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Barriers to Self-Management of Serious Mental Illness and Diabetes

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Abstract

Objectives—Individuals with serious mental illness (SMI) (major depressive disorder, bipolar disorder, schizophrenia), and diabetes (DM), face significant challenges in managing their physical and mental health. The objective of this study was to assess perceived barriers to self-management among patients with both SMI and DM in order to inform healthcare delivery practices.

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Human Subject Approval Statement

The study was approved by the MetroHealth System Institutional Review Board (IRB), FWA00003938, Protocol number IRB00000685.

Conflict of Interest Statement

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Methods—In-depth interviews were conducted with 20 subjects who had diagnoses of both SMI and DM. All interviews were audiotaped, transcribed verbatim, and analyzed using content analysis with an emphasis on dominant themes.

Results—Transcript-based analysis generated 3 major domains of barriers to disease self-management among patients with both DM and SMI: (1) personal level barriers (stress, isolation, stigma); (2) family and community level barriers (lack of support from family and friends); and (3) provider and health care system level barriers (poor relationships and communication with providers, fragmentation of care).

Conclusions—Care approaches that provide social support, help in managing stress, optimize communication with providers, and reduce compartmentalization of medical and psychiatric care, are needed to help these vulnerable individuals avoid health complications and premature mortality.

Keywords

barriers; self-management; serious mental illness; diabetes

INTRODUCTION

Individuals with a serious mental illness (SMI), (schizophrenia/schizo-affective disorder, bipolar disorder or severe major depressive disorder), die earlier than individuals in the general population, losing on average 9–32 years of life.¹ Much of the premature mortality among persons with SMI is due to chronic medical comorbidities such as diabetes (DM), which complicates both psychiatric and medical health outcomes, and inflates costs.² There is a robust literature suggesting that the prevalence of DM in people with schizophrenia as well as in people with bipolar disorder and schizoaffective disorder is 2–3 times higher than rates seen in the general population. Causes of this disparity are due to a variety of factors including genetics and lifestyle factors such as inactivity and obesity as well as treatment effects from psychotropic drugs used to treat SMI.³

It has been demonstrated that chronic disease self-management programs can lead to improved health outcomes. However, there are few practical and effective treatment models for people with SMI that target self-management of mental and medical disorders concurrently.⁴ A recent literature review of studies that specifically focused on medical conditions and risk behaviors among persons with SMI found that the strength of evidence was low for most interventions. While multiple studies have described self-management programs for DM and SMI individually,⁵ few have addressed self-management of DM and SMI concurrently.⁶ To help address this gap in practical approaches that target comorbidity self-management, this qualitative analysis assessed perceived barriers to self-management among patients with both SMI and DM as part of a larger National Institutes of Mental Health (NIMH)-funded study (R01MH085665; PIs: Sajatovic & Dawson). Findings from a pilot study of the new approach are reported elsewhere.⁷ Qualitative findings can enrich our understanding of processes that are personally salient for individuals with SMI and comorbid DM, and may inform integration of these factors into care delivery practices.

METHODS

Sample and Setting

Subjects (N=20) from the larger study described above were recruited for the present analysis. For qualitative research, this sample size is within the recommended number of 5–25 individuals who have all experienced the same phenomena. Inclusion criteria included a diagnosis of SMI (schizophrenia, schizo-affective disorder, bipolar disorder, or major depression), in addition to DM. A sampling grid, designed to ensure variability in gender, race/ethnicity (African-American, Hispanic and Caucasian informants), and psychiatric diagnosis, was used in the recruitment of participants.

The mean age of the respondents was 53.9 years (SD=8); 14 (70%) were women and the mean level of education was 12 years (SD=1.9). Ten (50%) identified themselves as African-American, 8 (40%) as Caucasian, and 2 (10%) as Hispanic. Thirteen (65%) had major depression, 4 (20%) had schizophrenia or schizoaffective disorder, and 3 (15%) had bipolar disorder. The mean duration of SMI was 19.7 years (SD=13) and the mean duration of DM was 10 years (SD=8).

The study was conducted in an urban safety-net care setting and was approved by the Institutional Review Board of the participating institution. All participants provided written informed consent.

