

RESEARCH ARTICLE

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Changed Body Image as Perceived by Jordanian Women Undergoing Breast Cancer Treatment

Raya Yousef Alhusban*

Abstract

Background: Breast cancer is the most common cancer affecting women worldwide. The purpose of this study was to generate an understanding of women's perceptions of changes to their body image due to breast cancer treatment. **Method:** A phenomenological qualitative approach was taken and semi-structured interviews conducted with 20 women who underwent breast cancer treatment at a public hospital in Jordan. Results: Data were analyzed following Colaizzi's methodology, yielding a core theme ("Broken things cannot be repaired") and four subthemes: changes in physical wellbeing ("my body fall apart"), changes in emotional wellbeing ("broken heart"), changes in social wellbeing ("broken future"), and coping strategies ("repairing what has been broken"). Religion and family support were major factors helping the women cope with their condition. **Conclusion:** Nurses and other healthcare providers need to be aware of body image changes of women with breast cancer to initiate timely, and culturally sensitive nursing intervention and support. Therefore, nurses should support patients in finding their own sources of strength to facilitate their healing process.

Keywords: Breast cancer- body image- breast cancer treatment- phenomenology

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Introduction

Breast cancer is the most common cancer affecting women world-wide as well as second leading cause of death among Jordanian women (Jordanian National Cancer Registry (NCR), 2012). According to the NCR, there were 1008 breast cancer cases among Jordanian women in 2012, with a crude incidence rate of 32.1 per 100,000 of the female population (NCR, 2012).

Besides being a life-threatening illness, breast cancer requires treatment whose impact on the patients' body image is so intense that it can cause psychological distress and impair quality of life (Helms et al., 2008; Montazeri, 2008; Aguado Loi et al. 2013; Han and Park, 2014; Bagheri and Mazaheri, 2015; Fazzino et al., 2017). Body image is a psychological construct that captures a person's perceptions, emotions, and attitudes towards his/her own body (Cash, 2004). In oncology, changed body image is a psychological dimension of the experience of cancer, which varies according to the clinical features and phases of the disease and its effects on functioning and quality of life (Fazzino et al., 2017).

Body image may be particularly important to women treated for breast cancer due to loss of a breast, surgical scarring, alopecia, weight changes, and lymphedema (Aguado Loi et al., 2013; Rosenberg et al., 2013; Bagheri and Mazaheri, 2015; Rani et al., 2016; Fazzino et al., 2017). Tolerating changed appearance is a continuous and

complex process influenced by the type of surgery and survivorship phase of women with breast cancer (Buki et al., 2016). Buki et al., (2016) found two themes regarding Latina women's experience with body image post breast cancer treatment: (a) perception of loss and reconstruction, (b) and achieving body image acceptance.

Moreover, apparent changes in women's body image were accompanied by negative psychological consequences (Aguado Loi et al., 2013; Han and Park, 2014; Bagheri and Mazaheri, 2015). Bagheri and Mazaheri (2015) found a significant difference between female patients with breast cancer and healthy women in body image and quality of life. In addition, altered body image has been identified as a risk factor for depressive symptoms within five years of cancer diagnosis (Aguado Loi et al., 2013). Similarly, the psychological consequences of breast cancer were investigated by Luutonen et al., (2011), who showed that 32% of the participants had depressive symptoms, while 28% experienced emotional distress.

The experience of breast cancer can also seriously impact marital relations due to sexual and body image difficulties (Nasiri, et al., 2012; Wang et al., 2012). Wang et al., (2012) identified seven main themes related to sexual wellbeing among 20 Chinese women post breast cancer treatment: (1) decrease in sexual frequency, (2) lack of sexual interest, (3) menopausal symptoms, (4) body image changes, (5) effects on marital relationships, (6) misconceptions about sex, and (7) the need for

professional consultation. Similarly, Nasiri et al., (2012) conducted a grounded-theory qualitative study of 18 men in Iran after breast cancer diagnosis and treatment of their wives. Five themes emerged: sexual relationship changes, sexual avoidance, sexual abstinence, sexual restraint, and efforts to normalize the relationship.

