Learning what matters for patients: qualitative evaluation of a health promotion program for those with serious mental illness

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SUMMARY

Sedentary lifestyle, poor dietary behaviors and metabolic alterations associated with psychiatric medications contribute to poor health and high rates of obesity among individuals with serious mental illness (SMI). Interventions that increase engagement in physical exercise, dietary modifications, lifestyle changes and preventive health care can provide health benefits across the lifespan. These interventions have led to substantial physical improvements in some persons with SMI, while others have not improved or have experienced worsening physical health. We set out to identify characteristics of a health promotion program that persons with SMI associated with physical health improvements. Interviews were conducted with eight participants from the In SHAPE health-promotion program who lost at least 10 pounds or diminished their waist circumference by at least 10 cm. Interviews aimed to determine which aspects of the program were perceived to be most helpful in promoting physical health improvement. Among successful participants, three themes emerged, highlighting the importance of: (i) individualized interventions promoting engagement in the program; (ii) relationships with health-promotion program employees and (iii) self-confidence resulting from program participation. Health-promotion programs that target these areas may have better success in achieving health benefits for persons with SMI.

Key words: health promotion; exercise; diet; mental disorders

INTRODUCTION

According to the World Health Organization, neuropsychiatric diseases cause 10.5% of the burden of disease and injury worldwide; serious mental illnesses (SMI), including schizophrenia, bipolar disorder and major depression, account for three of the top 30 leading causes of years with disability (Murray and Lopez, 1997). SMI affects an individual's ability to work, engage in relationships and live independently in the community; it also constitutes an important risk factor for morbidity and mortality (Mueser *et al.*, 2001; Evans *et al.*, 2007). Individuals with SMI die an average of 10–30 years earlier than the general population and have disproportionately greater rates of medical co-morbidity (Felker *et al.*, 1996; Daumit *et al.*, 2002; Lambert *et al.*, 2003; Colton and Manderscheid, 2006). High rates of obesity, sedentary lifestyle, metabolic alterations associated with psychiatric medications and poor dietary habits are

associated with poor health outcomes in people with SMI (Brown et al., 1999; Allison and Casey, 2001; McCreadie, 2003; Strassnig et al., 2003; Jones et al., 2004).

Health-promotion interventions that increase engagement in physical exercise, dietary modifications, lifestyle changes and preventive health care can provide potential health benefits across the lifespan (Hammond *et al.*, 1997). There is a growing recognition that persons with SMI can modify health and lifestyle behaviors and accrue substantial benefits for their health and well-being (Richardson et al., 2005).

Among the various approaches to the evaluation of health-promotion interventions, most have assessed a small number of outcomes using quantitative methods (Littrell et al., 2003; Evans et al., 2005; Kwon et al., 2006). However, a purely quantitative approach has limited capacity to capture participants' individualized experiences. Qualitative approaches may offer additional insight into the process of engaging persons with SMI in health behavior changes (Soundy et al., 2007; Ussher et al., 2007).

The purpose of this study was to identify elements of an individualized health-promotion program that persons with SMI perceived to be most influential in helping them achieve physical health improvements, and to use these insights to improve the In SHAPE program. The In SHAPE intervention is described in a treatment manual and includes the following components: (i) an individualized fitness and healthy lifestyle assessment; (ii) a fitness plan with diet and exercise goals; (iii) weekly meetings with fitness trainers, called 'health mentors' because of their dual roles in supporting healthy eating and exercise; (iv) individualized healthy eating and exercise instruction; (vii) funded access to local fitness facilities; (viii) an incentive program for meeting physical activity and nutritional goals and (ix) group motivational 'celebrations'. Results from a quantitative evaluation of the In SHAPE program are reported by Van Citters et al. (A. Van Citters et al., under review).

METHODS

Appreciative inquiry

Because we wanted to identify elements of the In SHAPE program that worked best, we interviewed participants who were most successful in making physical improvements using an organizational change methodology called appreciative inquiry (AI) (Whitney and Trosten-Bloom, 2003). AI was developed in the business consulting field as a way to learn from the most highly functioning parts of organizations and to use these lessons to improve the rest of the organization. The concept is summarized by AI's developers, Cooperrider and colleagues: 'Organizations can and do learn from their successes—their positive deviations—times when people, functions, and the organization as a whole have been at their very best. Those positive deviations are best identified when we purposefully ask questions about peak experiences and high points' (Cooperrider et al., 1995).