Study Design

In this exploratory/observational study, a phenomenological approach was used to develop a deeper understanding of the perceived barriers to managing optimal self-management of SMI and DM. Data collection in phenomenological studies consists of one-to-one in-depth interviews with participants. In one-to-one in-depth interviews, the goal is to explore a topic more openly and to allow interviewees to express their opinions and ideas in their own words. These types of in-depth interviews are an appropriate strategy for learning the vocabulary and discovering the thinking patterns of the target audience as well as for discovering unanticipated findings and explore hidden meanings.

Qualitative Data Collection and Analysis

The interviews explored participant views on barriers relevant to their self-management of SM and DM as well as what they felt their clinicians could do to help them. A semi-structured interview guide focused the discussion on main topics and specific topic-related questions. For example, under the topic, “barriers to managing DM and SMI,” the following question was asked: *“What sort of things get in the way or prevent you from managing/taking care of your diabetes and serious mental illness?”* The guide also included examples of follow-up probes such as *“would you explain further,” “please describe what you mean,”* and *“would you give me an example.”* Three investigators (CB, AP, SK) conducted the qualitative interviews, each lasting approximately 30–45 minutes.

In qualitative research data collection, coding and analysis occur simultaneously rather than sequentially. Emerging insights can be incorporated into later stages of data generation,

enhancing the comprehensiveness of the results. Goulding, in her comparison of phenomenology, ethnography, and grounded theory has made it clear that researchers blend techniques in order to serve the purposes of a specific study. Phenomenology has been described both as a methodology and a philosophy. In the case of our study of individuals with both SMI and DM, we felt that what was needed was to develop a framework for understanding the shared experience of participants, rooted in the descriptions provided by the participants themselves. Therefore, after interview audiotapes were transcribed verbatim, the data was analyzed using content analysis as a means for making inferences about what was said by the participants. Dominant themes were identified by a descriptive label, which helped to organize the text within and between transcripts for comparison.

A coding manual to list codes and their definitions was modified iteratively. After descriptive coding, all transcripts were reviewed using the final coding manual to ensure that all possible codes had been applied. Three coders (CB, AP, SK) separately coded all the transcripts to ensure coding consistency and transparency. Discrepancies were resolved by discussion. To further enhance analytic rigor, another member of the research team listened to the tapes and further compared the content to the verbatim transcripts. Additionally, an audit trail (researchers' analysis, notes, minutes of researchers' meetings) was performed throughout the research process. NVivo was used to assist with the analysis coding. Code-based files contained all coded text for each code across all respondents. The research team then reviewed and discussed these files to further elaborate, refine, and differentiate the codes. We repeated this process of data engagement and discussion until all discrepancies were resolved and no new insights emerged. The significant statements and themes were used to write a description of what participants experienced (textural description). They were also used to write a description of the context or setting that influenced how participants experienced the phenomenon, (structural description). Aggregation of data in this manner enabled us to write a composite description that represented the essence of the phenomenon (perceptions of "how" and "why" individuals with SMI-DM have problems with self-managing).

RESULTS

Transcript-based analysis generated 3 major domains of barriers to disease self-management among patients with both DM and SMI: (1) personal level barriers, (2) family and community level barriers, and (3) provider and health care system level barriers.

Personal level barriers

Table 1 shows themes, descriptive codes, and illustrative quotations emerging from the discussion of personal level barriers to self-management. We classified these barriers into the 4 categories that reflected the personal issues that our respondents faced in trying to concurrently manage DM and SMI: psychological, knowledge, lifestyle, and multiple physical co-morbidities.