In the Arab world, there is a scarcity of studies concerning body image and breast cancer. However, some studies indirectly studied the lived experience of women with breast cancer, including Doumit et al., (2010), Nazamili et al., (2011), Goldblatt et al., (2013), and Alqaissi and Dickerson (2010). Doumit et al., (2010) identified four core themes in the experience of Lebanese women living with breast cancer: loss, guilt, fears and uncertainty, and the need to know and share that knowledge. Similarly, Nazamili et al., (2011) explored the experiences of 17 Syrian women after chemotherapy treatment for breast cancer. They found four themes: psychological discomfort, physical problems, social dysfunction, and failure in the family role.

In summary, there is a dearth of literature concerning Arab women's perceptions of body image changes. The findings of such research would help improve nursing care for Arab women with breast cancer. Also, it is important to study body image because it influences survivors' quality of life and physical rehabilitation (Fazzino et al., 2017). Therefore, this study seeks to describe the perceptions of body image among Jordanian women undergoing breast cancer treatment.

Materials and Methods

Research design

The purpose of this study was to disclose body image changes as perceived by Jordanian women undergoing breast cancer treatment using descriptive phenomenological approach. Descriptive phenomenology is a philosophy and a research methodology that follows the tradition of Husserl (1962). This method is used to explore individuals' experience of everyday life, and the structure of this experience (Matua and Van Der Wal, 2015). This approach was used in this study to better understand the changed body image among Jordanian women so that the health care professional can attain needed knowledge to address their clients' needs.

Sample and setting

Women undergoing breast cancer treatment were purposively recruited from cancer clinics at a public hospital in Amman, Jordan, that is a reference center for many specialties including cancer care. The inclusion criteria included: (a) women over 21 years of age, (b) without evidence of psychiatric disease (the author checked the medical records and asking the health care provider about this issue), and (c) informed of their diagnosis (sometimes Jordanian physicians conceal cancer diagnoses from their clients). The adequacy of the sample size was determined by data saturation, deemed reached when no new themes emerged from the participants, so that nothing new would be added by continuing to collect data (Speziale and Carpenter,

2007). In this study, saturation was based on consensus between the researcher and an independent researcher with experience in qualitative research who volunteered to help. Twenty women participated in this study; Table 1 lists the demographic and clinical data of the participants.

Ethical considerations

The study received ethical approval from the subject hospital's Institutional Review Board. The researcher approached women who might participate in the study and provided an explanation of the study and the consent process, including the purpose, procedures (semi-structured interview and voice recording of the interview), time period, risk, and benefit. The researcher then obtained their informed consent to participate and assured them that their participation was voluntary and they had the right to withdraw from the study at any time. Confidentiality and anonymity were maintained through the use of pseudonyms, and all raw data were kept in a locked cabinet.

Data collection procedure

The investigator conducted the interviews in Arabic in a private room at the selected center. Each interview lasted from 45 minutes to one hour, and all were conducted by the main researcher. A guide list of questions developed by the researcher about the experience of body image changes following breast cancer treatment was followed (see Table 2). Participants were encouraged to talk freely and tell stories using their own words. At the end of each interview, the researcher reminded the participants about the need for a second contact via telephone to discuss the study findings and to make sure that the study findings reflected their own experiences. Interviews were tape-recorded and transcribed verbatim, then translated into English. The translations were verified through back translation and comparison with the transcribed texts by a bilingual translator.

Data analysis

Data analysis used a qualitative content approach. Transcripts of the women's descriptions of post-treatment changes to their body image were analyzed following the seven steps of Colaizzi's (1978) study: (a) Each transcript should be read and re-read in order to obtain a general sense of the whole content; (b) from the transcript, significant statements and phrases directly pertinent to the changes in body image were extracted; (c) meanings were formulated and were organized into themes illuminating commonalities of meaning across texts; (d) the formulated meanings should be sorted into categories, clusters of themes, and themes; and (e) finally, the findings were integrated into an exhaustive description of the meaning of body image change (Speziale and Carpenter, 2007). The trustworthiness and credibility of the data were established through member checking as follows. Follow-up telephone interviews were used to explore issues raised at the earlier interviews and to validate the data. Finally, the exhaustive description was returned to the participants for validation. To ensure coding reliability, two doctoral nurses analyzed each transcript alone, then

discussed the results and reached agreement.

