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Patient perspectives on how living with a mental illness affects making and maintaining healthy lifestyle changes

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Abstract

Objective—To understand the ways that mental health symptoms interfere with achieving health goals.

Methods—Individuals with mental illness diagnoses and varying levels of preventive service use were recruited from federally qualified health centers and an integrated health care delivery system and interviewed. Thematic analysis was used to characterize descriptions of how mental illness experiences influenced lifestyle change efforts.

Results—Three themes described patients' (n=163) perspectives on barriers to making healthy lifestyle changes: 1) Thinking about making lifestyle changes is overwhelming for individuals already managing the burdens of mental illnesses; 2) Depression makes it difficult to care about a healthy future; and 3) When mental illness symptoms are not adequately treated unhealthy behaviors that provide relief are unlikely to be discontinued. Participants also made suggestions for improving health care delivery to facilitate positive behavior change.

Conclusion—Patients with mental illnesses need their clinicians to be empathic, help them envision a healthier future, address unmet mental health needs, and provide resources.

Keywords

Mental illness; lifestyle change; patient experience; qualitative

1. Introduction

Approximately 1 in 5 adults in the US has a mental illness. As a group, these individuals are sicker and die earlier than the general population, with a reduced life expectancy of at least a decade [1–4]. Some of this health disparity may be related to cardiometabolic side effects of

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certain psychiatric medications [5–8], but much is due to modifiable health behaviors including sedentary lifestyles [9, 10], poor diet [11], and smoking [12, 13] that, left untreated, can result in higher risks of cardiovascular disease.

Primary care providers serve as a primary point of contact within the medical system for counseling and communication on behavior change and preventive health care. While some providers are able to refer patients to evidence-based lifestyle change interventions designed for patients with mental illness [14–17], these programs are not widely available. In the absence of such structured programs, primary care clinicians should understand what makes it difficult for their patients with mental illnesses to follow their recommendations to improve health behaviors and reduce cardiovascular risks so that they can help them manage and overcome barriers.

Several studies have documented patient-level barriers encountered *during engagement in behavioral interventions* among people with serious mental illnesses, including lack of motivation, unhealthy food choices, stigma of having a mental illness inhibiting attendance at conventional weight loss programs or gyms, weather, and unsafe neighborhoods for exercising [18–21]. However, patient perspectives about making and maintaining lifestyle changes *on one's own*, outside of the context of intervention studies, while managing mental health symptoms are sparse [22–24]. In this observational study, part of a larger mixed-methods study looking at preventive service use patterns among individuals with mental illnesses, we sought to understand how patients with mental illness diagnoses describe barriers to making lifestyle changes. As many logistical barriers (e.g. transportation) and obstacles related to social circumstance (e.g. poverty) have been previously documented [25–28], we focused our analyses on how individuals described the specific role that their mental health symptoms play in impeding their ability to make lifestyle changes. We also documented patient-reported insights for how providers can facilitate engagement in lifestyle change and improve care delivery that supports health promotion in this population.

2. Methods

2.1. Setting

Participants were recruited from Kaiser Permanente Northwest (KPNW) and from federally qualified health centers and eight safety net community health clinics (CHC) belonging to the OCHIN network. KPNW is a not-for-profit, private integrated health plan that provides care for approximately 570,000 members, including individuals with Medicare and Medicaid coverage, in Oregon and southwest Washington. OCHIN has more than 400 federally qualified health centers (FQHC's) in 18 states and provides its network members a common electronic health record (EHR) platform. OCHIN clinics serve a diverse clientele: 29% of patients report Hispanic ethnicity, 28% are non-white, and 53% are at or below the Federal Poverty Level [29]. As interviews were conducted in-person, all OCHIN-affiliated CHCs were located in the Portland, Oregon metropolitan area. The KPNW Human Subjects Protection Office approved and monitored all research activities. Patients provided written informed consent prior to their participation.

2.2. Recruitment

Patients were eligible if they were at least 19 years old and had one or more of the following types of diagnoses: schizophrenia spectrum disorders, bipolar disorder/affective psychoses, major depressive disorder, or anxiety disorders. Individuals were excluded from participation if they were cognitively impaired and therefore unable to provide consent.