Psychological barriers

Stress: While some respondents could articulate the relationship between stress and its effect on their disease, others described the tension of managing both DM and SMI as a cycle of despair:

“When I start worrying and feeling depressed about a lot of different things, I don’t try to do something physically to burn off sugar. Then it starts to affect my thinking and if the other one gets worse the cycle begins all over again!” Respondent #20

Others freely admitted that the downs of depression, or the euphoria of mania, often affected medication adherence and the cycle started all over again:

“When I’m going down and I begin to see things and all of that, taking my diabetic medicine is very low on the list.” Respondent #212

“If I want to feel the manic, because sometimes I do, so I don’t take my medication and I clean everything in the house! Then all of a sudden I’m down again.” Respondent #200

Stigma/isolation: Feelings of “being different” whether it was from diabetic restrictions or symptoms of SMI were articulated by many respondents:

“...you have to get up every morning and you have to check your blood and take your meds and eat. Anybody else has to get up every morning, take a shower, grab coffee and run out; but when you’re a diabetic, you can’t do that!” Respondent #256

“... I can tell I’m making other people uncomfortable, which is no big surprise, because I’m making me uncomfortable too! And when I was first diagnosed, I felt as conspicuous as if they had painted me purple...” Respondent #455

Knowledge barriers

Diagnosis and causes: Some respondents were confused about their diagnosis and what it might mean:

“I asked her is there some kind of test that I could take to see if I am bipolar or something? And she says no. And I said, well how do you know I’m not? Because she told me that I was not. I’m like how do you know that I’m not? Then she gave me Seroquel, and it said it was for bipolar! And I’m like, I’m confused here!” Respondent #97

“I’ve been diagnosed with schizoaffective disorder and I don’t really have a clear understanding of that”. Respondent #212

Some had little, or incorrect, knowledge about the causes of their illnesses:

“It’s a disease [schizophrenia] that you catch when you don’t sleep right or you just catch it from anything or you just get caught with it.” Respondent #117

“Diabetes, no, nobody talked to me about how I caught it. I mean, how it got there.” Respondent #455

Glucose testing: Some respondents had questions about the process and interpretation of glucose testing:

“And I was totally, totally depressed and scared, because I didn’t know if I was pricking my finger right, I just didn’t know what was going on!” Respondent #256

“The thing is, I’ll check my sugar and I’m always in the money, 110, 130, you know. And then I’ll get the A1c and it shows the average in the last 3 months. And I go, “Why do I check it every day if at the end they give you the average?” Respondent #83

Lifestyle barriers

Finances: Having little or no money to manage a healthy lifestyle was the number one personal barrier to self-management cited by most of the respondents. Some cited inability to pay for medications and other health care needs:

“It [medication] helps me because there was a time when I couldn’t take it, because I didn’t have insurance and I had to stop taking it and I couldn’t focus. My head was like all gone. “ Respondent #209

“I just couldn’t afford the test strips, even when my discount at the time was like \$25.00. So now that this insurance they got pays for my medications and it’ll pay for the test strips too.” Respondent #382

Others cited lack of money as the main barrier to buying the proper foods for diabetes:

“Number one is money. Buying the proper things that you need, especially food, because if you want to eat good, you’re going to pay some money for it, a lot of money and that I don’t have, so I do with what I can do.” Respondent #20

Poor dietary habits: Lack of money forced many to make unhealthy food choices:

“..I cannot afford the wheat bread because it costs about \$2.75 more than the white bread.” Respondent #578

“... money was very, very tight, so I ate at free food places and their foods are not exactly nutritious.” Respondent #200

Others admitted they didn’t read labels when they went food shopping :

“Another thing, I never even consider looking at a label. You know I just went to the store and got this, got that, or whatever, especially things that I’ve been eating all my life.” Respondent #412

And others skipped meals:

“For years and years when I worked, my breakfast was 3 cups of coffee or 2 cups of coffee and cigarettes, so now that I’m not working, that’s exactly what I do. You cannot eat one meal a day when you’re diabetic, but I do that. I have no appetite when I wake up.” Respondent #256

Transportation problems: Lack of transportation was an important limitation to getting to medical appointments and buying food:

“Sometimes when my car, well it’s not running now, matter of fact it’s in the shop. I need that to get around for appointments and stuff like that. And it’s kind of hard for me to get on the bus to go to the grocery store and I can’t walk that far.”

