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Influence of supportive care on chemotherapy patients' self-care behaviour and satisfaction: A pilot study conducted in Karachi, Pakistan

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Recommended Citation

Shams, S., Jabbar, A., Nanji, K., jan, r., Tharani, A. (2018). Influence of supportive care on chemotherapy patients' self-care behaviour and satisfaction: A pilot study conducted in Karachi, Pakistan. *Indian Journal of Cancer*, 55(1), 115-121.

Available at: https://ecommons.aku.edu/pakistan fhs son/347

Develoaded free from http://www.indianjcancer.com on Tuesday, March 5, 2019, IP: 221.132,113.69] Influence of supportive care on chemotherapy patients'

self-care behaviour and satisfaction: A pilot study conducted in Karachi, Pakistan

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Abstract

Article

BACKGROUND AND AIM: Cancer is a daunting illness affecting a vast number of people globally. During the illness trajectory, cancer patients suffer from physical and/or psychosocial issues. These physical and psychosocial issues demand conscious actions by patients to maintain their well-being. Hence, the objective of the pilot study was to evaluate the level of self-care behaviors and satisfaction in women suffering from cancer after exposure to supportive care (education and mind diversion activities) delivered via a patient help group program. **METHODS:** The study was conducted at the chemotherapy day care unit of one of the tertiary care hospitals located in Karachi, Pakistan. In this study, supportive care interventions were offered via the patient help group program over a 5-week period, and in the 6th week, data were collected. The total sample size of this pilot study was n = 17. Female cancer patients receiving weekly chemotherapy regimen and diagnosed with breast or gynecological cancers were a part of the study. Outcome variables, self-care behavior and satisfaction, were assessed via a self-developed questionnaire. Content validity index of the questionnaire was calculated on the basis of expert review and was found to be 96% for relevancy and 94% for clarity. Frequencies were calculated to evaluate outcome variables. Outcome variable satisfaction was also assessed via few open-ended questions. **RESULTS:** Participants reported moderate-to-high self-care behaviors and satisfaction after exposure to supportive care interventions delivered via the patient help group program. **CONCLUSION:** Counseling and mind diversion activities are effective in producing a positive change in chemotherapy patients' self-care behaviors and satisfaction. Therefore, oncology nurses must utilize them in chemotherapy patient care. Future studies should evaluate the effectiveness of these interventions with larger sample size and comparative analysis.

Key Words: Counseling, mind diversion activities, patient satisfaction, self-care behaviors, supportive care

Introduction

Cancer is a daunting illness affecting a vast number of people globally. The Global Burden of Cancer Statistics estimated approximately 14.1 million new cancer cases in 2012, 48% of these cases, including 54.9% of deaths, occurred in Asia. [1] Most of these cases from the Asian part of the world are with advanced disease presentation. [2] Therefore, they require intense treatment with combined modalities such as surgery, chemotherapy, and radiation therapy. Among three treatment approaches, chemotherapy because of its systemic nature of treatment, results in numerous physical and psychosocial concerns.

Various studies on women suffering from breast and gynecological cancers have highlighted inadequate support offered by health-care professionals in fulfilling their physical and/or psychosocial needs.[3-5] Cancer patients' multifaceted concerns related to the physical, practical, psychological, and spiritual aspect of life are termed as supportive needs.^[5] The Canadian Association of Psychosocial Oncology has emphasized that every cancer patient must receive supportive care for these multidimensional needs that arise during the illness trajectory. [6] Addressing the multifaceted care needs of women following cancer diagnosis, and during the chemotherapy phase of treatment, would result in better physical and affective symptoms control, less chemotherapy-related complications, [7] and improved quality of life.[8] In addition, it would result in less interruption in

the treatment schedule and enhance patients' satisfaction with the provided care. [4]

A large body of literature has highlighted the role of self-care behaviors in managing chemotherapy-related symptoms. [9,10] Self-care behaviors are deliberate self-care actions initiated by a person during times of illness. It is defined as "a human regulatory function that is a deliberate action... needed for continued life, growth and development, and maintenance of human integrity."[11]