Results

The data analysis revealed one core theme and four main subthemes. The essence of the body image phenomenon was the core theme: “Broken things cannot be repaired,” which contained changes that women experienced in their physical, emotional, and social wellbeing corresponding to sub-themes of “my body fell apart,” “broken heart,” and “broken future.” A final sub-theme concerned their strategies for coping with the changes from breast cancer and its treatment: “repairing and healing what has been broken.”

Core theme: Broken things cannot be repaired

The core theme, “Broken things cannot be repaired,” reflects the meaning that Jordanian women assigned to the impact of breast cancer and its treatment on their bodies, emotional status, and social life. This core theme means that some things cannot be repaired and denotes that after breast cancer treatment, the body will not return to its previous state; this essence was identified from the words of one of the participants, a nurse named Muna:

You try to forget this crisis [cancer], but you can't. What has been broken will never be repaired.

First subtheme: “My body falls apart”

Women in this study suffered from the physical effects of breast cancer and its treatment. The “my body falls apart” theme corresponds to physical consequences such as fatigue, vomiting, dizziness, and changed appearance due to chemotherapy treatment, such as hair loss and pale skin. These changes were articulated by Huda, aged 38 years, a mother of three working as a hairdresser:

I had many problems because of chemotherapy, and it is the most difficult period because I always have fatigue, diarrhea, vomiting, and dizziness. Also, my face always looks pale and yellowish.

During chemotherapy, women were shocked at losing their hair and ceasing to menstruate. These changes caused them to be socially isolated, as stated by Faten, aged 34, who had been diagnosed with cancer four month earlier:

I was shocked when they removed my breast, and when I experienced the hair loss and the menstrual loss. Also, I was isolated from people and there was dark skin with bruises and dark pigment under my skin. My nails even fell out!

Participants found that surgical treatment was disfiguring, leaving scars as a continuous reminder of breast cancer. They were shocked immediately after the surgery and felt the loss of a valuable part of themselves, as vividly expressed by Marah, a mother of two aged 34:

When I had the mastectomy and saw the site of the wound, I fainted. After the mastectomy I felt that I had lost something. The site of the surgery was shrunken and dry.

Second subtheme: Broken heart

The “broken heart” theme included emotional upset and altered body image. The emotional upset manifested itself as anxiety, depression, loss of control, and

hopelessness. Women also reported fear of recurrence and metastasis of their cancer and fear of death, especially when they heard that other people with cancer had died. Consequently, participants expressed feelings of loss of

Table 1. Demographic Characteristics of Sample (N = 20)

Characteristic / Category	Frequency	Percentage
Age (years)		
20–30	2	10
31–40	6	30
41–50	8	40
51–60	4	20
Marital status		
Married	17	85
Single	3	15
Diagnosis		
Medullary carcinoma	2	10
Ductal carcinoma	12	71
Glandular carcinoma	3	14.3
Adeno carcinoma	3	7
Time since learning about the diagnosis (months)		
1–12	8	42.9
12–24	8	42.9
25–48	4	14.2
Stage of disease		
I	2	7.1
II	8	42.9
III	6	28.6
IV	4	21.4
Employment status		
Employed	6	14.3
Not employed	14	85.7
Occupation		
Housewife	16	85.7
Teacher	2	7.14
Hair designer	2	7.14
Income (JD)		
100–200	10	50
201–500	7	7.14
501–1,000	3	21.4
Living with		
Spouse	14	78.6
Spouse & family	2	14.5
Relatives	4	7.1
Educational level		
Illiterate	4	14.5
Less than high school	6	28.6
High school	6	28.6
University	4	28.6
Health insurance		
Available	16	78.6
Not available	4	21.4

Table 1. Continued

Characteristic / Category	Frequency	Percentage
Treatment		
Mastectomy	12	78.6
Lumpectomy	4	7.1
Not surgically treated	2	7.1
Axial dissection	2	7.1
Taking chemotherapy	16	85.7
Not taken	4	14.3
Taking radiotherapy	14	71.4
Not taken	6	28.6

control and uncertainty about the future. They believed that their health was subject to an external power, such as God's. Mariam, a 32-year-old single woman living with her family, said:

Look, when they told me that I had cancer, my emotional state was very bad. I felt broken inside. I had depression, chronic depression. I thought that I'd never recover and there was no hope of recovery from this illness, and people thought that I was sick. I don't know what will happen to me. Cancer is known to come back again. Now I feel very upset and worried and afraid, especially when I heard that a patient with cancer had died.

