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Persons with psychosis perceptions of participating in a lifestyle intervention

Rikard Wärdig, Margareta Bachrach-Lindström, Sally Hultsjö, Torbjörn Lindström and Anniqa Foldemo

Aims and objectives. To describe how persons with psychosis perceive participation in a lifestyle intervention, and use these perceptions to present factors to for consideration in future interventions.

Background. Metabolic syndrome is common in persons with psychosis. A healthy lifestyle is the primary option for preventing and treating metabolic syndrome, which is why the importance of lifestyle interventions has come into focus among health care professionals. Identifying perceptions of participation in a lifestyle intervention can increase the understanding of how to design future interventions.

Design. A qualitative, phenomenographic approach was selected, using semi-structured interviews.

Methods. The sample consisted of 40 participants with a psychotic disorder, who had undergone a lifestyle intervention focusing on theoretical education in healthy eating and physical activities. The interviews were conducted in 2011 and 2012, six to seven months after the intervention had been completed.

Results. The findings comprise three categories that emphasise the need for a moderate intervention level that facilitates participation and thereby social interactions among group members. The experience of success in the intervention supported the perception of oneself as a capable individual. However, it could also be the opposite, another experience of failure.

Conclusion. Content in moderation can facilitate participation, and participants can thereby achieve health benefits and find social contacts. In addition to physical activity and lifestyle habits, interventions should have a social focus and be continuous. Professional support is a prerequisite and should facilitate the participants’ ability to mirror themselves against healthy people in society by introducing activities that ordinary people do.

Relevance for clinical practice. Identifying perceptions of participation in a lifestyle intervention can increase the understanding of how to design and manage

What does this paper contribute to the wider global clinical community?

- Content in moderation should be the foundation for lifestyle interventions targeted at persons with psychosis. This can facilitate continued participation, and participants can achieve health benefits and find social contacts.
- Physical health should be a prominent theme in mental health services, and the approach should be long term, continuous, and aim for further individualisation.
- Nurses should facilitate participants’ ability to compare themselves with healthy people in society by introducing activities that people who do not suffer from psychosis do.
future interventions. This is also an aspect that is important to consider in everyday clinical practice.

Key words: lifestyle intervention, metabolic syndrome, nursing, perceptions, psychosis, qualitative method

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Introduction

Elevated waist circumference, triglycerides, blood pressure and fasting glucose, together with reduced HDL cholesterol are the elements that constitute metabolic syndrome (Alberti et al. 2009). Metabolic syndrome is common in persons with psychosis, resulting in an increased risk for premature morbidity and mortality (De Hert et al. 2011). A healthy lifestyle is the primary option for preventing and treating metabolic syndrome, which is why the importance of lifestyle interventions has come into focus (Bonfili et al. 2012, Vandyk & Baker 2012). However, there have been many dropouts in such interventions, and they have not involved major lifestyle changes for the participants (Richardson et al. 2005, Vandyk & Baker 2012).

Background

Nurses face a number of challenges in this work as persons with psychosis often prioritise their mental health over their physical health (Hultsjö & Brenner Blomqvist 2013), and are not always aware of their physical health risks (Brunero & Lamont 2010). It has also been found that nurses prioritise antipsychotic medication to reduce psychotic symptoms before physical health (Blythe & White 2012). The side effects of this medication; for instance, weight gain, are risk factors for metabolic syndrome (De Hert et al. 2011).

When working with a lifestyle intervention, a close, intimate approach that strengthens the relationship and therapeutic bond with the participant is important. This approach can promote sensitivity to individual needs. Making individual needs the starting point has proved to be important for compliance to treatment (Kinter et al. 2009, Forsberg et al. 2010). Interventions promoting a healthier lifestyle can also improve attitudes towards physical activity and affect the motivation to continue or resume previous forms of exercise (Bradshaw et al. 2010, Forsberg et al. 2010), and create hope for a better life situation (Forsberg et al. 2010).

Nursing interventions should strengthen the self-care ability in persons with psychosis. Self-care is considered essential for managing long-term illnesses (Riegel et al. 2012), but nonadherence to medical advice and mental illness can make self-care difficult. Therefore, support is required when a person has a self-care deficiency (Riegel et al. 2012). To provide suitable support, patients’ perspectives and needs have to be taken into consideration (Vandyk & Baker 2012).