Cancer patients commonly utilize pharmacological and nonpharmacological strategies to promote self-care and to avert effects of symptoms' disruption produced as a sequelae to chemotherapy treatment and cancer diagnosis. [12,13] The National Center for Complementary and Integrative Medicine has termed these diverse sets of nonpharmacological approaches that are used simultaneously to supplement conventional medical treatment as complementary therapies. [14] Common complementary therapies utilized by patients includes diet, exercise, rest, sleep, lifestyle modifications, prayer, meditation, television watching, interpersonal communication, reading, and others. [15] Various studies have observed elevated self-care in patients following utilization of these strategies. [16-18]

To improve participants' self-care initiatives and their satisfaction with care, supportive care was offered in this study via counseling and mind-body interventions – termed

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How to cite this article: Shams S, Jabbar AA, Nanji K, Jan R, Tharani A. Influence of supportive care on chemotherapy patients' self-care behaviour and satisfaction: A pilot study conducted in Karachi, Pakistan. Indian J Cancer 2018;55:115-21.

Access this article online

Quick Response Code:



Website:
www.indianjcancer.com

DOI:
10.4103/ijc.IJC_621_17

as patient help group program. Participants were provided with routine hospital care by the unit assigned staff, while the nurse investigator was responsible for providing supportive care on a weekly basis for 5 consecutive weeks. Participants were provided with supportive care during their admission to the chemotherapy day care unit during their routine visit. Hence, none of the participants were asked to make special visit to the unit for supportive care. Topics covered in the counseling sessions were information regarding cancer, chemotherapy, and its physical and psychosocial side effects management strategies. In psychosocial counseling, participants were made aware of ways or strategies that can enhance their psychosocial well-being; for instance, express your feelings, try to focus on positive things in life, keep up with your regular grooming habits, and others. Mind diversion activities offered in the patient help group program included television watching (comedy movies), guided imagination, and spiritual practices (prayer and slide show of natural scenes). Supportive care was delivered through group therapy approach.

Earlier studies in Pakistan focused on breast cancer patients' education on physiological side effect of chemotherapy and offered emotional support to patients, as needed.[19,20] Literature affirms that the management of physiological symptoms with cancer and chemotherapy are highly considered whereas psychological symptoms and elements of sexual well-being are often missed out. Hence, this pilot study is unique as it provided structured supportive care which comprises physical and psychosocial counseling along with mind diversion activities to further improve psychological and emotional well-being of women with breast and gynecological cancer under chemotherapy treatment in Pakistan. Hence, the purpose of this study was to evaluate the level of self-care behavior and satisfaction level of chemotherapy patients when offered supportive care. Following research question was formulated to achieve the desired study aim:

What is the level of self-care behaviors and satisfaction reported by participants after attending patient help group program?

Methods

The study was conducted from February 2015 to May 2015 at one of the private hospitals located in Karachi, Pakistan. Before the commencement of the study, approval was taken from the Ethical Review Committee of the Aga Khan University Hospital (3355-SON-ERC-14). Informed written consent was obtained from all the study participants. Consecutive sampling technique was employed for participants' recruitment. Therefore, all eligible participants were recruited during the specific recruitment period of over 2 weeks. [21] Eligibility criteria of the study were, women under weekly chemotherapy treatment, will be receiving chemotherapy for at least six consecutive week in selected study setting, aware of diagnosis, and willing to participate. Most study participants were at initial cycles of chemotherapy and had

received 2–4 cycles at the time of joining the patient help group program [Graph 1].