Women also suffered and viewed their bodies as distorted and disfigured because of the loss of their breasts and hair. The resulting impairment of the sense of wholeness of their bodies made them more self-conscious, so that they grieved, cried, felt shocked, and were overwhelmed, as illustrated by the following quotes:

I felt dismayed for my hair because it is long and beautiful... I don't want to lose my hair... my hair is beautiful and my husband adores it so much. How shall I look without hair?

Believe me, the impact of my hair falling out was stronger than that of removing the breast because one can replace the breast with something and it's hidden, but everyone can see that you've lost your hair.

I was so upset when I found myself bald and especially when I looked in the mirror.

*You know that the breast is a matter of major importance to a woman's beauty. You see, I felt...different from other women... **My body had totally changed ... it is distorted...** I cannot stand looking at other women while my body is **disfigured**. I can no longer dress like*

*before.... I felt so bad that there was **something missing from my body**.*

Many women were dissatisfied with the appearance of their scars post mastectomy due to the side-effects of radiotherapy. These changes affected their sexual identity and they feared that changes in their appearance might damage their relationships with their husbands, who might no longer find them attractive. Participants were particularly sensitive regarding their sexual unattractiveness, as exemplified by this comment from Mariam, a 32-year-old mother of three:

I wear a scarf day and night because I'm afraid that my husband will be upset seeing me without hair, so I fear that he will leave me for another woman. He was very considerate in avoiding touching the mastectomy site, but I viewed myself as ugly and I was very nervous.

Third subtheme: Broken life

The changed appearance of women in this study affected their family life and particularly their relationships with their husbands. Participants' depressed mood was another major factor affecting this relationship, as stated by Sally, aged 32 years:

The breast cancer and mastectomy affected my relationship with my husband and for two weeks there was no sexual contact. I wore a scarf all the time and it was a very difficult period, especially when it came to my husband seeing me without breast, hair, and eyebrows, and I thought he might leave me and marry someone else.

I don't know why I've changed towards him. I don't accept him as I did in the past, before I got the disease, and he knows that I have depression because of my disease.

Other women reported concealing their real feelings of emotional distress from their children and close caregivers to protect them from emotional upset. Women also complained about having to deal with their children's reactions to the changes in their appearance, such as hair loss, as can be seen in the following transcripts:

I used to force myself to hide my feelings in front of my children. I didn't want them to see me broken, so I used to cry a lot alone. My mother was taking care of me and I used to hide my feelings. My daughter even cut her doll's hair to make it just like her mom.

Participants were worried about their uncertain future, such as raising their children. Some wanted to get pregnant again, and single women with breast cancer feared the lack of marriage opportunities, as stated by Rawan, a 34-year-old pharmacist:

Table 2. Interview Guide Questions

1. Please describe your experience with changes in your body due to breast cancer treatment.
2. Please tell me how breast cancer and its treatment have changed your body.
3. Please tell me how breast surgery has changed your appearance.
4. Please tell me how chemotherapy treatment has changed your body.
5. Can you describe your emotions regarding changes in your body due to chemotherapy or surgery?
6. Can you describe your thoughts about changes in your body due to cancer treatment?
7. Please tell me how changes in your body have affected your daily life.
8. Please tell me how changes in your body have affected your relationships with your husband, your social network, and your work.

In fact I'm afraid of thinking of tomorrow, and I'm afraid of the coming future. I don't think of marriage and just say that my God will take care of me.

A mother said:

I keep thinking of my children after my death and how I'll leave them to be raised by another woman. Whenever I think of this possibility and about myself being taken care of by another strange woman, I really find it a tough experience.

Breast cancer was perceived by some as adding a burden to their maternal role, because being sick affected their employment status and made them socially isolated. Nevertheless, some women responded by trying their best to take care of home and family despite suffering from breast cancer, as this young woman's account suggests:

I do whatever I can to take care of seven children and my house; but the disease has affected my work at the beauty shop. Due to the chemotherapy treatment, I lost all my hair, which devastated me emotionally. I was isolated and always thinking of the next dose of chemotherapy.