Respondent #409

Alcohol/drugs: While several respondents struggled with alcohol problems, taking non-prescribed pain medication and illegal substances were also mentioned:

“I guess if I had some control of the pain I had and everything, it wouldn’t be so hard. I hate to say it, but sometimes I go to visit my sister in another city and get one of my sister’s pain pills.” Respondent #409

“I’m a pot smoker because of my neuropathy because all I was receiving was like one Vicodin a day.” Respondent #578

Multiple co-morbid conditions—Most of the respondents had multiple co-morbid conditions in addition to their SMI and DM:

“I am a breast cancer patient, too. Every time I start doing something I always start getting this pain that feels like it’s a heart pain but it’s not heart pain its chronic pain that I have in my left side that I get because of the radiation they gave me.”

Respondent #209

“I have more trouble with my congestive heart failure than with my diabetes. That makes me weak....” Respondent #97

Confusion about medications: *Multiple co-morbid diseases required multiple medications which often led to confusion about function, dosage, and side effects:*

“Man, it’s a lot of pills I take and right now I take cholesterol pills, too! I can’t sleep because I have pain and I think it’s from the cholesterol pills. So I asked the other doctor, why can’t I stop my cholesterol pills because my cholesterol always comes out fine. Well he said I can’t stop them because of the situation I have for my heart, you know with the blockage in my heart. Respondent #209

Functional limitations: Multiple co-morbid conditions often bring functional limitations and our respondents described how these limitations interfered with their ability to walk or exercise:

“My knees have been flaring up really bad lately. To the point where they are giving out constantly, so I kind of stay a little bit more closer to a chair or a bed or whatever.” Respondent #258

“I walk a little bit, but I get tired real easy, because of the fact that I’m on dialysis, it just drains you out. The days that I have dialysis, I don’t usually end up walking. I usually end up using my scooter.” Respondent #26

One respondent summed up the difficulties of managing SMI and DM and his other comorbid conditions as “a never ending battle!”

“Yeah! Pain in my legs, my blood pressure, my diabetes! I get my sugar under control, here goes my blood pressure, then it’s the heart disease. It’s like a never ending battle! “ Respondent #20

Family and community level barriers

Table 2 shows themes, descriptive codes, and illustrative quotations emerging from the discussion of family and community level barriers. These barriers were classified into the 2 categories that reflected family and community level issues that our respondents faced in self-managing their co-morbid conditions: lack of support from family and friends and unsafe neighborhoods.

Lack of support from family/friends—In addition to their feeling isolated and alone, our respondents keenly felt the lack of support from family and friends in helping them deal with the burden of their SMI and DM:

“I don’t have a lot of family support anymore, it’s gone.” Respondent #20 Lack of understanding

Most of the respondents felt that the lack of support from family and friends stemmed from a lack of understanding of their illnesses. One respondent cited recent school shootings and the resultant publicity as examples of furthering negative attitudes toward people with mental illness:

“People just don’t understand! Like this thing that happened in Connecticut and Ohio. They said these kids had schizophrenia. It makes it look like everybody that has a mental illness is violent and we are not violent people! It’s labeling!” #330

Because of misinformation and beliefs, family members sometimes gave respondents bad advice about managing SMI and DM:

“See my brother don’t believe in what the doctors have to say. So he’s telling me I should get off my medicines. He doesn’t think I should take any medicines for my schizophrenia or for my diabetes. He said I should just tell God, whatever it is, to take it away.” Respondent #97

Estrangement: Perceived lack of understanding often led to estrangement from family and friends. Deciding not to discuss their illnesses with family was an option taken by some to avoid conflict:

“I chose not to tell my family for personal reasons. They just wouldn’t understand and they already have voiced their opinions of doctors and psychiatrists.” Respondent #212

Stressful Relationships: Among those who were not estranged from family and friends, friction and misunderstandings were often the norm, adding stress to individuals who were already finding it difficult to manage their SMI and DM :

“I live downstairs in a two-family house. Wish it was a single house because my wife’s sister lives upstairs with her family. That’s a trip. I wish my wife hadn’t invited her to move upstairs. And my life has not been the same since then. Always interfering. I guess that’s why I’m kind of depressed. I want to move. I mean, I love the family, but we need to be far apart!” Respondent #409

“My boyfriend tries to rationalize everything. He goes, “when you’re hallucinating, just say it’s not real.” How can I say it’s not real? It’s real to me, but he doesn’t understand. He doesn’t get the picture!” Respondent #258

