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Medication Adherence among Older Adults with Schizophrenia

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Abstract

Older adults with schizophrenia are a growing segment of the population yet their physical and mental health status is extremely poor. The paper presents findings from a qualitative study that explored the understanding older adults with schizophrenia have of their physical health status. The study was conducted among 28 older adults with schizophrenia from a variety of settings using semi-structured interviews and participant observation. Self-management of psychiatric and non-psychiatric medications and its affect on their health status was one of the central themes that emerged from the study. Different styles of medication adherence were identified and factors associated with each style are presented. The findings provide insights into the design of clinical interventions aimed at promoting medication adherence among older adults with schizophrenia.

Keywords

Schizophrenia; Medication Adherence; Chronic Disease

For persons with chronic diseases, achieving optimal health is often dependent on their own ability to manage their condition. If this self-management is neglected or done improperly, their conditions may worsen. People with schizophrenia are often managing multiple chronic physical illnesses in addition to a chronic mental illness, a situation that challenges self-management capacity. Older adults living with schizophrenia may be especially susceptible to difficulties managing their physical and mental health due to multiple factors, including psychiatric symptoms and aging (Leutwyler, Wallhagen, & McKibbin, 2010). Given the variable course of both psychiatric and non-psychiatric chronic conditions, nurses

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in a variety of settings can benefit from knowing effective ways of providing care tailored to the unique needs of older adults with schizophrenia.

The number of older adults with a serious mental illness is predicted to more than double, reaching 15 million by the year 2030 (Bartels, 2004). Those with schizophrenia comprise the largest group of older people with severe mental health problems (Cohen et al., 2000). Although there are increasingly better psychiatric treatment options and better responses to these treatments (Mittal et al., 2006; Howard, Rabins, Seeman, Jeste, & the International Late-Onset Schizophrenia Group, 2000), age adjusted mortality rates for people with schizophrenia are two times that of the general population (Folsom et al., 2002) and people with schizophrenia live 25 fewer years than those without a severe, persistent mental illness (Parks, Svendsen, Singer, & Foti, 2006). It is common for people with schizophrenia to have cardiovascular disease, chronic obstructive pulmonary disorders (COPD), gastrointestinal diseases, liver disease, diabetes, and skin infections (Chafetz, White, Collins-Bride, Nickens & Cooper, 2006). In addition, older persons with schizophrenia are more likely to be diagnosed with multiple medical problems as compared to younger cohorts with schizophrenia (Kilbourne et al., 2005). These medical comorbidities may both lead to, and be the result of poor physical health. Contributing factors to poor physical health include sociodemographic characteristics, iatrogenic effects of medication, and health care disparities (Allison et al, 2009; Chafetz et al., 2006; Chafetz, White, Collins-Bride, & Nickens, 2005; Dickerson, Pater, & Origoni, 2002; Folsom et al., 2002; Kilbourne et al., 2005; Simon, Lauber, Ludewig, Braun-Scharm, & Umbricht, 2005)

Although there are data on factors contributing to poor physical health in this population, there are only limited data about how older adults with schizophrenia manage their physical and mental health with medications. Medication adherence is generally defined as the extent to which patients take their medications as prescribed by their health care providers (Osterberg & Blashke, 2005). Optimal medication adherence promotes better health outcomes (Horowtiz & Horowtiz, 1993). Non-adherence to psychiatric medications among people with schizophrenia is associated with poor clinical outcomes such as relapse and hospitalization (Csernansky & Schuchart, 2002). The majority of medication adherence literature in schizophrenia focuses on younger adults. Yet, older adults with schizophrenia may be more susceptible to issues with adherence than their younger counterparts due to more complex medication regimens associated with the treatment of multiple chronic conditions. Limited data indicate that adherence to both psychiatric and non-psychiatric medications is problematic among older adults with schizophrenia (Dolder, Lacro, & Jeste, 2003). How older adults with schizophrenia manage their complex medication regimens may play a part in their poor physical health.

We will present findings from a qualitative study exploring the understandings older adults living with schizophrenia have of their physical health. Understanding the perspective of these older adults can provide information regarding their health self-management strategies and insight into effective clinical interventions that can improve both patient health status and nurses' abilities to assist patients in managing their health. Self-management of psychiatric and non-psychiatric medications and its affect on their health status was one of the central themes that emerged from the study.