The social life of the participants was further affected by other people's misconceptions of the cancer diagnosis, which resulted in social stigma and pity for them, as stated below:

I felt that I was worthless and I was really bothered by the questioning and comments of other people, because they think that patients with cancer will not survive. So I was isolated from people to avoid them feeling pity for me and I refused to visit anyone to avoid seeing their pity.

Fourth subtheme: Repairing and healing what has been broken

Despite the dramatic experience of these changes, participants in this study found distinct ways to repair what had been broken through their faith in God and social support. Religion was identified first and emerged as a powerful force, as illustrated in the following quote:

I depend on my God in everything. I swear that I don't care about anything. I trust my God and I owe my hope to my God. I swear that I don't care at all, I don't think about it [cancer], because I accept God's will, and life is full of crisis.

The second common strategy used was social support especially that of the husband, which was a major factor that helped participants to restore normality. Women also acknowledged the support of their family and their relatives, as Wedad, a 34-year-old mother of three, said:

Look, my husband is very supportive of me and doesn't behave as if I look abnormal or that my appearance is not beautiful. He carries on giving me all his respect and love. "What matters is to see you healthy again," he said. He even started to love me more after the surgery and showed more respect.

Discussion

In Jordanian culture, as in many others, womanhood is bound up with a perfect body related to the symbolic breast, beautiful hair, and physical associations of being a woman. Our analysis shows that there were physical, emotional, and social changes endured by the participants.

Most participants found it difficult to deal with the physical consequences of breast cancer treatment, as represented in the "my body falls apart" subtheme. The physical side-effects of cancer treatments, such as fatigue, nausea, vomiting, breast loss, and hair loss, disturbed their body image and resulted in anxiety and isolation. These findings are similar to those of previous studies (Aguado Loi et al., 2013; Rosenberg et al., 2013; Han and Park, 2014; Buki et al., 2016; Rani et al., 2016; Fazzino et al., 2017). Furthermore, Rani et al., (2016) assessed the grade of alopecia and perceived body image changes among 60 patients undergoing chemotherapy treatment for breast cancer. Findings revealed that alopecia impacted physical appearance, coping strategies, femininity, and intimate relationships. Similarly, Choi et al., (2014) appraised the effect of chemotherapy-induced alopecia distress on body image, psychosocial well-being, and depression among 168 Korean women with breast cancer. They found that 55% of them experienced high levels of distress from alopecia and were more likely to have a poor body image. Therefore, health care providers should pay more attention to symptom management and side-effects of cancer treatment and should provide practical guidance to help patients cope with the disease. Moreover, timely and proper interventions for physical distress during breast cancer treatment would help to establish a positive body image. In addition, radiation therapy, surgery types, anxiety, depression, fatigue, weight gain, and musculoskeletal pain symptoms were all associated with more body image concerns (Rani et al., 2016).

In addition to physical problems, most of the women in this sample experienced emotional distress, as expressed in the "broken heart" subtheme. This includes fear, anxiety, depression, loss of control, and helplessness. This is consistent with previous studies (Luutonen et al., 2011; Aguado Loi et al., 2013; Han and Park, 2014; Bagheri and Mazaheri, 2015). This distress can be explained by the chronic and life-threatening nature of cancer and the traumatic experience of cancer treatment. Conversely, Rani et al., (2016) found that most participants were satisfied with their body image.

Participants used scarves, sponges, and bras to hide the loss of hair and breasts, thus avoiding body stigma. Wearing a scarf to cope with hair loss was not an issue for the participants, since they would customarily wear traditional Islamic clothing (hijab). Similarly, Esmaili et al., (2010) found that 46% of their sample used artificial breasts and other appearance modification strategies to make themselves better looking. The Jordanian healthcare system should perhaps help in providing prostheses, artificial breasts, and wigs to patients who cannot afford to buy them.

On the other hand, participants sometimes conceal their real feelings of emotional distress to protect and empower their families. A similar finding is reported by Goldblatt et al., (2013), who explain that in Arab culture the family takes precedence over individual needs. Nurses should play a major role in assessing, referring, and supporting these patients, with particular emphasis on their emotional needs.

