

Managing physical and mental health conditions: Consumer perspectives on integrated care

Angela L. Rollins, PhD, Jennifer Wright-Berryman , PhD, Nancy H. Henry , BA, Alicia M. Quash , BS, Kyle Benbow , BA, Kelsey A. Bonfils , MS, Heidi Hedrick , MA, Alex P. Miller , BS, Ruthie Firmin , MS & Michelle P. Salyers , PhD

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Key words: Severe mental illness, integrated care, mental health services, primary care services

Abstract

Background: Despite the growing trend of integrating primary care and mental health services, little research has documented how consumers with severe mental illnesses manage comorbid conditions or view integrated services.

Objectives: We sought to better understand how consumers perceive and manage both mental and physical health conditions and their views of integrated services.

Methods: We conducted semi-structured interviews with consumers receiving primary care services integrated in a community mental health setting.

Results: Consumers described a range of strategies to deal with physical health conditions and generally viewed mental and physical health conditions as impacting one another. Consumers viewed integration of primary care and mental health services favorably, specifically its convenience, friendliness and knowledge of providers, and collaboration between providers.

Conclusions: Although integration was viewed positively, consumers with SMI may need a myriad of strategies and supports to both initiate and sustain lifestyle changes that address common physical health problems.

Introduction

People with a severe mental illness (SMI), such as schizophrenia, bipolar disorder, and major depression, experience shortened lifespans compared to their peers without major mental illnesses. Recent reviews document that people with SMI die 15-25 years earlier than the general population, and the trend towards early mortality has accelerated in recent years (Jones et al., 2004; Morden, Mistler, Weeks, & Bartels, 2009; Saha, Chant, & McGrath, 2007). The causes of this unfortunate phenomenon are complex. Some research attributes excess mortality to the high rates of physical comorbidities: 75% of adults with SMI have one or more comorbid physical health conditions and 50% have at least two such conditions (Jones et al., 2004; Morden et al., 2009). Other research suggests risky health behaviors, such as smoking, poor diet, and sedentary lifestyles, contribute to a wide range of these comorbid conditions, like cardiovascular disease, diabetes, cancer, and chronic pulmonary illness. Prevalence rates for cardiovascular disease, for instance, are 22% for people with SMI (Jones et al., 2004), compared to 11.5% for the US general population adults (Centers for Disease Control and Prevention, 2012). Many of these factors can be attributed to a metabolic syndrome associated with extended use of atypical antipsychotic medications. Metabolic syndrome is described as a group of risk factors (such as weight gain, hypertension and insulin resistance) that occur together to increase the risk for cardiovascular disease, type II diabetes, and stroke (Deakin et al., 2010). For example, Casey et al. (2004) reported that people with schizophrenia using antipsychotics such as olanzapine and clozapine were six times as likely to have insulin resistance compared to the group using conventional antipsychotics. Although metabolic syndrome has been associated with weight gain and subsequent insulin resistance, the exact causes of the syndrome are not fully understood (De Hert, Schreurs, Vancampfort, & Van Winkel, 2009).

The mental health field has focused on the integration of primary care and behavioral health services as one method of addressing the early mortality and physical comorbidity challenges for people with SMI. A recent initiative by the Substance Abuse and Mental Health Services Administration (SAMHSA) of the US Department of Health and Human Services funded 100 demonstration projects for integrated primary care and behavioral health. However, published data from these demonstrations have not included how consumers experience comorbid mental and physical health conditions, or the integration of their physical and mental healthcare services. The majority of studies in this area focus on the benefits and challenges of providing mental health services within traditional primary care settings (e.g., (Bailey, 1997; Bindman et al., 1997; Lester, Tritter, & Sorohan, 2005; Rogers, 2001)). For example, Lester and colleagues (2005) asked consumers with SMI about their experience of traditional primary care services. In this study, consumers reported that quick access to primary care services, provider optimism, continuity of care, and listening skills were more important than specific mental health knowledge from their primary care provider (Lester et al., 2005). In the same study, primary care providers reported less comfort with the specialized mental health care needs of persons with SMI and recognized struggles in communicating with this patient population (Lester et al., 2005). To our knowledge, there has been only one study focused on consumers' perspectives of integrated primary care services within specialty mental health contexts. In this study, consumers endorsed their preference for consumer providers (over traditional clinician-delivered services) and hands-on guidance on healthy lifestyle management (Cabassa et al., 2013). We sought to better understand how consumers experience both mental health and physical health conditions, how they attempt to manage these conditions, and how they perceive integrated care in the context of a particular demonstration project focused on integrating primary care services within

a specialty mental health clinic. This information can contribute to the limited but growing knowledge base on consumer perceptions and experiences of integrated care, and can be used to create more consumer-centered services.