To gain a broad understanding of barriers and facilitators of making lifestyle changes among people with varying engagement in primary care and preventive services, we used a purposeful sampling procedure [30, 31]. We categorized potentially eligible subjects based on the number of incomplete preventive services (0, 1, 2, or 3+) for seven common preventive screenings documented in the electronic health record [see 32 for more information on preventive services]. With the goal of recruiting 150 participants, we then randomly selected equal numbers of individuals from each setting and category. We attempted to balance our sample on gender and mental health diagnosis.

We mailed recruitment letters to 1130 eligible participants; 231 were returned as undeliverable or we discovered they had disconnected phone numbers. Of the remaining 899 individuals, we called up to six times over the month following the recruitment letter and were able to contact 470 individuals (52%). Of those, 227 refused participation (48%): typical reasons included not being interested or being too busy. We left messages or made contact with an additional 80 individuals but were unable to enroll them. We enrolled the remaining 163 individuals for a participation rate of 35% (163/470) and an overall response rate of 18% (163/899).

2.3. Self-Administered Survey

Questionnaires were sent to participants' homes for them to complete prior to their interview appointment. Questionnaires took approximately 45 minutes to complete and focused on current health behaviors, interest in changing health behaviors, quality of care, and barriers to and facilitators of engaging in preventive care. Participants brought completed questionnaires to the interview or completed questionnaires at the appointment if they needed assistance or were not finished. In three cases, questionnaires were returned uncompleted or were never returned.

2.4. In-Person Patient Interviews

At the interview, we used a structured interview guide with semi-structured and openended follow up questions designed to elicit context and detail. Master's level interviewers who had significant experience working with individuals with mental illnesses conducted all interviews. Upon completing the survey and the interview, participants were compensated for their time with a \$50 gift card. We were unable to complete interviews with five participants due to scheduling problems. All survey instruments and interview guides are available from the authors upon request.

2.5. Qualitative analysis

Patient interviews were recorded using encryption-enabled devices and were transcribed verbatim. The qualitative analysis team (CG, BJY, SS, MY) met weekly while reading initial

transcripts of each interview to develop descriptive code lists. We had no *a priori* codes identified before reading transcripts, and therefore began by using open coding techniques to identify broad concepts expressed by participants [33]. Coders (SS, MY) continued to meet weekly until no new codes were encountered and met monthly for the remainder of the project to discuss themes of interest. The team used Atlas.ti software to manage coding and queries. Thirty-six of 158 patient transcripts (23%) were double coded; agreement was 85% between the two coders.

We used thematic analysis [34, 35] to characterize patients' descriptions of their beliefs and actions. Responses coded and included in the final themes documented within this report could have been in response to a number of questions, but most often came in response to the following two: 1) "In what way might your mental or emotional health prevent you from following through or making health changes (like stopping smoking, improving your diet)?" or 2) "Can you tell me more about your concerns that making lifestyle changes could make your mental or emotional health worse?" In this analysis, we reviewed queries of all text coded "Barriers— mental health" and "fears of worsening mental health" in order to derive barriers to making behavioral health changes; and "facilitators" and "thoughts on improving care" for themes related to how care could be improved. We actively sought disconfirming quotes [36] and modified our themes to accurately represent the descriptive range expressed in the interviews.

3. Results

Enrolled patients had a mean age of 47 years (SD=14; range 19–87), 53% were female, 68% who reported a race were white, and 19% reported Hispanic ethnicity. Individuals had diagnoses of bipolar disorder/affective psychoses (33%), schizophrenia spectrum disorders (27%), major depressive disorder (25%), and anxiety disorders (15%). More than one-third had annual incomes under \$10,000; nearly one-quarter had a college degree. Table 1 presents additional patient demographic characteristics.

We identified three important themes describing patients' perspectives on mental healthrelated barriers to making lifestyle changes and provide patient-reported insights for improving the delivery of preventive care.

Thinking about making lifestyle changes is overwhelming for individuals already managing the burdens of mental illnesses.