The other changes experienced by the participants

affected their social roles and relationships with their husbands, family members, and society. These results are similar to those of Robertson (2008), who found that life events that alter one's body, such as breast cancer, can have a devastating impact on how one perceives oneself and functions in society. One of the cultural aspects of their experience was their fear of the loss of the marital relationship, because in Jordanian culture a man is allowed to marry another woman, especially if his wife is sick, which threatens any woman's position and current relationship. Therefore, nurses should incorporate sexual counseling in the nursing care of women with breast cancer and so that they can express their feelings and concerns on issues such as sexuality.

Participants adopted many strategies to heal what had been broken, the most common being faith in God and social support. Faith in God during breast cancer treatment was described as having a significant role in coping with the disease. According to Morgan et al., (2006), faith and spiritual beliefs were identified as giving a sense of purpose and meaning to life. Furthermore, Morgan et al., (2006) found that people with the strongest religious faith had the highest levels of coping. This can be explained by noting that praying and reading the Holy Qur'an are very frequent practices for Muslim in both health and illness, as the Prophet Mohammed (peace be upon him) said that "the prayer of the sick person will never be rejected, until he recovers." Healthcare personnel can use religious phrases and provide clients with religious books and appropriate places for praying.

The second most common coping strategy that participants reported using was to seek social support, which is consistent with the findings of a number of authors (Helms et al., 2008; Sheppard and Ely, 2008; Alqaissi and Dickerson, 2010; Esmaili et al., 2010). Esmaili et al., (2010) found that 36% of their sample had the support of their husbands and 47% that of their children. In Jordanian culture, Islam invites people to support each other in times of illness. Muslims are required to show empathy and console each other, because the Prophet Muhammad (may the mercy and blessing of God be upon him) said, "The parable of the believers in their mutual love and mercy is like that of a living body: If one part feels pain, the whole body suffers in sleeplessness and fever." Furthermore, God instructs men to be good to their wives and to treat them to the best of their ability, both in sickness and in health. Therefore, nurses should support patients in finding their own sources of strength, choosing and sustaining means and appropriate coping strategies to facilitate the healing process.

The changes due to breast cancer treatment experienced by the women in this study can be dealt with if discovered early. First of all, health care personnel should understand the perceptions of their clients in order to positively influence their emotions and encourage acceptance of these changes by providing culturally tailored supports. Nurses can help women to cope with these changes by preparing them through explanation, education, and counseling before starting treatment. Also, the development of psycho-educational programs for male partners may play a role in their partner's body image

acceptance. During treatment, the provision of valid and reliable tools to determine the different changes facing women with breast cancer can save time and effort and enhance timely management of these changes, thus helping to prevent further complications by early identification, referral, counseling, and support. Nurses should use evidence-based protocols to manage these patients in collaboration with other members of the healthcare team. After treatment, follow-up is needed either during clinical visits or via phone calls.

This study interviewed women undergoing breast cancer treatment to investigate their perceptions of their changed bodies. Their reported experiences were painful, although this finding cannot be generalized beyond the participants in this study. Jordanian women were in need of supportive services to provide them with information, psychological support, options for reconstruction, and focus group therapy. Culture may strongly affect the reactions to symptoms or a diagnosis of illness. In Jordan, body image concerns are considered personal and sensitive issues and women may find it difficult to negotiate body image problems with a male doctor. Therefore, nurses are in good position to assess body image and sexuality needs of those women and make appropriate referral.

The women's traumatic experience was found to be balanced by religious practices and family support, which helped them to heal what, had been broken. Nurses and other healthcare providers therefore need to be aware of these changes in the physical and psychosocial lives of women with breast cancer. They should work in multidisciplinary teams to appraise specific problems and to initiate timely nursing interventions to support affected women.

Recommendation

The findings of this study are important in helping the health care providers to better understand body image changes among women with breast cancer to provide holistic care to heal their body, spirit and mind. Therefore, nurses should support patients in finding their own sources of strength, and choosing appropriate coping strategies to facilitate the healing process. So that future research studies that examining the effectiveness of intervention such as cognitive-behavioral group therapy on the reduction of body image concern in women with breast cancer are needed. Hopefully, more research will uncover culturally sensitive interventions, and additional findings about this important issue.

Ethics approval and consent to participate

Ethics committee approval was received for this study from local ethics committee, and informed consent was obtained from patients who participated in this study.

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Conflict of interest

No conflict of interest was declared by the author.

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