Methods

The community and academic partners involved in this study received a SAMHSA integration grant in 2010 to implement a primary care clinic within a community mental health center (CMHC) in a Midwestern city. The primary care clinic staff were employed by a federally-qualified health care center with whom the CMHC had a long-standing partnership. The primary care provider (a nurse practitioner) and nurses met weekly with CMHC staff (primarily nurses) to coordinate care and review clients' charts. A nurse care manager, employed by the CMHC, was also assigned full-time to the primary care clinic to serve as another conduit for coordination of care. At the time of this particular study, the program had enrolled over 300 individuals with SMI to receive their primary care services within the new clinic.

We conducted semi-structured interviews with 39 consumers who were participating in a larger study of physical health decision-making autonomy preferences in integrated care settings. Participants were all diagnosed with a major mental disorder, including schizophrenia (n=19), major affective disorders (n=16), or other mental health disorders (n=4). Using convenience sampling, research staff approached consumers and invited them to participate as they arrived for their primary care appointment at the integrated health clinic. Consumers who agreed to participate were asked to provide written informed consent and were compensated \$20 for their time. Most interviews took 30 minutes to complete. Of the 47 consumers approached, 39 agreed to participate in the interview. Interviewers were bachelor's and master's level research assistants who had received training in qualitative interviewing techniques. None of the

interviewers had clinical responsibilities for research participants. Interview questions were designed to answer 4 key research questions: 1) What health conditions do participants have and how do they manage them? 2) Are there differences in how consumers manage their physical health versus their mental health? 3) What do consumers think about relationship of mental and physical health? 4) What are consumer perceptions of integrated care? Research protocol probes then included: What are your thoughts about having your primary care clinic at the mental health center? What do you like about getting your primary care services at your mental health center? Is there anything that you would change about it? What condition(s) cause you to seek services here? How are you managing those conditions? How do you think your mental health and your physical health affect one another? Are there differences in what you do to take care of your mental health versus your physical health? All study procedures were reviewed and approved by the Indiana University Purdue University Indianapolis Institutional Review Board.

Interviews were recorded, transcribed, and coded using a combination of content analysis and an iterative, consensus-based approach to identify emergent themes (Charmaz, 2006). Pairs of raters (eight total) divided the transcripts for coding. Two raters read each transcript and independently extracted quotes that reflected answers to each of the four questions. The two raters then compared notes and came to consensus on which quotes reflected the particular domains. Then each team developed a summary for a particular question, reading the quotes across participants within a domain and linking responses together, looking for similarities and differences across participant responses. One person took primary responsibility for the summary, and the second rater re-read the quotes and edited the summary.

Results

What health conditions do participants have and how do they manage them?

Participants were asked to indicate if they have any of a list of specific health conditions (diabetes, hypertension, COPD, heart disease, and cancer) or other health issue(s), and if so, participants were asked how they manage that condition. Table 1 lists the frequency of conditions disclosed by participants and methods of managing these conditions. Of the 39 participants interviewed, 37 (94%) reported having at least one chronic physical health condition.

Most (68%) of participants reported having *hypertension*. Participants reported managing their hypertension by taking medications as prescribed, getting exercise, and being conscientious of what they consume. Participant 1009 stated, “I take medicine, so I'm okay every day as long as I take my medicine... And, I walk a lot. I've got a dog, so I walk at least three times a day... And the apartment I live in has an indoor pool...It's relaxing for me and it kind of relieves stress for me”. Participant 1009 also addressed the importance of a healthy diet saying, “I do eat fruits. I just need to work on the vegetables....and cut back on my [soft drinks]”.