Selection bias is inherent in AI. As the goal is to discover what worked well rather than what failed, only successful participants are interviewed. Rather than creating a sense of deficiency by determining what is wrong and how to fix it, AI calls attention to 'what is right, what is working and how to have more of it' (Suchman and Williamson, 2004). AI methods have been used successfully in nursing and medicine to promote cultural change and to improve communication with patients (Havens et al., 2006; Inui and Frankel, 2006). Using AI principles, we developed a semi-structured qualitative interview to elicit self-identified factors perceived to be influential in improving health outcomes such as reduction of weight and waist circumference.

Our approach elicited participant-generated themes grounded in their experience within the program. Four topics were covered in the semistructured qualitative interviews, including: (i) the best aspects (e.g. highlights, peak experiences) of the In SHAPE program, (ii) personal attributes that seemed most valued and important to success in the program, (iii) core factors that helped make the program successful and (iv) suggestions for program improvements. Core questions appear in Table 1. All interviews were audiotaped and transcribed. Participants were interviewed by the lead author between February and March 2007. To further broaden the data set, informal conversations took place with In SHAPE health mentors after interviews with participants. This provided a basis for analytical triangulation.

Participants

Participants had SMI and were enrolled in the In SHAPE health-promotion program, which

Table 1: Semi-structured interview

- 1 What did you think of the In SHAPE program? -How did you come to participate in the In SHAPE program?
- 2 What about the program was most helpful to you? -Why was this helpful?
- 3 Tell me about your relationship with your health mentor.
 - -How did your health mentor help you?
 - -What are the key ingredients to a good health mentor relationship?
- 4 Tell me how you were able to make improvements in your physical health.
 - -How did you maintain your improvements? Or
 - -What kept you from maintaining you
 - improvements?
- 5 Can you think of a special time when you were most engaged in the program?
- 6 You probably remember what you had in mind when you agreed to participate in the In SHAPE program. How did your actual experiences compare to your initial expectations?
- 7 If the program were looking for other people like you who might want to participate in the In SHAPE program, how might they find these people? –What kinds of people should they be looking for?
- 8 The way we have thought about it, the core elements of In SHAPE are (i) helping you figure out your diet and exercise needs, (ii) pairing you with a health mentor to help you along the way and (iii) celebrating your successes. Would you agree with this? What would you add or subtract?
- 9 What things do you think would ruin the program if you took them away?
- 10 What do you wish might be strengthened or built into the program?
- 11 If you were going to help improve the In SHAPE program to make it even better, what kinds of things would you want the program leaders to do?
- 12 What advice would you offer to someone entering the In SHAPE program today?

was developed at Monadnock Family Services, a community mental health center in New Hampshire and delivered in integrated community sites. This qualitative study was nested in a larger 1-year quantitative pilot study. Consistent with the AI approach, inclusion criteria for participants in this qualitative study were: (i) substantial improvement in physical health, as measured by a 10-pound weight loss or a 10-cm drop in waist circumference in the quantitative study and (ii) willingness to participate in a detailed interview. These categorical identifiers of improvement were chosen as we hoped they would represent tangible success to participants. Of the 74 In SHAPE quantitative study participants with SMI and at least one quarterly

follow-up interview, 24 had the requisite drop in weight or waist circumference. The In SHAPE health mentors evaluated the degree of each of the 24 participant's active involvement in the program. Potential ease of contacting participants was used as an additional selection criterion. Sixteen participants were deemed to have been actively involved and available for research solicitation. Eight of these participants agreed to the 1-h interview. Of these eight participants, five had achieved or maintained the required level of improvement at 12 months, two at 9 months and one at 6 months. Institutional Review Board approval was obtained from two Committees for the Protection of Human Subjects. All participants provided written informed consent prior to participating in the interview.

Analytic process

Notes were taken during the interviews and audiotapes were reviewed to identify themes (common, prominent, shared ideas). The audiotapes were then transcribed and all sensitive or identifying information was deleted. We used standard thematic analysis to analyze the transcripts. Thematic analysis is the systematic examination of text by identifying and grouping themes and coding, classifying and developing categories (Miles and Huberman, 1994; Pope and Mays, 1995). After creating broad categories based on interview notes and reviews of the audiotapes, transcripts were coded by the primary author. The second author independently examined the data before critically inspecting the first author's coding scheme. After discussion, both authors agreed on the prominence of the three themes listed in the results. This step, know as multiple coding, was performed to reduce the risk of investigator bias (Whitley and Crawford, 2005).