And some received double messages from, supposedly, supportive family members:

“Yes, he supports me, but he’s always calling me crazy and I get tired of him calling me crazy.” Respondent #97

Cultural taboos: Food plays a large part in some cultures and one Latino respondent felt that the food, and family pressure to eat it, was a barrier to managing her DM:

“It’s all carbs and we eat rice twice a day, every day. Rice, rice, rice! Eating is addicting in Latino culture and when I visit my sister or my mom they always give me food. They’re pushing food and I say, “no, I’m not hungry” or “no, I don’t want that” and you feel the pressure to eat. Because they insist and say “hey, you’re too thin, you’ve got to eat”. Respondent #83

Unsafe neighborhoods—Lack of finances often necessitated living in dangerous neighborhoods:

I live in a double decker house and my brother lives downstairs with his wife and he’s got 3 boys and the area is terrible!” Respondent #20

“It’s downtown and they’ll knock on your door and ask for sugar and toilet paper. I like my apartment, but it’s just the neighbors begging for stuff.” Respondent #578

Provider and healthcare system barriers

Table 3 shows themes, descriptive codes, and illustrative quotations emerging from the discussion of provider and healthcare system level barriers. These barriers were classified into 2 categories that reflected provider and health care system issues that respondents faced in self-managing their co-morbid conditions: patient/provider relationships and fragmentation of healthcare.

Patient/provider relationships—While issues of trust and feeling short-changed with the amount of time providers spent with them were cited as barriers to effective management of their SMI and DM, respondents also felt that their providers did not really care about them as individuals:

“And I feel like doctors, they don’t really care, they’re just going through the motions.” Respondent #409

Poor Communication: However, the major barrier to having a good patient/provider relationship for many respondents was the inability of their provider to communicate effectively with them. They also felt that their providers did not listen to, or understand, what they were saying about management of their conditions:

“I still can’t figure out my doctor, like I said before. I tell her what’s wrong with me, why I hurt and when I hurt, and she’ll say something off the wall, like did you try this, try that. I’m looking for information from her to help me!” Respondent #409

“He’s not understanding anything I say! I think that’s where we’re at right now. I got to get them to understand that the medicine is not working. He just keeps adding a little tiny bit and changing it around. It’s not working!” Respondent #26

In some cases there were barriers to communication because of language differences:

“Like when you go to the emergency or something and they send a foreign doctor in there, I ain’t being funny, but I can’t understand them, I want somebody I can understand!” Respondent #97

Fragmentation of care

Falling through the cracks: Most of the respondents received their care from resident physician trainees who often rotated off the service after a period of time:

“I only had 6 visits with the therapist and after that she told me she wouldn’t be able to be on my case anymore.” Respondent #412

Which left them feeling that they were “falling through the cracks” of the healthcare system:

“I’ve had problems with contacting a new doctor because the old one left and I haven’t got an appointment for the new one. It’s like I’m falling through the cracks, it’s in between!” Respondent #209

Lack of communication between providers: An often cited barrier to self-management of SMI and DM was having separate providers for each chronic disease who didn’t communicate with each other:

Dr. B reads Dr. A’s notes from endocrinology and that’s the only part he reads in my chart. I don’t believe he went anywhere else regarding my mental health, my rheumatoid arthritis, my broken back. The doctors need to grasp the whole picture!” Respondent #212

How healthcare providers can help patients manage both DM and SMI

In order to gain insight into what kind of help our respondents wanted from their healthcare providers in managing their SMI and DM, we asked them to tell us what their providers could do to help them co-manage their physical and mental health.

Table 4 shows themes, descriptive codes, and illustrative quotations emerging from this discussion: tangible help, more research, better provider communication, and) treat the whole person.

While providing tangible help in the form of having someone to cook and prepare meals, others suggested that providers do more research on DM and SMI. However, most respondents wanted their healthcare providers to communicate more effectively with them. Discussing the causes of their diseases, which would allay fears and misconceptions, was cited as an important missing component during healthcare visits.