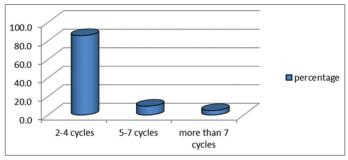
Sample size was calculated using the following assumptions; because this is the first study from Pakistan, the proportion of self-care behaviors and patient satisfaction from supportive group was considered to be 50% (for maximum variance) along with 95% confidence level and an error of 5%. The total sample size was calculated to be 385. However, because this was a pilot study, 5% of the total sample size, i.e., $385 \times 5/100 = 19$ study participants, was planned to be recruited.

Outcome variable of the study was the initiation of self-care behaviors among participants and their level of satisfaction with the supportive care which were delivered via the patient help group program. Outcome was evaluated at the terminal point from the participants (n = 17) once they had attended the patient help group program. Supportive care was offered for a 5-week period. However, each participant had to attend one session per week. In the 6th week, data were collected. Through consecutive sampling technique, initially, 28 women were screened for eligibility; out of these 28, 25 met the inclusion criteria. However, four refused to participate in the study. Hence, 21 women were enrolled in the study. However, over a 6-week period, the sample size reduced to 17. Specific reasons for dropout were uncomfortable with group therapy approach and treatment hold because of refractory disease.

A questionnaire was developed after thorough literature search. It was further independently reviewed by three oncologists and one psychologist. This questionnaire was used to assess outcome variables, self-care behaviors, and satisfaction. Both the outcome variables were jointly assessed on a single questionnaire. Overall, the questionnaire contained four parts. Part I comprised 31 questions, out of which 16 questions were related to self-care behaviors and 15 were related to outcome variable satisfaction. A Likert scale ranging from 1 (agree) to 4 (not applicable) was used to obtain participants' responses on Part I of the questionnaire.

Part II of the questionnaire evaluated the effectiveness of each counseling session separately. There were six questions in this section. Likert scale ranging from 1 (agree) to 3 (disagree) was used for Part II responses.

Part III of the questionnaire assessed how much each one of the mind diversion activities was admired by the



Graph 1: Number of chemotherapy cycles participants had before enrollment in study

participants. During the program, four mind diversion activities were offered to the study participants. A rating scale ranging from 1 (satisfactory) to 5 (excellent) was used to obtain responses for this section of the questionnaire. Part IV of the questionnaire took participants' subjective viewpoints about the patient help group program. Five questions were asked in this section.

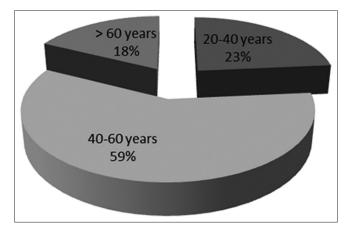
The content validity index of the tool was calculated on the basis of expert review, and the figures obtained were 96% and 94% for relevancy and clarity, respectively. Validity of the questionnaires was evaluated through rating of relevancy and clarity of each question by expert reviewers on Likert scale. Each expert reviewed every question and marked it on a scale of 1-4 (4 being highly relevant/highly clear, 1 being not relevant/not clear). After these, ranking the sum of each question was calculated and those with <50% were deleted, and the final tool had 43 items. Subsequently, the tool was pilot tested on 10% of the total sample size as well as on nonpatients. Pilot testing was done on nonpatients because the questionnaire was based on the assumption that the participants had undergone the program. Pilot testing of the tool (Urdu version) helped in the identification of linguistic shortcomings.

Quantitative data analysis was done through the Statistical Package of Social Sciences version 19.0 (Armonk, NY: IBM Corp). Descriptive statistics were applied to analyze the demographic and clinical information of the participants. Frequency and proportion were calculated for the outcome variables, self-care behaviors, and patient satisfaction.

Results

Twenty-one participants were recruited, out of which four participants dropped out during the study, yielding a response rate of 81%. The final data analysis was done on 17 study participants. The main reason for dropout was being uncomfortable with the group therapy approach and treatment on hold due to refractory disease.