Chronic obstructive pulmonary disease (COPD) was the second most prevalent health condition reported amongst our participants (28%). Several others also mentioned difficulty breathing at times. Using oxygen, inhalers or nebulizers, and/or quitting smoking were the most commonly reported strategies for managing this condition. Participant 3001 reported that attending support groups along with using the nicotine patch helped to reduce smoking: “I'm trying real hard to quit smoking and that'll help it a lot...I do pretty well. I tried several methods to quit smoking. The patch works real well for me, and nicotine gum works well for me and I, over the past year, I've probably not smoked more than I smoke [now], which does affect COPD a lot. [It would help] to have the smoking cessation class come back. There was, like, a get

together group for people to support each [sic] and not smoke.” While it is ideal to stop smoking, several continued to struggle with cessation, as participant 1011 shared: "It managed me... I smoked for 40 years. I didn't manage it for 40 years."

Diabetes was another commonly endorsed condition (16%). Monitoring blood sugar, taking insulin, and being cautious about eating habits are a few ways participants reported dealing with this physical health condition. Participant 2002 stated, “I test my blood at least once a day. I take my insulin shots. I changed my diet once I knew I was diabetic. I cut out a lot of sugar and sodium.”

Three participants reported having *heart disease* while four more reported a heart condition including irregular heart rate and heart valve issues. These individuals reported managing heart disease or related conditions in a variety of ways such as: taking medication, exercising, quitting smoking, and having a healthy diet. Participant 2003 also discussed getting support to lose weight and eat healthy, saying, “I've had people inspire me to do that, and it's given me that little bit of a push, [more] than I had before where I just had to make up my own mind. It's kind of hard to do that. And if you have somebody kind of give you a little bit more inspiration and [sic] willing to do it with you or give you that 'go for it' kind of attitude... That's what makes me motivated to make it better.”

While some participants are succeeding in managing their particular health condition, there is still room for improvement in obtaining resources and learning how to properly manage these problems. As seen in Table 1, although many reported taking prescribed medication, getting adequate exercise, and constructing healthy eating habits to maintain good health, others were still struggling to manage their conditions. For example, several participants (n=7) reported relying on medication alone. However, the majority of participants (n=26) used two or more

methods to manage their health, with diet and exercise being the most frequently reported behavioral strategies.

Are there differences in how consumers manage their physical health versus their mental health?

Yes, there are differences. Of the 39 people who participated in the interviews, 21 people (54%) responded that they do, in fact, approach the management of their physical health and mental health differently. For some, there appeared to be different levels of perceived control. For example, Participant 1007 indicated that she had more control over mental than physical health, without mention of medication as an intervention. “I try to coax myself out of a mental slump if I’m in one. A physical slump—not—I can call a doctor or do something about it, but basically I’m not too much in control of that. But, mentally, I try to work on it and, and get in a better state of mind.” Similarly, Participant 1008 shared:

With mental health, I try, I sit and study, thinking about things that might help...do self-help things, and sometimes it does help for the time being. As far as my physical health, I mean I do the best I can. When my foot – I got this gout – and when my foot hurts I stay off of it. Like, I’ve been in bed for about five days here.

Conversely, one participant (Participant 1021) offered an alternate perspective, believing he had more control over physical health through exercise and weight loss, for example. When asked about mental health management strategies, however, he simply replied, “I pray” without much additional elaboration.

In addition to the theme of control, some participants explicitly described different management strategies for mental vs. physical health. For example, Participant 1020 seemed to equate mental health management strictly with pharmacologic intervention, but thought physical

health could be managed with general wellness strategies. “Mental is medication...Physical, I eat more properly and exercise and stuff like that.” Another participant (1017) reported that she takes preventative measures for physical health and relies on social support for her mental well-being. “Well, my physical health—I just need to make sure that I drink plenty of water because when I went into [health center] the first time I was dehydrated.” She added in reference to her mental health, “I’m down here [the CMHC] and I have my brother and sister-in-law to check up on me.” Participant 2005 also differentiated helpful activities for mental vs. physical health, stating “I read a lot, which keeps your mind occupied...Well, cooking relaxes me mentally; but physically, it ain't going to do a dang thing.”

It should be noted that three participants initially answered “No” when asked if there were differences in the management of their mental and physical health needs, but went on in their interviews to describe distinctly different ways in which they manage each area. As such, these three responses were considered to manage their physical and mental health differently.