Only a few other qualitative studies have addressed this patient group’s experiences of lifestyle interventions (Forsberg et al. 2010, Pearsall et al. 2014). Identifying perceptions of participation in a lifestyle intervention can increase the understanding of how to design and manage interventions in the future.

The aim of this study was to describe how persons with psychosis perceive participation in a lifestyle intervention, and use these perceptions to present factors for consideration in future interventions.

Methods

Design

A qualitative, phenomenographic approach was selected, using semi-structured interviews for data collection. Phenomenography is a suitable approach to describe varying perceptions of a phenomenon as experienced by a group of people (Sjöström & Dahlgren 2002). This methodology aims to understand the different ways phenomena are experienced in the surrounding world, describe people’s perceptions of reality and the world in which they participate. In phenomenography, this is called the second-order perspective, because the descriptions are based on the informant’s point of view, not the researcher’s point of view (Marton 1981).

Participants

All participants were patients in psychiatric outpatient care. The sample was purposeful (Patton 2002), and consisted of 40 participants who had undergone a lifestyle intervention.
Inclusion criteria were: diagnosis of psychosis (International Classification of Diseases, 2011) and established metabolic syndrome or at risk of developing metabolic syndrome (International Diabetes Federation 2006). Exclusion criteria were being in an acute psychotic state, having a personality disorder or anorexia nervosa as primary diagnosis and being addicted to alcohol and/or drugs according to ICD 10 (2011). The leaders of the intervention (health coordinators) made a subjective assessment of whether a person had the cognitive ability to assimilate the intervention.

Context

The purpose of the intervention was to promote a healthier lifestyle. It followed the compendium ‘Solutions for Wellness’, which focuses on theoretical education in healthy eating and physical activities. Smoking habits and alcohol consumption were also addressed. The intervention was based on a model inspired by cognitive therapy (Porsdal et al. 2010), and consisted of group sessions with six to eight participants under the guidance of health coordinators (HC). The latter included trained psychiatric nurses (n = 3), physiotherapists (n = 3), assistant nurses (n = 2) and occupational therapists (n = 1). All had experience of working with people with psychosis and were trained in motivational interviewing.

The intervention took place for two hours each week in outpatient psychosis departments, and consisted of either nine or 20 meetings (nine meetings n = 17, 20 meetings n = 23). A standardised study protocol was used. In the first session, individual goals were identified. The following sessions included physical activity, theory and a break where healthy snacks, such as fruits, were served. The physical activity level was gradually increased in time and intensity up to one hour, and consisted of exercise to music and walks. Although each session followed a standardised protocol, the HCs were free to find physical activities that captured the participants’ interest on the day. However, one requirement was that the activity should be of such a nature that everyone could manage it.

The theoretical part included issues related to healthy eating, based on Nordic nutrition recommendations (Becker et al. 2004), and on how to achieve well-being and health. At certain points, anthropometric measurements, biochemical markers and health-related quality of life, using EQ5-D (Dolan 1997), were measured.

The HCs phoned or sent postcards to missing participants and asked why they had not attended the meeting. The participants were encouraged to perform physical activity between group sessions. Towards the end of the intervention, there was a discussion with the participants on how they could continue to be physically active. During the intervention, the research team had regular meetings with the health coordinators to synchronise the study protocol.

Data collection

In phenomenography, semi-structured, individual interviews are the preferred method of data generation, to capture variations of perceptions (Marton & Booth 1997). All authors cooperated in the development of an interview guide, which contained questions such as; What are your perceptions of the intervention? Can you tell me what you would change or develop in the intervention concept? The questions were used together with probing questions (Patton 2002). Four pilot interviews, not included in the analysis, with former participants in a similar lifestyle intervention were held, which led to a few minor changes in the guide.

The participants gave the case manager their consent and permission to forward their names to the researchers and for the research team to contact them. Participants were then contacted by the research team and asked to participate. They received written and oral information about the study and were informed that participation was voluntary. The interviews were conducted by RW and SH in 2011 and 2012, six to seven months after the intervention had been completed. The interviews lasted 15–60 minutes and were transcribed verbatim.