Methods

Design

The methodological basis for this study was Grounded Theory (Glaser & Strauss, 1967). Symbolic interactionism provides the theoretical framework for grounded theory methodology and supports the view that individuals' understandings occur within the context of relationships (Blumer, 1969). Institutional review board approval was obtained from the participating university's Committee on Human Research, and anonymity and confidentiality were maintained according to their guidelines. After providing consent to participate, each participant was interviewed in a private location using a semi-structured interview guide. Most interviews took place in a room at the facility the person lived at or the day treatment program they attended.

Participants and Settings

Inclusion criteria were that participants be: 1) at least 55 years of age or older; 2) diagnosed with schizophrenia or schizoaffective disorder; and 3) competent to consent based on an evaluation of their comprehension of the consent form. Since environmental contexts influence health beliefs and practices, the participants were recruited from three sites: a transitional residential and day treatment center for older adults with severe mental illness; a locked residential facility for adults diagnosed with serious mental illnesses; and an intensive case management program. Recruitment methods included posting study fliers at recruitment sites, informing staff about the study, and snowball sampling. Participants received 10 dollars for their involvement in the study.

Data Collection and Analysis

Recruitment and data collection began in August 2007 and ended in February 2009. Data collection included in-depth interviews and participant observation. The audiorecorded interviews lasted approximately 60 minutes. The semi-structured interview guide including questions such as: Please tell me about your health? Can you tell me about any medical problems you have? Can you tell me how you manage your health and/or medical conditions? What things do you do to take care of your health? Or to take care of your medical problems? The principal investigator (H.C.L) also spent a minimum of 5 hours conducting participant observation at each recruitment site. This allowed an opportunity to confirm preliminary data analyses and interpretations with participants.

Data collection and analysis were done simultaneously using a constant comparison analysis approach (Glaser and Strauss 1967; Clarke 2005; Charmaz 2006). Interviews were transcribed verbatim and then re-checked to the tape to verify transcription accuracy. Field notes and interview transcriptions were entered into NVIVO, version 8.0, software to assist with data organization. Initial open coding was done through transcript analysis with word-by-word and segment-by-segment coding. Axial and selective coding were used in order to determine key themes and properties in the data and to eventually develop a conceptual framework of codes and categories. Theoretical memos were used to document codes and categorical concepts as well as relationships between categories. Data-derived categories and relationships between categories were further discussed with a small group of

qualitative researchers. Theoretical and methodological notes were maintained during the analytic process. The methodological rigor for this study was based on criteria proposed by Guba and Lincoln (Guba & Lincoln, 1989).

Results

Twenty Eight people (22 men and 6 women) participated in the study. Participants selected a pseudonym to be used in lieu of their real names. The average age of the sample was 61 years (s.d.=6, age range 55 to 76). Seventeen participants were European American, 5 were African-American, 3 were Asian/Pacific Islander, 2 were Native American, and 1 was Hispanic. Twenty participants had a diagnosis of schizophrenia and 8 had a diagnosis of schizoaffective disorder. Regarding living situations, 1 person was living in their own apartment, 7 lived in a single residency occupancy hotel, 1 lived in cooperative housing, 8 lived in a board and care setting, 4 lived in transitional housing, 6 lived in a locked facility, and 1 person was homeless.

In the descriptions of how participants carried out self-management, medication management of both psychiatric and non-psychiatric medications evolved as a central strategy. Participants described their medication regimens which illustrated different styles of adherence. Some described how they blindly adhered to the medications prescribed by their clinician while a few took a more active role in their medication plans and made efforts to stay informed about their medications. Some participants practiced different styles of adherence depending on the medication, the problem being treated, or their current mental health status. In general, regardless of the type of adherence, most participants recognized the importance of taking their psychiatric medications, acknowledged that medication was key to caring for the rest of their physical and mental well-being, and that if they were not managing their psychiatric symptoms there was little, if any, chance of managing their physical health. For example, when questioned about how he cares for himself when he is feeling psychotic, John responded:

John: No. Usually, I don't try and take care of myself when I reach that point and I'm not thinking clearly.