RESULTS

Of the eight participants interviewed, three had chronic major depression, two had bipolar disorder and three had a schizophrenia-spectrum disorder. Five participants were men and the mean participant age was 43.0 (\pm 15.3) years. All participants were Caucasian. Two participants were married, two were divorced and four were single. Four had pursued some education

beyond high school. Three participants were engaged in part-time employment. Five participants were living independently, two were living with their families and one was living in a supported setting. Participants had an average of 2.4 co-morbid medical conditions (\pm 1.4 conditions) and six of the eight were overweight or obese at the beginning of the program. The average baseline weight was 207 (\pm 45) pounds; the average baseline waist circumference was 105 (+19) cm. Improvements for this group during the 12-month quantitative study included an average maximum weight loss of 18.25 pounds (range, 56–0 pounds) and an average maximum waist circumference loss of 13.5 cm (range, 27–7 cm). All participant names used are pseudonyms.

Three main themes emerged regarding participants' views of what led to their success in the In SHAPE program. These are: (i) individualized interventions to promote engagement in the program; (ii) relationships formed in the program and (iii) enhanced self-confidence. Broadly, these themes are related in that they are all linked to participants' sense of a transformative experience. There was inevitable overlap between the three themes as they are not orthogonal.

Engagement

The engagement theme refers to factors in the In SHAPE program that facilitated participation in regular exercise and improved eating habits. Social, financial and health-care aspects of the In SHAPE program promoted engagement. Most participants reported that they had been referred to the In SHAPE program by someone on their medical or mental health treatment team. Financial support in accessing fitness facilities and residential proximity to those facilities were identified as important. Strategies that were tailored to participants' understanding of foods and nutrition and the ability to tailor the program to fluctuating medical status were also noted by successful participants.

Prompting by a primary care physician or mental health provider was the most common reason cited by participants for changing eating habits and exercising. Participants typically described a conversation with their health-care professional that facilitated their understanding of how their illness might be improved by diet and exercise. As one participant noted, participation in the In SHAPE program was seen as an alternative to medical infirmity:

The reason I was encouraged so much to join In Shape is because I have diabetes, and at that particular time they were saying if you don't straighten out you are going to be put on insulin. So that was one of the motivating factors to get me started, and I went on the exercise routine two or three days a week, plus I went on a low-carb diet ... and the pounds just came right off.

Most participants noted that open access to fitness facilities helped them engage in exercise. However, membership by itself was not typically enough to ensure that participants actually went to the gym. Some participants had free or discounted gym memberships in the past, but had not used the facilities. They cited the presence of the health mentor at the gym as a facilitating factor because it enabled them to feel comfortable going to the gym, a place they had often found intimidating in the past. Often, it was sufficiently reassuring to simply check in with a mentor upon arrival at the gym and to know that the mentor was in the building during a workout session. As one participant noted, the expectation of validation from a mentor was sometimes enough to overcome barriers to visiting a fitness facility:

... having somebody to report to...it makes me feel good to say 'Shirley, I went to the gym three times this week', and she's proud of me because I did it. That's important to me, having somebody to say I did it, I went three times this week or I went twice this week, or I increased my reps, I increased my weights you know, that's important to me.

Fitness facilities were often inaccessible if they were too far from the participant's home. Several participants described a decline in their exercise when a gym in a small town served by the community mental health center closed. Some participants were able to get exercise by walking in their neighborhoods, though many avoided doing so because they felt unsafe. Active illness was also a barrier, with most participants reporting a break in their exercise and diet routine surrounding an exacerbation of their chronic physical or mental disorders or those of a family member. Several participants described how mentors would prescribe isotonic exercises to be performed in bed when they were bed-bound. One participant described how

he maintained his connection with the In SHAPE program during a bout of depression:

I had a lot of periods I went through where I was crying and upset, but it didn't stop me. I wanted to quit everything a number a times, but I forced myself to keep going...I really don't like taking the time to exercise, but I know it is the best thing I could do for myself, and so it helps in the other areas.