There was time for conversation before and after the interview. The purpose was to make the participants feel comfortable about talking and asking questions, and to give them an opportunity to reflect on whether new issues had arisen during the interview.

Ethical considerations

The principles of written informed consent were followed. The study was approved by the Regional Ethical Committee and was performed in accordance with the Declaration of Helsinki (WMA General Assembly 2013). The declaration states that all vulnerable groups should receive specific protection, and to meet this requirement, the interviews were conducted by nurses specialised in psychiatric care.

Data analysis

The phenomenographic analysis followed Dahlgren and Fallsberg (1991). First, the transcripts were read repeatedly by RW and SH to become familiar with data. The work continued by identifying each informant’s most significant
answers that were relevant to the research question. Long answers were shortened and condensed to find key elements. Similar answers were grouped together in a preliminary classification. This was then used to make preliminary comparisons between categories to ensure that the categories were separated from each other. A description of the unique character of each category, as well as the varying perceptions within the category was made. Finally, a description of each category and how the categories are logically related to each other was made. This is presented in the outcome space, which is the main result in phenomenography (Marton & Booth 1997). The analysis was flexible, moving back and forth.

**Rigour**

There is a limited number of ways of experiencing a phenomenon within a group of people (Marton & Booth 1997). Forty participants with varying backgrounds are likely to cover these variations. To achieve credibility, quotations from the interviews are provided so that the reader can judge if the categories are relevant (Sjöström & Dahlgren 2002).

**Findings**

The participants came from two different locations in Sweden. The degree of psychiatric morbidity varied greatly. All participants who had attended at least one session were asked to participate in the interview. Thirty-five participated in more than 50% of the group meetings in the intervention. (See Table 1)

**Table 1 Clinical characteristics of the persons with psychosis at the time of inclusion in the intervention (n = 40)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Median</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 27–65 years</td>
<td>40</td>
<td>46</td>
<td>48</td>
</tr>
<tr>
<td>Women</td>
<td>19</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>15</td>
<td>37.5</td>
<td>37</td>
</tr>
<tr>
<td>Schizoaffective disorder</td>
<td>10</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td>Delusional disorder</td>
<td>3</td>
<td>7.5</td>
<td>7.5</td>
</tr>
<tr>
<td>Psychosis NOS</td>
<td>4</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Bipolar disorder</td>
<td>8</td>
<td>20</td>
<td>20</td>
</tr>
</tbody>
</table>

**The outcome space**

The outcome space comprises three related categories, with the category ‘Everything in moderation’ acting as the essential fundament (Fig. 1). Moderation was perceived to be necessary for participation. Leadership that could find content on a level that was suitable for the individual was also required, as described in ‘The HC should balance and individualise’. A moderate intervention level created opportunities for social interactions, as described in ‘Caring and comparing’, and prerequisites for a healthier lifestyle, as illustrated in ‘The continued journey’.

The category ‘Caring and comparing’ is about how the intervention gave opportunities for ‘social interplay’ and sharing experiences with each other. New friends could be essential for ‘The continued journey’. However, the participants compared their skills and level of function to each other, as described in ‘In comparisons with others’. Still, some did not value the social dimension and did therefore not perceive themselves to be a part of the social interaction, as described in ‘Caring and comparing’.

Varying perceptions of the intervention emerged and formed prerequisites for ‘The continued journey’. The category ‘With gain or pain’ explains the emotions or conditions that the participants may deal with in their continued journey. The message of the intervention was passed on to relatives and friends as described in ‘The butterfly effect’.

**Everything in moderation**

This category illustrates the importance of a moderate intervention level, without underestimating the participants’ ability. An appropriate group size was also important, so that the participants could share their experiences. The HC appeared to have a multifaceted role in balancing different needs and individualising the content.

**Content in moderation**

Everything in moderation seems to be the fundament for starting and continuing the journey towards a healthier lifestyle. The intervention was experienced as being on a moderate level, and the size of the groups encouraged the participants to talk. The combination of theoretical, physical and practical elements was helpful for increasing knowledge. Simultaneously, a picture emerges in which this

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moderation is explained; moderation enabled participation for many, but the participants themselves could manage more. However, when their own or others’ psychiatric health deteriorated, the pace of the practical and theoretical elements still made it possible to continue:

Many of us can get tired and lose concentration … When you’ve had a psychosis you work a lot with thoughts darting around inside your head.