A frequent request for improved provider communication was to listen more and ask questions:

“To listen, not just hear, but to listen, because there’s a difference. I hear what she’s saying, but I don’t listen, because she’ll say, “did you hear what I said?” Excuse me, I’m sorry, I wasn’t paying attention. Ask me, “what’s wrong, why didn’t you take your medication?” “Do you feel that I should change your medication because its making you feel this way or that way?” If I’m not forthcoming with questions which you feel that should be asked, you know, ask them of me so that I can give you the answer that might be necessary to be heard. Because, I mean, not everybody knows how their body behaves in their manics or their depressions.
“ Respondent #200

Involving family members by talking with them about SMI and DM was another communication request for providers:

“I would say get together with my little brother and talk to him more about it, you know what I mean? Because he seems like he knows everything, he’s read books but he can’t understand what it is to live with it and see things that aren’t there. He seems to think I can rationalize it away!” Respondent #258

The majority of respondents wanted their providers to provide a more holistic approach to management of their health and to understand the connection between the effect of one disease on the other:

“I’d ask him does he have any idea how depression affects diabetes? Do you know what I’m going through? Do you want to know why I’m stressed, or you’re just going to go by numbers? They need to be more sensitive to that issue, since mental health is a big issue. ... It’s like if you confront them, they’re taken aback because you had the audacity to say anything to them, to question them.”
Respondent #330

Working more closely with their provider to integrate management techniques for both SMI and DM was a common theme given that respondents had different providers for their SMI and DM:

“I would say, first of all, let’s make a plan that integrates what’s necessary for the diabetes and what’s necessary for the bipolarity in terms of med management and work all this into the plan of care. That knowing that the bipolarity will always be managed by a different individual than manages the rest of my physical health, how do I establish that you know what each other are doing, because that’s very important. You know, everything but my brain gets treated by this doctor and my

brain gets treated by that doctor, and never the twain shall meet. When did my brain stop being part of my physical body?" Respondent #455

DISCUSSION

To the best of our knowledge, this is the first reported qualitative study to inductively identify barriers to self-management of SMI and DM among patients with both these conditions. Several observations about the data deserve mention. First, participants identified personal, family/community, and provider/healthcare system domains as barriers to self-management of SMI and DM which is consistent with McLeroy's social ecological model of health behavior. This model posits that behavior, actions, and events, are influenced by individual, interpersonal, organizational, community and policy factors. Second, stressful experiences in people with SMI and DM might affect diabetes through biological stress response and via stress-coping behaviors. Others have similarly noted the strong association between stressful life events and psychiatric illness. Managing multiple co-morbid conditions and the functional and social limitations imposed by them; dealing with the stigma and isolation imposed by having SMI and DM; and having inadequate knowledge about the causes and management of their chronic conditions, were all barriers to self-management and contributors to a worsening cycle of stress.

Third, while social support is known to be helpful for chronic illness self-management, our study participants reported a marked absence of social support from family and friends. Limited understanding of SMI and of DM by family and friends, stressful relationships, and family estrangement were important barriers to self-management. For some individuals with SMI and DM, there are strong cultural taboos about having an SMI, and families may pressure individuals with DM to consume foods inconsistent with diabetes self-management.

Fourth, effective communication is a central clinical function in building a therapeutic doctor-patient relationship and important in the delivery of high-quality care,¹⁷ yet respondents noted ineffective communication with providers and perceived lack of concern. Importantly, more effective communication was cited as one of the major forms of help respondents wanted from their healthcare providers in assisting them in their self-management efforts. Poor provider communication and resultant dissatisfaction is not unique to the participants in our study and patient surveys have consistently shown that they want better communication with their doctors.