There are no differences. Twelve participants (31%) reported no appreciable differences in how they managed mental vs. physical health problems. Of those 12 people, half of them specifically mentioned medication (either alone or along with other strategies) as an intervention they use to manage both physical and mental health issues. For example, when asked if there was a difference, P1014 said, “No. They both— pretty much I just take the pills.” P1029 elaborated a little more, “Well, I take medicine for both of them. So, I try to relax. I can’t think, I try to just rest and try to relax. That’s basically what I do for both of them, even if they’re independent or separate.” Some participants had multiple strategies for both conditions. For example, P1002 reported, “See the doctor on a regular visit, take my medicine, exercise, music and go to movies, entertain, have friends.” Interestingly, this same participant also reported that

he partakes in boxing as a health management technique. When queried about whether boxing was for mental or physical health, he indicated that this activity was effective in managing both areas: “Yeah, because you get your aggression out, too.”

What do consumers think about the relationship between mental and physical health?

While one person indicated he found no relationship between mental and physical health and others provided responses indicated uncertainty, 32 participants (82%) reported that they believe there is some relationship between the two areas of health. Multiple themes emerged in this area and are discussed below.

Mental health affects physical health. Thirteen participants (33%) indicated that their mental health has an effect on their physical health. For example, Participant 1023 simply stated: “if you’re depressed, you’re probably not going to feel good.” Several clients reported that a decline in their mental health often resulted in lethargy. “Sometimes with my mental health,” said Participant 1014, “I want to sit and sleep.” Participant 1026 made a similar observation stating that feeling “lonely” leads to inactivity: “I get lazy, and I don’t want to do nothing.” Participant 3000 had similar feelings about the link between depression and activity level: “You’ll be depressed and don’t want to get out of bed.”

Only one participant (2001) discussed a link between the use of psychotropic medication and physical health side effects from those medications. “I take [medication] and it makes me a little dizzy and stuff.” When further queried by the researcher, this participant added: “Like, you could be tired too much. You could be dizzy.... you could get a stomachache. Your muscles could tense up.”

Physical health affects mental health. Of the 39 participants, 10 people (26%) endorsed the belief that physical health has a unidirectional, mostly negative, effect on mental health. As

Participant 1007 stated, "... mostly if I don't feel physically well, sometimes it could drag me down." Another participant had a similar response, stating "whenever I'm physically ill or having symptoms more than usual, it affects my depression and my anxiety." (P1019).

A few participants cited physical injuries or conditions as triggers for mental health problems. For instance, Participant 1024 reported that a back injury necessitated a job change, which negatively impacted his income and thereby his mood: "my income was way lower than what I was used to making. That was a big reason why I think depression kind of set in." Similarly, Participant 1025 reported that a knee injury limited physical activity, which contributed to the onset of depressive symptoms: "And I know that the fact that I'm less physically active is a concern for me and leads to depression." Participant 1017 noted specifically that menstruation took a toll on her mentally: "I was crying at the drop of a hat."

One participant expressed a more positive outlook, that taking preventative measures for physical health such as exercise and proper diet can positively influence mental health as well. "Yeah, it does affect the mental health also," said Participant 3001. "It strengthens your ability to, um, feel better."

Mental health and physical health affect each other.. Nine participants (23%) reported the effects of each health dimension reciprocally influence the other. As Participant 1003 said, "If one is bad, the other one's bad." Participant 1002 concurred: "If, you know, one's out of whack, it's going to cause the other to be." Participant 3003 spoke eloquently on this issue:

Well, if your mental is not working right, your physical's not going to be right. They work together. You know, you've got to have one to have the other. But, mental affects your physical as well as the physical affects the mental, so you got to have them working

together. That's why it's so important, like I said, you got to be able to exercise and sleep, and that way your physical is working for the mental. You know, so it all goes together.

What are consumer perceptions of integrated care?

Convenience. The most common response when asked about the positives of integrated care was convenience. Many participants liked that they could make only one trip for all their physical and mental health needs. Participant 1015 stated, "I like that it's easier to interact with both doctors." Another key point included location and travel, with many citing how close the clinic was from where they were living. Many people also stated the convenience of not having multiple appointments at multiple locations. Participant 1030 highlighted this saying, "you don't have to worry about having to rush from place to place and missing appointments or being late, so I think that's really cool."