Most study participants were married, in their middle ages [Graph 2], lived in nuclear family system, and spoke Urdu. Female cancer patients diagnosed with breast and gynecological cancer patients receiving weekly chemotherapy at least for 6 weeks were part of the study. With respect to the clinical profile of the study participants, the



Graph 2: Age distribution of study participants

majority of the participants were with the diagnosis of breast cancer [Graph 3], and almost half were receiving neoadjuvant chemotherapy. The majority of the participants were either at Stage II, III, or IV of the disease. More than half had no comorbid illnesses such as diabetes and hypertension.

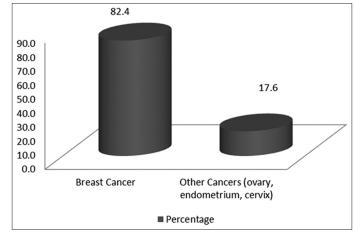
Need assessment was done along with demographic and clinical characteristic assessment. Almost all (95.2%) participants received information about the physical side effects of chemotherapy. Approximately 45% reported that they had received information about the physical side effects of chemotherapy from both the health-care professionals (doctors and nurses). In relation to psychological counseling, 52.4% shared that they had received brief counseling.

Likert scale was used to evaluate self-care behaviors and satisfaction of participants with the patient help group program. For most questions related to self-care behaviors, a positive response was received from the participants, as shown in Table 1. Two questions (Q20 and Q25) had multiple responses. For these, maximum responses were received for Q20.1 and Q25.2.

The remaining questions in Part I of the questionnaire assessed the participants' satisfaction with the patient help group program as presented in Table 2. Almost all were satisfied with the program, as depicted with the higher frequencies for positive stems and disagree responses for negative stem questions.

Part II of the questionnaire assessed the effectiveness of each counseling session in terms of knowledge enhancement and helpfulness in daily life, as presented in Table 3. For all three counseling sessions, the highest number of responses were received for the agree category. Psychological counseling was highly appreciated by the participants compared to the other two counseling sessions. On the contrary, the participant viewed sexual counseling session as least helpful in comparison to the other two counseling sessions.

Part III of the questionnaire evaluated the degree to which each individual mind diversion activity was liked by the study participants, as shown in Table 4. The degree to



Graph 3: Site of cancer

Table 1: Participants' self-care behavior scores	A = = = = (0/)	Nautual is (0/)	Discours of (0()	Not applicable = (0/)
Statements		Neutral, n (%)	Disagree, n (%)	Not applicable, n (%)
Q10. Program helped you to better manage your physical symptoms such as: Nausea/Vomiting	17(100)	_	-	-
Q10.1. Diarrhea	16(94.1)	_	1(5.9)	
Q10.2. Lack of appetite	13(76.4)	_	2(11.8)	2(11.8)
Q10.3. Body ache	16(94.1)	1(5.9)	_	
Q10.4. Joint Pain	13(82.3)	1(5.9)	2(11.8)	
Q10.5. Headache	14(82.3)	3(17.6)	_	
Q10.6. Numbness or tingling in fingers	13(76.4)	2(11.8)	_	2(11.8)
$\ensuremath{Q} \ensuremath{11}.$ You have become physically active after attending the patient help group program	14 (82.4)	1 (5.9)	1 (5.9)	1 (5.9)
Q12. Participation in household activities has increased	10 (58.8)	2 (11.8)	5 (29.4)	-
Q13. Program has positively influenced your life	14 (82.4)	2 (11.8)	1 (5.9)	-
Q14. Helped in accepting the disease and its treatment	16 (94.1)	1 (5.9)	-	-
Q15. Helped in controlling worrying thoughts	16 (94.1)	1 (5.9)	-	-
Q16. Empowered you in controlling low moods	14 (82.4)	3 (17.6)	-	-
Q17. Positively changed your outlook toward life	16 (94.1)	1 (5.9)	_	
Q18. Interest toward life has increased	13 (76.5)	3 (17.6)	1 (5.9)	
Q19. Helped in redefining priorities of life	16 (94.1)	_	1 (5.9)	
Q20. Do you take time out to indulge in activities/tasks that please you: Each day	2 (11.8)	-	15 (88.2)	-
Q20.1. 1-2 times in a week	12 (70.6)	-	5 (29.4)	-
Q20.2. 2-3 times in a week	2 (11.8)	-	15 (88.2)	-
Q21. Program has assisted in alleviating feelings of powerlessness	6 (35.3)	3 (17.6)	3 (17.6)	5 (29.4)
Q22. Program has helped in reducing feelings of hopelessness	6 (35.3)	4 (23.5)	1 (5.9)	6 (35.3)
Q23. After attending the program, have you worked to improve your physical appearance?	13(76.5)	1 (5.9)	2(11.8)	1 (5.9)
Q25. Counseling and mind diversion activities were helpful in keeping you relaxed after hospitalization? For a day	1 (5.9)	-	16 (94.1)	-
Q25.1. For a week	6 (35.3)	-	11 (64.7)	-
Q25.2. More than a week	10 (58.8)	-	7 (41.2)	-
Q26. Have you practiced positive coping strategies learned during the weekly sessions in your daily life?	12 (70.6)	4 (23.5)	1 (5.9)	-