An additional finding from this qualitative analysis is that patients with SMI and comorbid DM desire a holistic approach to care that provides integrated management of physical and mental health conditions. However, in direct contrast to what our participants with SMI and DM expressed as a preferred health approach, mental health treatments are often delivered separately from clinical settings for primary or other medical specialty care. Community Mental Health Centers (CMHCs) have played an important role in providing mental health services to a broad range of people since the early 1960s when they were created by Congress to serve all members of the community, regardless of their ability to pay, and creating a "mental health safety net." Many individuals with schizophrenia, bipolar disorder, and chronic/severe depression, receive psychiatric services in CMHC settings. CMHCs

generally provide an array of mental health services, however care is often not integrated with primary care or other specialty care. At the same time, medical settings may be poorly equipped to assess and manage individuals with more severe psychiatric symptoms. A recent systematic review on mortality in mental disorders noted that approximately 2/3 of the deaths in people with mental disorders is due to “natural” causes like heart disease and diabetes, and that care of chronic medical conditions in those with mental illness requires an approach that promotes healthy behaviors and coordinates care between mental health and medical systems. It is possible that changing elements in the healthcare climate such as increased presence of medical homes, the addition of primary care services to CMHC infrastructures, and increased use of electronic health records that facilitate communication between primary and specialty care providers, as well as between providers and patients, may help to minimize the barriers to physical and mental health integrated care delivery so explicitly noted by our study respondents. A recent investigation of CMCH-based integrated care suggested that such services improve primary care access and some physical health outcomes for adults with SMI. Tapping into the talents and expertise of people with SMI to help train others in managing their own physical health is another opportunity to integrate care that is person-centered rather than discipline or specialty specific.

While our findings have implications for informing care delivery for people with SMI and DM, there are some limitations. Patients with comorbid DM and SMI from other parts of the country may have different experiences in managing these diseases and different types of encounters with providers and healthcare systems. The small convenience sample and the conduct of the study in a single urban area may limit the generalizability and impact of the study findings. These limitations are offset, to some extent, by the use of rigorous qualitative research methods described in this study. In addition, the self-report method is direct, versatile, and yields information that would be difficult, if not impossible, to gather by other means.

In conclusion, individuals with SMI and DM face significant challenges in managing their physical and mental health. Care approaches that provide social support, help in managing stress, optimize communication with providers and reduce compartmentalization of medical and psychiatric care are needed to help these vulnerable individuals avoid health complications and premature mortality.

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Table 1

Personal Level Barriers to Disease Self-Management Among Patients with Both Diabetes and Serious Mental Illness (n =20)

Themes and Categories	Illustrative Quotations from Respondents
<p>Psychological Barriers</p> <p><i>Stress</i></p> <p><i>Stigma/Isolation</i></p>	<p><i>“I know stress always plays havoc on my diabetes, always! It’s like I’m the poster child for it.” Respondent #330</i></p> <p><i>“Yeah, it’s [having SMI] isolating definitely, because it becomes a very, me and the T.V. and the Chinese restaurant and the pizza place on speed-dial, not a real constructive way to live.” Respondent. #455</i></p>
<p>Knowledge Barriers</p> <p><i>Causes</i></p> <p><i>Diagnosis</i></p> <p><i>Glucose Testing</i></p>	<p><i>“I guess it’s from taking drugs or something when I was younger and it messed me up.” Respondent 97</i></p> <p><i>“Some of them tell me I have depression, but I have not really been diagnosed.” Respondent #20</i></p> <p><i>“I don’t know if I’m doing it correctly [glucose testing] or not, or whether I should bring my glucose meter to my doctors and have her show me how to do it or what? Respondent #258</i></p>
<p>Lifestyle Barriers</p> <p><i>Finances</i></p> <p><i>Poor Dietary Habits</i></p> <p><i>Transportation Problems</i></p> <p><i>Alcohol/Drug Abuse</i></p>	<p><i>“.... I haven’t got no glasses ‘cause I don’t have the money. Respondent #256.</i></p> <p><i>“Being greedy, being gluttony. You see the sweets, you eat them anyway. Just by that, over eating. Disobeying what the doctor say to do.” Respondent #578</i></p> <p><i>“I used up all my rides with the insurance company and I didn’t have any more rides to get to dialysis“ Respondent #26</i></p> <p><i>“I drink a lot, but I’m trying to stay sober. “When my mother died I started back drinking. “ Respondent #97</i></p>
<p>Multiple Physical Co-morbidities</p> <p><i>Confusion about medications</i></p> <p><i>Functional Limitations</i></p>	<p><i>“I’m on so many medications, it’s hard to keep track of them from one day to the next.” Respondent #258</i></p> <p><i>“When I get the chronic pain I have on my left side, I can’t move or walk.” Respondent #209</i></p>