Patients reported that being asked to significantly alter their lifestyle caused additional stress when they were already overwhelmed by trying to cope with mental illness symptoms. As one participant succinctly described previous attempts to make behavioral health changes: "*I felt so overwhelmed already that it just adds more stress...*". Another man elaborated:

"When you're already overwhelmed...it's just another thing. It doesn't bring more order to your life, it brings less. More things to say, oh, now something else I got to feel guilty about not being done, you know..." (#14 male, black, major depressive disorder)

Patients reported that knowing they need to change a behavior when they do not have the bandwidth to do so can add to feelings of guilt and discouragement:

“Well, knowing I need to do something and not being able to do it--then I stress ‘cause I haven’t did it, you know. So I ponder on that forever and that makes me withdraw even more into myself. It’s like, ‘What’s the use?’. I can’t get through what I’m going through right now, so why even [bother]...knowing that I should do something and not doing it, that might make it worse.” (#70 female, black, bipolar disorder)

Depression makes it difficult to care about a healthy future.

A majority of participants acknowledged in our survey that emotional or mental health problems interfere with their ability to follow preventive care recommendations: 34% reported a great deal, 23% a moderate amount. In particular, patients who reported depression as a barrier recognized that mood symptoms, including amotivation and anhedonia, influenced future-oriented thinking, sometimes by making it difficult to think ahead:

“So, where I’m at mentally really will dictate how...things will improve. So, if I’m in a kind of depression...I’m just not able to focus on anything other than what seems to be the immediate solution...I want to feel better, but I’m not interested in whatever it might take to feel better other than, again, the immediate. If I can take a pill or anti-anxiety medication it makes me feel a little bit less anxious, great. That’s what I want to do.” (#54 female, black, bipolar disorder)

And sometimes by making it difficult to envision or care about a healthier future:

“My depression is a good chunk of ‘The future looks bleak. Why bother?’ And when I’m in that mindset, why eat right to extend my life by another five years... when I don’t see myself caring that far out? So, I get in a mindset where it’s, ‘Why look to the future? Why not just live right here in the now? Why not skip eating that carrot and instead eat a donut?’” (#33 male, white, major depressive disorder)

In response to a question about whether her mood impacts her ability to make healthy lifestyle changes, one woman said:

“It will, if I am in a depressed state, I may go and vegetate on the couch or in the bed for 3–4 days and that means I’m not doing any aerobics. I’m not lifting any weights, I’m not walking, I didn’t pull out the bike. I’m eating chocolate cake, donuts...” (#50 female, black, bipolar disorder)

When mental illness symptoms are not adequately treated unhealthy behaviors that provide relief are unlikely to be discontinued.

Participants were specifically asked whether they were concerned that preventive care recommendations made by their doctor could worsen their emotional or mental health. Most participants (53%) reported that they were not at all concerned. However, some patients reported that certain unhealthy behaviors provided relief from mental health symptoms, making the patients unlikely to give up the behaviors. For example, one participant

described how eating unhealthy food brought a sense of pleasure that temporarily provided relief from anhedonia and thus made it difficult to maintain a healthy diet:

“I used to be super healthy and active and fit and ate healthy and everything, but the longer the depression goes on, the harder it is to find any kind of joy or pleasure or satisfaction in anything, and...food is a place that that can still happen, and so that makes it difficult...[and] it tends to be the most unhealthy foods are the ones that have an instant [gratification]...like whole wheat pasta? Not so much. A donut? Yeah...And so, again, it’s not that I don’t want to, it’s just it’s hard to get myself to actually do it.” (#32, male, white, major depressive disorder)

For individuals in our sample who smoked, many described how smoking effectively, if temporarily, alleviated their anxiety. As one young woman described:

...[physicians] can tell me over and over, ‘smoking’s not good for your health’, and I’m like, “I totally agree. I’m still going to do it...” ‘cause I just need to figure out something to deal with that anxiety.” (#30, female, white, bipolar disorder)

In addition to reporting barriers to making health changes, participants also provided insight into how health care providers could help facilitate their attempts to make lifestyle changes.