Four styles of medication management were identified: 1) Blind Adherence (BA); 2) Informed Adherence (IA); 3) Distrustful Non-adherence (DNA); and 4) Intentional Non-adherence (INA). The four styles are described below.

Blind Adherence

Blind adherence refers to a pattern where participants took medications as prescribed but did not completely understand the reason for taking them or took medications because they trusted their provider. Freud illustrated blind adherence when he talked about why he takes aripirazole daily:

Freud: It's minor. It's 15 mg of abilify in the morning. I'm not sure it's helping me, but I don't have any qualms about taking it. It was prescribed. I took it at the suggestion of the [clinic]. And I kept it up in jail, and without fail, and I keep it

now – loyally. And I guess it's helping me. I don't want to give it up, just as a safety precaution.

Similar to Freud, Zach partly adhered to his medication because he felt his doctor knew best:

Zach: But there's nothing I can do about it, because they're the doctor — he's my case manager and doctor. And they know what's best for me, I guess. And now they put me on this other medication this morning — some kind of blocker for the side effects for the anxiousness...Yeah, that's what he told me. He said maybe it will block that anxiety, but it's not.

Other participants were even less informed about their medications yet continued to adhere to a given medication regimen. This was especially true of participants that lived in residential or locked treatment facilities who took medications based on a routine schedule. During our participant observations, we observed how some participants would blindly take the medications they were given without asking what medication was in the medication cup, sometimes without even looking at the medications in the cup.

Informed Adherence

A few participants described how their mental health clinicians maintained open communication and a collaborative relationship with them regarding their medications. Patients with this type of relationship with their providers described an informed style of medication adherence. Earl described this type of collaborative relationship with his psychiatrist:

Earl: And then when I went to [Hospital], I come out there and they assigned me to a doctor. I had a doctor to talk to, psychiatrist who's started medication for me every month. But I talked to him — I talked to him once a week, and then he had asked me how the voices are doing, and I'd tell him how the medication is doing. He said do you want to try a different type of medication and I said no.

Zach described how he relayed the importance of adherence to his psychiatric medication to his providers:

Zach: I tried to commit suicide. Right from this day, I still feel suicidal. I even told the doctor that. I told [case manager]. I told [psychiatrist], that even from this day, I should still take medication, because I still feel suicidal.

Participants also described informed adherence to medications for their non-psychiatric problems. For example, pain was a common symptom experienced by the participants and some talked about medications they took to deal with this problem:

Frances: I take my medication, which is Norco, or hydrocodone, which is like Vicodin, except has less — it has less Tylenol.

Interviewer: Yeah. What do you take that for?

Frances: Arthritis in the hips and the back, the hands, the knees — sometimes in my legs.

However, participants like Frances had both pain and anxiety that still required treatment. Individuals like Frances often had trouble getting medications due to what appeared to be a clinicians' apprehension about the patient's drug abuse history, situations that complicated their ability to use medications effectively to manage their health conditions:

Frances: I'm an old person. I'm not out for cheap thrills. I just want to be free of pain in a legal way. All those drugs they have, I don't think they have one for anxiety. I don't think crack helps anxiety, or cocaine helps anxiety, or speed helps anxiety...And that's what I don't want. I want legal drugs to help me.

Despite informed adherence to a medication regimen, the next example highlights why there is still a need for further education, such as the importance of exercise and diet to supplement the medication regimen:

Interviewer: What do you do to take care of the blood pressure, to keep it under control?

Harry: I take the tablets in the morning about—it's supposed to be about 8:15. I wait until about 8:20 to 8:30 and I go in and get my medicine.

Interviewer: Are there other things that you do to manage your blood pressure?

Harry: No, it's just one pill. It's real small.

When participants recognized the importance of taking their medications, some crafted approaches to managing complicated regimens with the help of providers. One participant described how he remembers to take his medications consistently:

MJ: I put it up in the same spot and it's all in the bubble pack...I get two of them twice a week — twice a week... take one bubble package each morning.