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Table 2

Family and Community Barriers to Disease Self-Management Among Patients with Both Diabetes and Serious Mental Illness (n =20)

Themes and Categories	Illustrative Quotations from Respondents
<p>Lack of Support From Family and Friends</p> <p><i>Loneliness</i></p> <p><i>Lack/limited understanding</i></p> <p><i>Estrangement</i></p> <p><i>Stressful relationships</i></p> <p><i>Cultural taboos</i></p>	<p><i>“I live alone. I get very lonely sometimes, I wish that, you know, someone would come and live with me or I could go live with someone.” Respondent #21</i></p> <p><i>“I feel that people just don’t understand, if like especially, if like they find out that you’re taking antipsychotic meds. They automatically label you as crazy and once they do that they never believe you anymore.” Respondent #2</i></p> <p><i>They treat me like a stranger.” Respondent #117</i></p> <p><i>“I’ve got a boyfriend who lives with me who has health problems, he’s on oxygen 24/7, C-pap, he had a severe heart attack. And my son who just turned 21 is an epileptic, and a diabetic.” Respondent #330</i></p> <p><i>“But the cultural foods and what effects diabetes is heavily against me.. In mental illness, there’s a lot of taboos in Latin America about, you know, people are crazy. If I were in Puerto Rico I would see more of this.” Respondent #83</i></p>
<p>Unsafe Neighborhoods</p>	<p><i>“.. I don’t carry a lot of money in case somebody tries to rob me.” Respondent #26</i></p>

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Table 3

Provider and Healthcare System Level Barriers to Disease Self-Management Among Patients with Both Diabetes and Serious Mental Illness (n =20)

Themes and Categories	Illustrative Quotations from Respondents
<p>Patient/Provider Relationships</p> <p><i>Distrust of provider</i></p> <p><i>Not enough time</i></p> <p><i>Just another patient</i></p> <p><i>Poor communication</i></p>	<p><i>“I have very, very strong trust issues with authorities, I never feel like they see my side of the story, always feel like you take the other person’s word before you even ask me..” Respondent #256</i></p> <p><i>“When I went to talk to her, that lady talked to me about 5 minutes and I was out the door. How am I getting some kind of good treatment from someone for 5 minutes, man?” Respondent #20</i></p> <p><i>“They don’t see me as an individual. That’s what I get from both of them [providers].” Respondent #330</i></p> <p><i>“Actually, I wish I had another doctor to tell you the truth. The one I have, I mean, how can I say it? We don’t really have communication, she just goes through the motions.” Respondent #409</i></p>
<p>Fragmentation of Care</p> <p><i>Lack of communication between providers</i></p> <p><i>Falling through the cracks</i></p>	<p><i>“One time I let my diabetes doctor know that I’m a schizophrenic. I tried to talk to her because I was depressed that day and she wound up putting me in a psychiatric ward!” Respondent #578</i></p> <p><i>I got no idea why she left. She’s never called me. I received a letter from, I suppose it was, Dr. X. It’s almost like falling through the cracks when the residents change..” Respondent #17</i></p>

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Table 4

How Healthcare Providers Can Help Patients Manage Both Diabetes and Serious Mental Illness (SMI) (n =20)

Themes and Categories	Illustrative Quotations from Respondents
Tangible Help	<i>"Well, it would be much easier as far as the diabetes, if I had someone to cook my meals." Respondent #461</i>
More Research	<i>"...could you just do research, more research about the disease, something that can cure diabetes? Because people die from diabetes everyday and anything that they could do to find a cure, it would really help the nation. And schizophrenia too. If they could find a cure, that could take a few years, maybe 5 or 10 years and then you'll be cured, that would be helpful." Respondent #117</i>
Better Communication	<i>"If I had ten minutes I would want him to discuss more of the cause of any disease whether its mental illness or diabetes. To discuss the causes because it would be very enlightening to find out if I did or didn't cause it. ."</i> <i>Respondent #212</i>
Treat the Whole Person	<i>"Well, outside of my diabetes and my mental health, help me keep up with my mammograms and my physical being, you know. That's about it." Respondent #256</i>

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