Suggestions for helping patients with mental illnesses make health changes: First invest in building the relationship, then provide tangible resources

First and foremost, patients explained that it was very important to them to have a collaborative relationship with their physician. As one woman noted:

“[What] help[s] me most is a good relationship with my doctor and trusting my doctor. So now I would listen to those things that they want me to do...When I was really struggling with my mental health symptoms, that’s what convinced me that I liked this guy [doctor] so much. He was nothing but positive and reassuring and he was great.” (#28 female, white, schizophrenia spectrum disorder)

Another woman stated:

“...I think medicine, there is a social services component to it...that I’m not sure if that’s the natural inclination of the profession. But I think that they might find people become healthier if they take more time with the patient...maybe having more of a connection with your doctor helps make you more accountable for making sure you’re following up.” (#54 female, black, bipolar disorder)

Patients also mentioned the need and appreciation for more tangible support between visits with the doctor and ongoing over time. Examples of these kinds of supports came from physician extenders including nurses, care managers, health coaches, nutritionists, peer support specialists, and in some cases peers or social media. As one man described:

“So, the plant-based diet that I’m on with [doctor], his nurse she reaches out to me, answers questions. And on Facebook they have a board, you know, where everybody can talk...but I think I would really benefit from more help...I don’t know whether it’d be like a face to face with [nutritionist]...I mean, she was awesome. Like when I first started my program she went to [grocery store] and

shopped with me... [but now] it's really hard to do it all by myself...And I almost have that feeling of you guys are helping me, but you're leaving me hanging..."
(#15 male, white, bipolar disorder)

Participants also suggested increasing access to fitness facilities. One man noted:

"I think it'd be good if they had...gyms where people could go to and then, in the gym, they could...have a trainer for diet or, you know, people that you could talk to if you have questions to help guide you in trying to eat healthy and exercise." (#81 male, white, schizophrenia spectrum disorder)

4. Discussion and Conclusion

4.1. Discussion

Though it is common for anyone to struggle with making and maintaining behavioral changes [37, 38], individuals with mental illnesses face additional mental health related barriers [20]. Lifestyle interventions tailored to this population have taken these mental health factors into account [39] and shown that individuals with mental illnesses benefit from group participation with peers, ongoing social and structural support, and highly supportive intervention facilitators who provide accountability and consistent encouragement [18, 20]. However, these tailored programs are not widely available and little research has focused on what busy primary care clinicians without access to these programs can do to support their patients to make healthy lifestyle changes. Through patient interviews we identified three specific ways mental illness symptoms interfere with lifestyle change and patient-centered recommendations for how clinicians can help.

Participants in the current study described the effort and energy needed to manage untreated or undertreated mental health symptoms. Particularly participants who lived with depression articulated feelings of futility and a sense of hopelessness that interfered with their ability to care about cultivating healthier habits. For some participants contemplating the additional discipline that would be needed to make or sustain further difficult behavioral changes was too much to bear, for others the perceived high likelihood of failure was overwhelming. Therefore, participants appreciated clinicians who were caring and took time to acknowledge the work they were already doing to manage their wellbeing. Participants used words like "encouraging," "positive," "reassuring," and "connection" to describe favorable clinician-patient relationships that were instrumental in moving them toward change. The power of a compassionate provider who listens, understands, and invests in knowing their patients and the importance of collaboration and trust have been demonstrated in the mental health recovery literature[40] and appear to be instrumental in helping patients initiate lifestyle change.

Providers can demonstrate empathy by acknowledging that patients may feel overwhelmed or unmotivated. Clinicians can break down behavioral goals into smaller achievable components, provide accountability, and reinforce even modest successes. They can help patients envision a healthier future and a path to it by providing available referrals to behavioral interventions and resources and connecting patients to ancillary supports between visits. It may be helpful for providers to communicate to patients that behavior change is not

linear [40, 41], just like mental health recovery is not linear [42], and that periods of more and less active engagement in behavioral change efforts are common. Helping individuals with mental illnesses understand that their peers [43] and the general public [37, 38] struggle to consistently maintain behavioral changes could help normalize their efforts and dispute feelings of failure.