The intervention was described as an appreciated repetition of prior knowledge as it was considered sufficiently challenging. At the same time, the need to elevate the theoretical and practical parts to a more challenging level was pointed out. The participants appreciated that the intervention did not prescribe fundamentality, as it was hard to refrain entirely from some unhealthy habits. Allowing a certain extent of some behaviour could still be perceived as meaningful and good.

Physical activity seemed to be perceived as more meaningful than thinking about the situation. However, it emerged that the participants appreciated learning about the amount of exercise that is needed to burn off various types of sweets. Other activities that were described as valuable were exercise and nutrition schedules, the use of a pedometer, and regular weight checks. The common denominator of these activities seems to be that they are concrete tools for changing behaviours. Concrete tools, given that they are perceived to be on a moderate level, overcome the discrepancy between the current situation and future goals.

It was suggested that more external actors, such as a nutritionist, would have provided new knowledge and opportunities. Participants could also see the benefit of performing more activities outside the hospital. Going to the gym or taking walks in areas of natural beauty were some ideas. It appears that the participants wanted to be active and meet people who reflect the reality outside psychiatric care:

That you are somehow released into the real world . . .

The health coordinator should balance and individualise

The HCs were significant for group functioning. Their good mood was motivating, and they could ‘maintain order in the class’. Their professional and pedagogic knowledge was manifested through acceptance of the participants’ differences, together with an ability to find individual solutions. Some described them as role models, while others perceived them as being at the centre of things:

The health coordinators were great people who made everything feel spontaneous. They were good at finding the right level for each and every one. Whenever a problem occurred, they came up with something else to do instead.

The HCs’ efforts to encourage the participants to attend the group meetings were highlighted. Phone calls and postcards telling those who had missed a class that they were wanted in the group created a feeling of genuine thoughtfulness. It seemed to be essential for the HC to further personalise the content, process and support. However, there was a duality in this request. While some would have wanted to be pushed further, others had problems with active coaching as they found it hard to resist, while they at the same time worried about injuring themselves during the activity. This could create a feeling of exclusion from those who enjoyed the active coaching. It therefore seems important to find out what the individual thinks might work:

I wish I had been pushed more, it would have been good if I could have been on Survivor on TV.

Caring and comparing

The importance of relating to others and the way social relationships affected the participants were highlighted. Caring meant that participants took responsibility for safeguarding the group members. The participants made it a point that everybody should participate on their own conditions, but compared themselves with the other group members and healthy people, who served as a point of reference for their own definition of normality. The social effect in the group inspired participants to continue the intervention.

Social interplay

The intervention was experienced as a positive event and contributed to new friendships, as a contrast to an, at times, uneventful life. Suddenly, the participants had an opportunity to do something that relieved their boredom and loneliness:

It’s good that you don’t need to be alone . . . in this hardship.

Learning to know others was described as important. This social context was valued and some described that the intervention would have suited them better had it been designed with only a social objective. Beside the benefits of these new social contacts, someone experienced it as troublesome when participants initiated contact away from the intervention:

You could say I’m a bit of a loner . . .

The participants wanted to mirror their own experiences against someone else with similar problems, and said that
this was the first time they shared their experiences of living with psychosis with nonprofessionals. Perhaps, for the first time they felt that they were being understood. It seems that by considering others they could also see themselves:

They understood … you could talk to them in a different way than with a healthy person. A healthy person doesn’t understand …

The importance of keeping each other involved was highlighted. The participants were concerned about each other’s health and became worried if someone was absent. Being part of a group was described as hard, but the social cohesion made the participants take responsibility and safeguard each other.

In comparison with others

The participants compared themselves with other group members regarding level of knowledge and mental well-being, or the ability to perform physical activities. As a result, many perceived themselves to be superior. This is manifested in their descriptions of how others could not understand the theoretical content, or did not manage the physical activities. Some experiences illustrate how participants felt upset by the others’ performance:

Half of them don’t listen. Many of them didn’t even wear that pedometer, and I always wore mine. Even when I slept I wore it. I think I was the most diligent one of us all.