Successful adaptation of healthy dietary practices, like engagement in exercise, required a combination of easily understandable suggestions and modeling. Participants often reported following simple messages from their mentors about replacing unhealthy foods with healthier alternatives. Instruction focused on expanding food choices and limiting portion size. For example, one participant seemed easily able to internalize messages about eating fruit instead of meatball sandwiches as snacks, and several others reported using smaller plates for meals at the suggestion of their health mentors. Expanding food choices usually required that participants shop or even prepare food with their health mentor. One participant reported a relationship with a health mentor that focused on expanding healthy food choices:

Trying new foods, that's very hard for me. I don't like vegetables. I like peas and asparagus you know. [My health mentor] got me to try like sweet potatoes, disgusting. She got me to try salmon, I love it. ..I love it. Oh my gosh–I sauté it in a little bit of olive oil with some garlic and oh my gosh. Same with scallops, she got me to try those. The salmon was really...I tell you it took me about 5 minutes to put that first bite in my mouth, it just looked so funky but yeah I love it...I'm going to be trying spaghetti squash this week...So you know she's like 'You've got to change your attitude woman about new foods.' She's really great.

Relationships

The theme of relationships refers to the interpersonal qualities of the In SHAPE staff that facilitated participants' commitment to the In SHAPE program. Participants often remarked on the kindness of the In SHAPE administrative staff, the support of the health mentors and relationships they formed with other In SHAPE participants. These factors seemed to facilitate success in the In SHAPE program. Participants talked as much about the relationships they formed as they did about diet and exercise changes that they made.

Many participants reported that the kindness of the In SHAPE staff was an important facet of the program. Though most participants described their health mentors as 'friends', they were quick to point out that the health mentors were different than other people in their lives, noting that they were supportive and nonstigmatizing. One participant who described a particularly good relationship with his health mentor was asked to describe the characteristics of health mentors:

Just make sure you have people that care about others, that aren't going to make them feel like they are just dust under their feet or whatever, or that they are better than other people; that doesn't go over very well, and then people don't want to come back. I know I wouldn't. It means a lot when people take the time to care and to work with you and others.

Participants reported that the mentor relationship provided direction, structure and motivation. They valued mentors' ability to listen and offer advice in areas unrelated to diet and exercise. Often, participants spoke more about the informal interactions that occurred during exercise than about the exercise itself. One participant described a mentor who was particularly skillful in weaving empathetic and reassuring conversation into an exercise routine as:

He talked to me, and he was easy to talk to, and it seemed like he was the kind of person that nothing could upset him, you know. He's been through it all, heard it all and just seemed like really calm, and I just enjoyed talking to him...he would increase the weight every once in a while on the weight machines, and he'd take me downstairs and weigh me and see if I was losing weight...he'd kind of watch me and talk a little bit...at the time I was having problems with a friend that stopped being my friend, and I was having personal problems with that. He was very helpful. He kind of helped me not to take things so seriously you know.

In some cases, participants could describe times when they exercised on their own or with a peer, but were quick to relate that they preferred the involvement of a health mentor. However, some participants reported that when mentors had to cancel an appointment at the last minute, they could get over the discomfort of exercising alone at the gym because they had already arrived expecting to see their health mentor. In suggesting ways to serve more people in the program, participants generally kept the mentor as a centerpiece:

It's a great thing once the mentors get to know the clients and once the clients get to know everything, try and set them up in small groups, you know, to each ability, you know, like you've got some people that only can walk 2 miles or 10 minutes because a lot of people I hear is 'Well we don't want to go by ourselves, we don't want to look like an idiot.' Well if there is too many clients and not enough mentors, put them into groups and let them try to decide like 'Oh let's meet here' and the mentor also needs to keep up on those groups...because you are going to need that in the beginning you know, the personal time with the mentor, because the mentor needs to be able to get to know you anyways and you've got to be able to get to know that mentor.

Self-confidence

Almost every participant commented on a positive relationship between physical improvements and mental improvements, and noted a decrease in social anxiety as exposure to integrated community settings increased. By gaining control over aspects of their health through diet and exercise, participants gained self-confidence as they developed new social skills and healthy behaviors and an enhanced sense of self-efficacy.