Informed and strict adherence to a medication regimen was rarely seen. Only a few participants described their medications regimens in detail and even fewer could produce a current list of their medications. Malcolm was an exception and not only brought a list of his medications to the interview but had also looked up their side effects and was in communication with his psychiatrist and primary care provider about his desire to eliminate some of the medications to avoid physical health problems:

Malcom: I have a medical sheet of all the pills that I'm taking, and the work — which ones would cause, you know, the side effects is what we- I was basically worried about, because of nausea. Some of them would even cause heart attacks, or strokes. It would bring on heart attacks, or strokes, and I would show them well, if I take this with these other meds I'm taking.... Well, I don't want to try anything that's going to bring on a possible heart attack, and that's the only thing that's really still good about me.

Unfortunately for Malcom, a recent change in his psychiatrist was further complicating his long list of medications:

Malcom: It was working out fine until I lost my — my first psychiatrist. And that's before they moved. When I got this last psychiatrist, she didn't know heads from tails of what they [other health care providers] were trying to do.

Just as we observed some participants blindly take medications, we also observed some participants routinely requesting information about the medications they were given at medication times and also self-advocate for a medication when needed (such as a prn pain medication).

Distrustful Non-Adherence

Distrustful non-adherence was seen in participants who did not fully trust their health care providers' recommended treatment regimen. For example, many participants discussed similar situations to Malcom's where they were stable on a medication regimen but when their care providers changed, their medications often changed as well and, for some, this led to a change in psychiatric status. Christina stated what many other participants expressed about mental health care:

Christina: Yeah, they use us for guinea pigs — any work that hasn't been done, they make you take medicine and follow you around.

It seemed that the perception of being a "guinea pig" contributed to non-adherence and distrust of the health care provider. One Feather also described a situation when his well established medication regimen was changed abruptly:

One Feather: I think it's connected to the trauma of removing me from my medication -- twenty four years...did not replace it with any other kind of medication...Nothing. Nothing except what they wanted me to get, new psychiatric drugs from the pharmaceutical house.... it had me crawling down the corridors. It was a real snake pill. It was psychiatric assault. I couldn't read. I couldn't write. I couldn't swallow. I couldn't walk. Everything turned screwy like a crazy house. I told them you would have to kill me to take that pill again.

Other participants also discussed how they felt their providers were in control of their medications with little to no input from the patient. Mia described how she felt she was at the mercy of her providers regarding their decisions about her medications:

Mia: ...what happened...when I went to the hospital. I used to carry around a sheet with all of my mediations with me in case I had an accident I could tell the police. I could show them the sheet. So anyway when I went to the hospital they changed the medication. Cut some off and added haldol. But they didn't tell me what for and they didn't tell me about the side effect.

Eventually, because of the poor communication between Mia and her clinicians she decided to discontinue some of her medications, including the abrupt cessation of her thyroid medication:

Mia: I don't see any...it doesn't make any difference. It doesn't make it [thyroid] any smaller

Intentional Non-Adherence

Some participants were active participants in their care yet were sometimes reluctant to adhere to the providers' recommendations and instead evolved their own approach to care. For example, one participant with multiple lower extremity ulcers that were infected decided

that his nurse practitioner was not providing the correct antibiotic for the infection so he began treating himself with questionable home remedies:

Spin: The thing that I do the most is use cleanser and boric acid. ..mostly all I've been doing is um...just keeping it covered with zinc oxide, diaper rash ointment. And then I've with a little bit of antibiotic and...thickly covering that ...with bleach...cleanser (shows interviewer the bottle of comet). They (health care providers) do everything they can to discourage me from ever using this.... Nothings strong enough to get down deep enough. To stop the active disease process from rotting out the inside of my foot.

Poor communication and lack of trust with the provider contributed to Spin's self treatment plan and non-adherence to his providers prescribed medication regimen.

Participants had a range of reasons for intentional non-adherence to a medication plan. Common reasons for intentional non-adherence to psychiatric medications was the stigma associated with them, their sedating side effects, and their inability to completely resolve symptoms. For Spin, it was inadequate symptom resolution with his leg ulcers that caused intentional non-adherence. A reason expressed by Zach:

Zach: It's the medication.... If the medication made me feel normal... maybe I can do better things and go bike riding — well, I can't ride my bike with my leg. But maybe I can like go places, go to Golden Gate Park, and take a walk through Golden Gate Park all the way down to the beach, or something like that, but I can't do that no more, because my leg's messed up.