Some described feeling sorry for those with a lot of problems. This reflection could create a feeling of not being equally affected, and that they themselves had resources they could cherish. There were also descriptions of how others did not reach their full potential and needed the group to acquire basic knowledge:

They don’t know potatoes should be boiled in water.

A feeling of not keeping the pace could make participants think that others worked harder. Some fought against their own feelings of inferiority. Furthermore, some of the participants argued that the intervention became a competition against themselves and the others. This was perceived as helpful for finding new habits and getting started, but it also had the opposite effect:

I felt pressured to do something, say something… that I was bad at it, that I needed to improve … It was actually quite hard.

The continued journey

Participants described that by giving them an awareness of unhealthy lifestyle habits and the insight that the mind and body are connected, the intervention had given them prerequisites for their continued journey towards a healthier lifestyle. From here, they could move on with a sense of having been taken seriously, and as people who have interesting aspects of health and lifestyle to share with their families. There could also be a sense of the opposite, another experience of failure.

With gain or pain

The participants said that they had made changes. Small changes could be motivated by being easier to adhere to over time. It appears that one new good behaviour predisposed to further improvements. The fact that the participants had been selected conveyed the image of them as being worthy of this investment. Practical consequences of these changes were better exercise capacity and perceptions of higher fat burning. The body and soul were described as being connected, and several of the participants felt happier during the intervention than in a long time:

The voices disappeared! And there was no fear, or terror, or anything.

The experience of success supported the perception of oneself as a capable and functional individual. However, everyone did not feel that they had succeeded. Another experience of failure could consolidate and strengthen a self-image of ‘I cannot succeed’: I had great expectations that I would really change my eating habits and lose weight…But that’s not what’s happened and it has made me feel really bad, because I feel that I have failed again.

In some cases, there was a general feeling that it was not worth the struggle. However, another complicating fact could be that focusing on eating habits and food increased the participants’ appetite, leading to weight gain:

I got such an appetite … They showed so many nice things to eat, and I wanted to eat all the time. That’s not good. They gave lots of advice, so I wanted to try, and that’s not good if you’re peckish.

Changing lifestyles was perceived as time-consuming, and it took time to develop motivation and awareness. Participants emphasised that physical health should be prioritised early on in the disease progression, and then be in regular focus.

The butterfly effect

The intervention had an extended effect, as participants could relay information to their families. This could form the basis for maintaining good habits as family members are often responsible for the daily cooking. This contributing
Changing lifestyle with moderation

role in the family was a way for the participants to identify themselves with something healthy. Some mentioned that their families experienced health benefits through changed habits:

Mom is good at cooking. She's got better at vegetables since I started asking her for them.

Families were described as being positive about the intervention and therefore contributed further to a healthy lifestyle. Among other things, they started doing healthy activities together, for instance going to the swimming pool, which indicates that something had happened to their self-esteem:

Heck... I would never have done that before. But I thought it's their problem, they'll have to shut their eyes if they don't like what they see.

Discussion

The aim of the study was to describe how persons with psychosis perceive participation in a lifestyle intervention, and use these perceptions to present factors for consideration in future interventions. The main findings illustrate an essential point; that moderation should guide the design and content of interventions. The importance of moderation is presented as the main argument for continuing, either in interaction with the group or alone, but still within the group. The HC had a crucial role in finding a moderate level and individualising the content. If participants perceived that these aspects were not taken into account, continued participation could be jeopardised, and feelings of hopelessness could arise. Our findings show that future interventions should be even more individualised. They should be based on the person’s wishes and ability, and include components that healthy people appreciate and thereby not underestimate the participants’ ability. To balance all this, a good leaders with a comprehensive view of psychiatry and physical health are required.

The findings show that the level covered by moderation should contain elements that participants perceive to be what 'ordinary people' do. When living with a diagnosis characterised by stigma and isolation (Lundberg et al. 2008), the quest for normality is something that health care providers should take into account. Earlier research has shown that there is a desire for normalcy among people with serious mental illness, such as wishes for normal things and experiences, and meaningful activities (Pickens 1999). Therefore, it seems reasonable that nurses should have the ability to become close and serve as a role model of ordinary people, by talking about their own choices and habits in relation to lifestyle, provided that they have a lifestyle worth aiming for.