Many participants saw themselves in new ways after participation in the In SHAPE program. One participant, who lost 60 pounds, was asked what personal quality had allowed him to accomplish this. Out of his determination to participate in the In SHAPE program came a new self-image:

I was just determined because I saw myself as being very fat. Someone who is determined to lose the weight... Cause you see yourself as really being obese, and you don't really like yourself, so it kind of gives you an incentive to lose the weight so now I look better.

Many participants gained new confidence to approach mainstream social activities. They identified new skills not only in diet and exercise, but in forming new relationships and in negotiating environments from which they had previously felt excluded. One participant described how the In SHAPE program taught him to feel comfortable leaving his home: It helped me to get out and break down barriers I had set up for myself. I was like 'I'll never be able to get into a group of people and talk to somebody', 'I'll never go out and start working with people', 'I'll never do this...' And then that kind of builds up in a brain with schizophrenia and it showed that I could actually put on a real conversation with somebody outside the family...I could actually go out and drive here. I could actually go out, I wasn't afraid, which was cool.

Furthermore, the In SHAPE program was seen by some as an integral part of their recovery process. The integration of the exercise program into community-based gyms seemed to foster a sense of normalcy. One participant described how the gym became a safe place, opening up the possibility that other community settings could be safe and that he could live a normal life:

It was just cool when I worked out, and I broke down those barriers that I should go...Even if it was just 10 minutes at a time, it was a good 10 minutes, and then it kind of grew into a larger space and started cascading into it like into a real deal where I was actually really ok...it was like teaching you that you can be kind of weird, not weird, but you can live a normal life, and you're a good person too you know...it was just like getting out in another part of recovery, it was another part of my deal.

DISCUSSION

Given the results of prior studies on this subject, it is not surprising that participants reported that the In SHAPE program's interventions were helpful in promoting engagement in healthier lifestyles. In a cross-sectional survey of 120 mental health clients, Ussher et al. found that a majority agreed or strongly agreed that they would exercise more if they talked to an instructor or were advised to do so by their doctor (Ussher et al., 2007). Although the vast majority of these clients believed in the benefits of exercise, they had little confidence in their ability to exercise when sad or stressed and received little, if any, encouragement from family and friends. Conducting semi-structured interviews with 16 persons with SMI, Soundy et al. found a similar mismatch between high receptiveness to the idea of becoming more physically active and perceived inability to negotiate barriers to doing so (Soundy et al.,

2007). The In SHAPE program helped to capitalize on clients' interest in healthier lifestyles by providing the required support to negotiate barriers.

Prior qualitative and ethnographic work has elicited the themes of self-confidence, the importance of relationships and symptomatic improvement in exercise programs for people with mental illness and other isolating conditions. Faulkner and Sparkes studied a small group of London hostel residents with schizophrenia and found that the process of exercise, through distraction and social interaction, decreased participants' auditory hallucinations, raised their self-esteem and improved their sleep patterns and general behavior (Faulkner and Sparkes, 1999). In another report by Faulkner and Biddle, case studies were used to illustrate the value of exercise in the context of participants' lives (Faulkner and Biddle, 2004). Participant motives for engagement in exercise ranged from promoting social interaction to improving body image and were highly dependent on individual factors. While programmatic factors facilitated engagement in the In SHAPE program, there was a dialectical interpenetration between relationships, self-confidence and physical health improvements.

While this study is unique in using methods of AI to learn more about successful participation in a health-promotion program for persons with SMI, several factors limit its generalizability. The first is the small sample size. We interviewed one-third of participants who met our inclusion criteria and used non-random sampling methods to select them. Participants who were not interviewed because they were not recommended by the health mentors may have had different views about how they made their improvements. However, given that emergent themes resembled those in similar work, we feel this study adds to the existing literature on health promotion in individuals with SMI. The second major limitation is that participants were interviewed only once for 1 h. Additional themes may have emerged had we spent more time with participants. However, the commonality of responses and triangulation with the health mentors suggest that we obtained consistent results.

In conclusion, we used AI to identify important factors associated with achieving physical health improvements in the In SHAPE program. These factors appear to be particularly important in promoting long-term engagement in health behavior change, and will be used to help improve the performance and sustainability of the In SHAPE model. Key factors include relationships and self-confidence developed in the context of long-term engagement in healthy behaviors, support from health mentors and activities that were integrated into community settings. Clinical service providers wishing to implement health-promotion programs for persons with SMI should ensure that these features are incorporated into program designs. Future research should examine the best ways to do so.

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