Friendly and knowledgeable staff. The on-site staff members were also frequently cited as positive aspects of integrated care. Many referred to staff as "really, really nice," "friendly," and "personable." Staff (including the front office workers, nurses, and doctors) also helped participants feel comfortable. Participant 1003 spoke to this point saying, "I appreciate [staff names] and I get along with them. I trust them and I just enjoy coming here." Similarly Participant 1009 said, "I like it here. I mean they treat me good...I don't have to wait long. And, if I do, they, they come and let me know. And, they take care of me. I like my doctor and I like my therapist. ... I like the people here, everybody here." Participant 1013 said "[Staff name] always has something funny to say to lighten people up... The doctor is nice as well as his nursing staff. Everybody's nice. They respect me, that kind of thing."

In addition to being personable, staff were considered knowledgeable. For example, Participant 1016 stated, "I really like my doctor. I really think he knows his stuff. I like, too, that

they're really also concerned about you psychologically. I like how it is holistic..." Similarly, Participant 1022 spoke about this knowledge saying, "if I have a question they'll answer it...I haven't gotten an 'I don't know'."

The overall environment of the setting was also considered a positive aspect of integrated care. Participant 4010 praised the staff for making the environment more comfortable than his previous experiences: "The feeling that it doesn't feel like a mental health center. It doesn't feel like I'm in an institution. I know there are people here with more severe situations than myself, but I think it feels very right at home." The highest praise came from participant 1011 who said the staff was professional, well-managed, and welcoming every time they visited:

They've been very accommodating here...I can tell you those persons along with the persons that work behind the counter out here make you feel mighty welcome when you come here...And, they're so good about keeping appointments, calling you a day ahead of time, uh, you know, it's just well managed here. And, the people are professional...It's – I mean, they're very professional. I've come to rely on them...I think highly of everyone here. I just really do.

Shared information and communication. Many consumers appreciated that mental and physical health doctors could easily communicate and collaborate. Participant 1025 spoke to this point, saying, "I think it's a good idea because then they can relate my physical symptoms to my mental treatment and they're there to know if it ties". Participant 1027 was more specific in explaining how the coordination between doctors can ensure that they are taking the correct medication: "Because I'm not getting medicine from this doctor and that doctor and then having to confer. They know exactly what I'm taking, when I'm taking it, and how it's supposed to be

taken." One participant (1028) had a very detailed response, highlighting how the coordination and communication specifically helped her:

I think it's a wonderful thing because not only can they communicate with each other, they can communicate with me...One time when I was having a test and it came out positive, my therapist that I was talking to went to see the doctor and [could coordinate when to see her]. When they're all working together, there's not such a big assumption that, 'oh, it's all in her head' So, if we're all communicating, we kind of can try to stay on the same page at least...And, also, if I do get some of the diagnosis [and] I don't know exactly how to react, or if they worry me, then I can talk to my therapist [there] and say, you know, "I feel a little worried," that kind of thing. And, and, I don't have to sign a release for another place. I've already signed all that. And, it's all coordinated. I like it.

Needed improvements. When asked about improvements to integrated care, 31 participants (79%) responded that they would not recommend any changes. Those who thought improvements were needed pointed to a few minor changes. Two participants spoke about missing equipment that was necessary for their treatment, including an X-ray machine and materials needed for blood testing. Another consumer wanted more prompt return on phone calls, while two participants mentioned that having more doctors would help their treatment. For example, Participant 2003 suggested, "There should be more, maybe more doctors or psychiatrists and stuff like that, to be available to maybe even give you a choice of your own, to pick out somebody. Maybe more counselors besides psychiatrists or doctors [for] maybe some kind of access for different information."