The moderate level was highly valued. At the same time, the level of theoretical or physical activities was perceived as being too low. The argument that everyone should have the opportunity to participate was raised, but what can this further imply? Can it be explained by a desire among the participants to portray themselves as capable when facing us as interviewers (Patton 2002), or as a way to distance themselves from the others by saying 'I can manage more'? Another theory for this duality could be the fluctuating course of the disease, that moderation can be appreciated when the disease is challenging. This assumes that the HC can perform this balancing act, and that they have specific knowledge about psychosis and the ability to tailor interventions to the individual’s capacity.

A moderate level is supported by the findings of Pearsall et al. (2014). They investigated the problems that patients with serious mental illness may experience when participating in healthy living programmes by contacting those who refused participation in an intervention. Several barriers were identified, such as the presence of psychiatric symptoms, the perception that they were not in need of an intervention or that physical health did not matter to them. Taking these findings into account, an intervention that sets the bar too high could jeopardise participation.

Our findings demonstrate the importance of social relationships between group participants. Some raised the social aspect as their main reason for participation. Meeting others in similar situations has proved beneficial in psychosis when peer support has been used (Castelein et al. 2008). It should not be forgotten that some did not perceive that they were supported by the group and therefore continued by themselves, but still within the group. It is important that health care providers have the ability to identify whether a person will benefit from an individual or group intervention. Research has shown that it is sometimes better with individual interventions (Richardson et al. 2005).

Our findings show that many perceived that they had made progress in their lifestyle habits. Starting to take care of oneself appeared to result in further efforts. This brings self-care into mind. The concept of self-care has been used to a limited extent in relation to mental health, but should be considered a necessity taking into account the additional burden of somatic illness that often results from psychosis. Research has shown that psychiatric symptoms constitute barriers to self-care (El-Mallakh 2006), and make it difficult for patients to receive adequate care for their physical health (De Hert et al. 2011, Happell et al. 2011). A lack of

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Journal of Clinical Nursing, 24, 1815–1824

1821
Having two interviewers can be seen as a limitation. To minimise any associated risks, the authors discussed all interviews carefully to understand the data. The six to seven months’ interval between the intervention and the interviews raises questions about recall bias. However, we find it reasonable to conduct the interviews some time after the intervention as this allows the participants to gain some perspective of this break from everyday life.

Previous studies evaluating lifestyle interventions in this context are mostly quantitative and do not take the individual’s experiences into account (Vandyk & Baker 2012). As phenomenography aims to understand the different ways phenomena are experienced in a given context and seek for variations (Marton 1981), the chosen method contributes to a deeper understanding of lifestyle interventions for persons with psychosis.

A strength of the study is therefore that we investigated the person’s own experience. Hence, this study may provide important perspectives. In this study, all who participated to some extent in the intervention were invited. This was done to capture the perceptions that could possibly cause dropouts. It was also consistent with phenomenography as it searched for maximum variation in the participants’ profiles (Marton & Booth 1997).

Conclusion

Content in moderation should be the foundation for lifestyle interventions targeted at persons with psychosis. This can facilitate continued participation, and participants can thereby achieve health benefits and find new social contacts. In addition to physical activity and lifestyle habits, interventions should have a social focus and be continuous. The challenge for nurses is to find a moderate level that does not underestimate a person’s capacity. Support by health care providers is a prerequisite and should facilitate the participants’ ability to mirror themselves against healthy people in society.

Relevance to clinical practice

Identifying perceptions of participation in a lifestyle intervention can increase the understanding of how to design and manage future interventions. This is also an aspect that is important to consider in everyday clinical practice. Our findings support that the introduction of activities that ordinary people do underpins a feeling that ‘I am capable’. In the long run, this can fulfil the desire for a healthy lifestyle and normalcy.
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Disclosure
The authors have confirmed that all authors meet the ICMJE criteria for authorship credit (www.icmje.org/ethical_author.html), as follows: (1) substantial contributions to conception and design of, or acquisition of data or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content and (3) final approval of the version to be published.

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