 3: The Centrality of a goal that is meaningful and important to the client is essential for shared decision making.

Sub Theme A: When a goal that is meaningful and important to the client becomes the focal point of shared decision making, clients are more engaged in Common Ground and involved in decisions made at medication clinic.

Sub Theme B: Clients make decisions based on how it impacts other areas of their life:

- 1) ability to care for child
- 2) ability to improve relationship with family
- 3) ability to keep job
- 4) feeling of self-worth ability to do other things that are important to them
- 5) ability to stay out of hospital
- 6) ability to maintain some amount of control

Sub Theme C: When concrete steps are taken to make progress towards a goal that is meaningful and important to the client, clients are more likely to follow through with decisions made in medication clinic.

Theme 4: The concept of personal medicine shines a new light on ordinary activities and causes a transformation in philosophy and practice that empowers clients in a new way.

Sub Theme A: Personal medicine increases the options for client's to stay well in addition to medications

Sub Theme B: Personal medicine can be a powerful aspect of treatment when reinforced and enhanced by service providers.

Sub Theme C: Focus on personal medicine can be an engagement strategy for client's who were previously not engaged in med clinic.

Theme 5: Peer Support enhances and in some cases is essential to the shared decision making process.

Sub Theme A: The availability of Peer Support can assist with engaging people in the use of Common Ground including:

- 1) helping people feel comfortable with using the computers
- 2) understanding the meaning of questions
- 3) serving as a visible marker of recovery
- 4) Assisting those who have difficulty reading
- 5) Assisting with the creation of personal medicine and power statements

Sub Theme B: The availability of peer support can assist with supporting people after decisions are made in medication clinic including:

- 1) Assisting clients with completion of Common Ground tools
- 2) Assisting clients with doing searches for additional information on diagnosis, medications, side effects, and alternative strategies.

Sub Theme C: The videos serve as an important mechanism of peer support including:

- 1) Engaging clients through shared experiences
- 2) Offering hope that recovery is possible
- 3) Offering strategies for coping with mental illness and moving forward in recovery

Theme 6: Case Managers vary in the extent to which they support client's use of Common Ground, but can serve as important auxiliary supports in the shared decision making process.

Sub Theme A: Case managers vary in the extent that they support client's use of CG.

- 1) Point of discussion for planning services
- 2) Indicator of Progress
- 3) Ways of knowing what's going on with the client
- 4) Follow-up with SD
- 5) Coach for self-advocacy/Preparing for med clinic visits

Sub Theme B: Time pressures and focus on productivity contribute to the varied involvement of CMs with CG.

Sub Theme C: Comfort level and motivation level with using the Website contribute to the varied involvement of CMs with CG.

Sub Theme D: The level of involvement the client has with CG contributes to the varied involvement of CMs with CG.

Sub Theme E. The way prescribers and nurses involve CMs around CG contributes to the varied involvement of CM's with CG.