Discussion

Consumers of this integrated health clinic had numerous and varied physical health conditions. Although they cited many different strategies to manage physical health conditions, the most commonly endorsed health management strategy was medication. For those who did identify a desire to make important behavioral modifications for physical health conditions (e.g., smoking cessation, increasing exercise, eating healthier diets), they reported struggling with these lifestyle changes. Some consumers indicated a need for multiple strategies (i.e., nicotine patches, gum, and smoking cessation support classes) as well as needing extra “inspiration” to make tough changes. Consumers with SMI may need a combination of strategies and supports to initiate and sustain lifestyle changes that address common physical health problems, in addition to medications. These notions are consistent with literature indicating the need for multi-pronged, sustained approaches targeted toward consumers with SMI, above and beyond interventions targeting the general population, to address smoking cessation (Cook et al., 2014; Evins et al., 2014; Schroeder & Morris, 2010) and weight reduction (S. Bartels & Desilets, 2012; Daumit et al., 2013).

Consumers’ perceptions of relationships between mental and physical health overwhelmingly indicated they feel a link between the two, whether one-directional or mutually influencing one another. Contrasting these findings were distinctions between how consumers reported managing their physical and mental health conditions. While some participants perceived less control over physical health conditions than mental health conditions, others described managing both conditions using medications or other strategies. The emphasis on medications was noteworthy in that, as a field, we may need to do more to activate consumers to

take steps to manage physical and mental symptoms with behavioral lifestyle choices. Though medications may be underutilized for some conditions, such as nicotine replacement and smoking cessation medications for people with SMI who smoke (Schroeder & Morris, 2010), there seems to be a tendency to rely solely on medications for at least a subsample of the SMI population.

When asked about their perceptions of integrated care, most participants endorsed the convenience of co-located healthcare services, as well as more general characteristics of being served by knowledgeable, friendly staff who are concerned with their whole health, rather than just mental or physical health. Consumers also were pleased with the level of collaboration and communication between providers overseeing primary care and mental health needs.

Respondents even alluded that primary care services in isolation of mental health integration feel more stigmatizing (“oh, it’s all in her head”). Participants highlighted how colocation facilitates collaboration: the ease of communication when a mental health provider can simply walk down the hall to communicate something important to primary care providers. This finding is consistent with past research indicating better treatment engagement in co-located services (S. J. Bartels et al., 2004) and the use of warm hand-offs often seen in well executed collaborative care models. Participants generated few recommendations for improvement, other than the need to broaden the array of services and procedures available at the integrated clinic (e.g., X-rays, wider range of blood work). This particular program is relatively small in scale, compared to some larger mental health programs. Larger programs may be able to justify the addition of these sorts of equipment or available procedures. Likewise, the relatively small caseloads of consumers in integrated care programs embedded in community mental health centers make it difficult to

justify the employment of multiple primary care providers that would allow consumers a choice in which doctor provides their care.

Conclusion

Overall, responses from consumers indicated a favorable view of the integration of primary care services within a specialty mental health clinic, indicating some distinct advantages from the consumers' perspectives on this integration approach. There are notable implications for practice. First, persons with SMI attending an integrated clinic may need practitioners to weigh a variety of physical health management options. Secondly, the use of medication should be emphasized in tandem with other behavioral and supportive techniques for healing and wellness. Lastly, practitioners should continue to facilitate the collaboration between integrated primary and behavioral healthcare, through communication and team planning, keeping the consumer at the helm of the team.

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Table 1. Common physical health conditions and management approaches

Physical Health Condition	# reporting condition
Hypertension	25
Chronic Obstructive Pulmonary Disease	11
Heart Condition/Heart Disease (other than hypertension)	7
Diabetes	6
Thyroid conditions (e.g., hyperthyroid or hypothyroid)	5
Arthritis and other joint pain	5
Asthma	3
Epilepsy/seizures	3
Cancer	2
Gout	2
Back pain	2
Acid reflux	2
Hyperlipidemia	2
Other (e.g., HIV, brain tumor, Alzheimer's disease, dysmenorrhea)	11
Ways to manage health conditions	
Medication	26
Other prescribed intervention (ex: Using Oxygen, Surgery)	5

Frequent Monitoring of condition (ex: testing blood sugar)	5
Diet or healthy eating	17
Exercise	12
Smoking Cessation	7
Relaxation or stress reduction	6
Avoid triggers	2
Get support	2
Number of strategies used (N=37)	
Reported 0	2
Reported 1	12
Reported 2	9
Reported 3	8
Reported more than 3	6