Discussion

Medication management is an important aspect of health self-management among older adults with schizophrenia. Four main styles of management were identified: blind adherence, informed adherence, distrustful non-adherence, and intentional non-adherence. Factors associated with blind adherence were locked living situations, routines, and trust in the clinic or provider. Factors associated with informed adherence were open communication with providers, insight into illness, routines and structure, medication reminders such as bubble packs, and possessing a current list of medications. Distrustful non-adherence was associated with independent living, history of negative experiences with the health care system, distrust, lack of patient education and poor communication with providers. Finally, intentional non-adherence was associated with independent living, history of negative experiences with the health care system, transitioning to new providers, poor communication with providers, stigma and lack of medication efficacy. Consistent with symbolic interactionism, our participants' adherence styles were influenced by their relationships with clinicians and the health care system. A common factor associated with non adherence was poor communication between patients and clinicians and distrust of the health care system. A common factor associated with adherence was a collaborative relationship with clinicians and trust in the clinic or provider.

Aspects of the Health Belief Model (HBM) (Rosenstock, 1966) have been applied to psychiatric medication adherence in adults with schizophrenia (Perkins, 2002; Dolder, Lacro

& Jeste, 2003). Our findings further support the utility of the HBM. Table 1 shows factors associated with adherence and non-adherence identified in our participant interviews and highlighted in the results section. The HBM as depicted in Figure 1 provides a way to understand the relationship between these factors and how the factors play a role in a patient's adherence to their medications.

In the HBM, two principal variables define whether a state of readiness to act exists: perceived vulnerability and seriousness. In our study, this was seen as insight into illness. The second class of variables include the extent to which a particular course of action is believed to be beneficial in reducing the threat and are labeled as perceived benefits of and barriers to taking action. In our study, an overarching benefit to taking medication was psychiatric stability and, sometimes, maintenance and promotion of physical health. Barriers to action in our study included the factors listed under the non-adherence column in Table 1. It is important to note that schizophrenia symptoms were a considerable barrier. Moreover, any amount of cue to action could not overcome the barrier of uncontrolled schizophrenia symptoms. Cues to action are another set of variables discussed by Rosenstock (1966). These are variables that must occur to trigger the health behavior (Becker et al, 1977). The level of readiness can provide the energy to act. Rosenstock suggests the combination of the variables could reach considerable levels of intensity without action resulting unless there is an instigating event, or cue to action, to set the process in motion. These cues may be internal, such as perception of a bodily state, or external, such as suggestions from practitioners. The intensity of the cue can also vary with level of readiness. Cues to action in our study are listed in Table 1 under the adherence column. Living situation was a modifying demographic factor that played a role in both adherence and non-adherence. For example, participants in the locked facility often adhered due to the routine and structure of the facility whereas participants that lived independently described more possibilities for non-adherence because no one was routinely giving them their medications.

Although the HBM is helpful in understanding how the various factors may influence medication management and ultimate adherence, the ways context influences the outcome is also critical. The majority of studies that have evaluated adherence to antipsychotic medication also found the clinician patient relationship (Beck, Cavelti, Wirtz, Kossowky, & Vauth, 2011; Carrick, Mitchell, Powell, & Lloyd, 2004) as well as trust (Pyne et al., 2006) is an important aspect for patient's adherence to their medication regimen.

Only four studies to our knowledge have evaluated adherence to medications for physical conditions among people with schizophrenia and all four were conducted among older adults with schizophrenia within the department of Veterans Affairs (Kreyenbuhl et al. 2008; Piette, Heisler, Ganoczy, McCarthy, & Valenstein, 2008; Dolder, Furtek, Lacro, and Jeste, 2005: and Dolder, Lacro, & Jeste, 2003). Relevant to our findings, Dolder, Lacro and Jeste (2003) evaluated middle aged and older patients with psychotic disorders taking antipsychotic maintenance therapy and oral antihypertensive, antidiabetic agents, or oral antihyperlipidemic agents. The authors found equal problems with adherence to psychiatric versus non-psychiatric medications. Patients filled their medications at appropriate time intervals only half the time and the average gap in therapy was between two to five days per month. Participants in our study discussed the importance of adherence to their psychiatric

medications in order to maintain their ability to care for their physical and mental health. Participants also cited examples of difficulties in adhering to both psychiatric and physical health medications. Dolder, Lacro, and Jeste (2003) also found the amount of medications was related to antipsychotic adherence thus reinforcing the need for simplified regimens. Our participants did not talk about this explicitly but they did bring up the importance of ways to organize complex medication regimens with tools like pill boxes.