Participants reported using unhealthy eating and smoking as coping mechanisms and noted that these behaviors could provide pleasure and relief when little else could. Given this, it is perhaps not surprising that obesity [44] and smoking rates [45] are more than twice as high among people with serious psychological distress than those without and that rates of smoking cessation are significantly lower among those with mental illness than those without [13]. However, research consistently shows an association between smoking cessation and improvements in anxiety, depression, stress, and quality of life, both in the general population and specifically in individuals with psychiatric conditions [46]. By acknowledging the powerful and temporary rewards of these unhealthy behaviors within a meaningful dialogue about the pros and cons of lifestyle change, perhaps using motivational interviewing techniques [47], clinicians could increase patients' willingness to consider making changes. Again, ancillary supports outside of primary care appointments may be necessary, as well as evidence-based behavioral interventions combined, for those who smoke, with smoking cessation medications[48].

Finally, providing nutritionist support, health coaches and other supportive staff resources, and free access to community-based gym memberships were also mentioned by our participants as ways to help them engage in and maintain behavior changes. Specifically, participants suggested that health systems could provide a gym to work out at in the health care setting, a potentially cost-effective way of assisting patients with their weight loss efforts.

Limitations—A few limitations should be noted. Our focus was on identifying mental-illness specific barriers and facilitators to behavior change; accordingly, we interviewed only individuals with mental health diagnoses which precludes us from directly comparing the degree to which stressors, barriers, and facilitators documented here are similar to or different from those faced by individuals without mental illnesses. Our enrollment rate was relatively low; however, previous analyses of this sample have shown that individuals we recruited successfully did not differ on key demographic and clinical variables from those who chose not to join the study [49].

4.2. Conclusion

To initiate and maintain lifestyle changes, patients with mental illnesses need their clinicians to be empathic; help them to create a shared vision for a healthier future, particularly when depression thwarts optimism; and address unmet mental health needs through referrals to appropriate, evidence-based treatment. Health care delivery systems can provide additional resources within and outside primary care visits including health coaches, peer supports, and gym memberships.

4.3. Practice Implications

To the extent possible in limited appointments with competing priorities, primary care clinicians should encourage their patients with mental illnesses to make healthy lifestyle changes. However, our results make it clear that clinicians need to be aware of how mental illness symptoms interfere with their patients' ability to follow recommendations and include discussions of mental illness symptoms in conversations about behavior change. Lifestyle change can be overwhelming when patients are struggling to manage mental health symptoms but waiting for complete mental health recovery to address modifiable health behaviors put patients at greater risk. Therefore, while pursuing adequate treatment and mental health recovery, clinicians should focus on acknowledging efforts and gains their patients are making and on building a trusting relationship as a foundation for accountability and support. Clinicians can help their patients envision a healthier future and an actionable path toward it by identifying resources that can provide scaffolding and support between primary care visits.

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Highlights

- Clinician empathy and support move patients toward lifestyle change.
- Depression can make it difficult to visualize a healthier lifestyle.
- Unhealthy behaviors that relieve untreated symptoms are unlikely to be discontinued.

Practice Implications

Primary care clinicians should encourage their patients with mental illnesses to make healthy lifestyle changes within the context of a supportive relationship. Lifestyle change can be overwhelming; clinicians should acknowledge progress and provide ongoing tangible support.

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Table 1.

Demographic characteristics

	Valid n	N	%
Setting	163		
KPNW		93	57.1
CHC		70	42.9
Diagnosis	163		
Schizophrenia		44	27.0
Bipolar disorder		54	33.1
Anxiety disorder		25	15.3
Major depressive disorder		40	24.5
Female	163	87	53.4
Race	163		
White		99	60.7
African American		32	19.6
Native American		3	1.8
Asian/Pacific Islander		5	3.1
Multiple races		7	4.3
No race reported		17	10.4
Hispanic ethnicity	152	29	19.1
Completed questionnaire in Spanish	163	16	9.8
Education	159		
Up to high school degree or GED		62	38.9
Some college or associate degree		60	37.8
College degree or higher		37	23.3
Annual income	149		
9,999		51	34.2
10,000–19,999		30	20.1
20,000–29,999		19	12.8
30,000–79,999		28	18.9
80,000+		21	14.1
	Valid n	Mean	SD
Age (range: 19–87)	163	46.9	13.6