Limitations

Our study has several limitations. It was not always possible to retrieve medication lists from the participants and many did not know their complete medication regimens. This again reinforces the need to educate patients about their medications and reinforce the importance of carrying a current list of medications. The participants were all engaged in the health care system to some extent, thus the findings may not be generalizable to participants not receiving consistent health care. Despite the limitations, this is the first study to our knowledge to explore qualitatively medication adherence as one component of physical and mental health self management among older adults with schizophrenia.

Recommendations for future research and practice

The factors associated with the different adherence styles can inform the practice of nurses treating this vulnerable population. First, regardless of adherence style, open communication with the patient is imperative for patients to adhere to a medication regimen while being informed about the proper use and indication of the medication. Second, nurses may also need to take into account a patient's living situation when assessing adherence. The participants in this study that blindly adhered to medication were often in locked facilities. When released from the facility and beginning to live independently, these participants did not understand the rationale for all of their medications thus reinforcing the need for constant ongoing education. Although it is possible that individuals in locked facilities might be reticent to refuse medications because of concerns about possible sanctions (e.g., length of stay extension), the data did not appear to reflect this interpretation. However, in order to avoid blind adherence and to promote better understanding of the rationale for taking prescribed medications, which would also minimize the possibility of perceived coercion, nurses working in locked facilities should routinely educate patients about their medications. Even simply telling patients the names of their medications can be a good starting point, especially for a patient in an acute stage of psychiatric illness. Even simply telling patients the names of their medications can be a good starting point, especially for a patient in an acute stage of psychiatric illness. Third, many participants' adherence depended on their trust in the system. Some participants would take a new medication just because a trusted provider suggested a new medication. Patients may be better off with their well established medication regimen and clinicians should consider consulting with patients about the efficacy of their current medications before switching to a new medication.

Additional data are needed to confirm and refine the findings of this study. In addition, future research should incorporate direct observation of patients and clinicians during clinic visits to better understand the interpersonal dynamics. Finally, observing the older adult in

their living situation may provide important details about the self management techniques used on a daily basis.

Conclusion

Understanding the perspective of older adults with schizophrenia can provide important insights into their health self-management strategies. Self-management of psychiatric and non-psychiatric medications is necessary to consider when providing care to older adults with schizophrenia. Cultivating a collaborative and trusting relationship with this vulnerable population may promote medication adherence. Nurses caring for older adults with schizophrenia may encourage informed adherence through the use of open communication and routine patient education.

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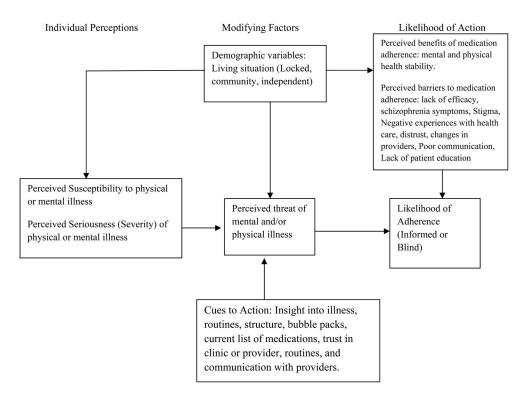


Figure 1. Medication Adherence Factors among Older Adults with Schizophrenia in the context of the original Health Belief Model (Becker et al., 1997).

Table 1

Factors associated with Adherence and Non-adherence

Adherence	•	Communication with providers
		Locked living situation
		Insight into illness
		Routines
		Structure
		Bubble packs
	•	Current list of medications
	•	Trust in provider or clinic
Non-Adherence	•	Independent Living
		Schizophrenia Symptoms
	•	History of negative experiences with the health care system
	•	Changes in health care providers
		Poor communication with providers
		Stigma
		Lack of efficacy
		Distrust of the health care system
		Lack of patient education