⁻ No response received for the given category

Questions	Agree (n)	Neutral (n)	Disagree (n)
Q1. The patient help group program increased knowledge related to disease, treatment, and other practical issues	15	2	-
Q2. Felt any problems while talking to a nurse	-	-	17
Q3. Information was presented in an understandable manner	17	-	-
Q4. Time allocated for each activity was appropriate	17	-	-
Q5. Opportunities were provided to express yourself	17	-	-
Q6. Opportunities for questioning were not provided	-	1	16
Q7. Program has met your expectations	16	1	-
Q8. Practical suggestions were offered to deal with medical/physical issues	17	-	-
Q9. Practical suggestions were offered to deal with psychosocial issues	17	-	-
Q24. Program was helpful in reducing your stress and anxiety with regard to chemotherapy treatment and hospitalization	16	1	-
Q27. It was a relatively better experience of hospitalization than previous hospital admissions	17	-	-
Q28. Presence of other patients with similar life situations was helpful (<i>n</i> =12)	12	-	-
Q29. Being part of a patient help group program has caused inconvenience during your stay at the unit	-	1	16
Q30. Will you join a similar program in the future?	14	2	1

⁻ No response received for the given category

Q31. Overall, your satisfaction with the program

which it was liked was analyzed through categories such as fair, good, very good, and excellent. Prayer received the highest score (82.4%). Guided imagination and natural

Table 2: Participants' satisfaction with the patient help group

scenes slideshow ranked second; both received equal scores of 58.8%. Comedy movies were least appreciated by the participants (35.3%).

Part IV of the questionnaire comprised open-ended questions, assessing the subjective viewpoint of participants about the patient help group program, counseling sessions, and mind diversion activities. Frequencies were calculated for responses to three questions (Q40, Q41, and Q42). Even when checked subjectively, the participants highly appreciated psychological counseling. Similarly, prayer received the highest score of 52.9%. Guided imagination remained the second (35.3%) and outweighed the natural scene movie (11.8%). The third open-ended question was related to suggestions for improvements; 88.2% of the participants provided no suggestions.

Q39 and Q43 were analyzed qualitatively. When the participants were asked about the best element of the patient help group program, the following categories emerged. Participants appreciated communication (verbal and nonverbal) skills and coordinating role of the investigator. Moreover, they liked the comprehensiveness of the program and found it comforting. Participants also regarded the program as an opportunity for ventilating their feelings and found it emotionally supportive. Some of the participants mentioned that the program was informative and improved their physical and psychological health. One of the participants said that it was a new experience.

Q43 provided an opportunity to the participants to ask questions that had not been addressed during the program or those that the participants would like to discuss further. Most participants did not ask questions. However, those who asked wanted to know their prognosis, recovery, and further treatment.

Discussion

For most questions related to self-care, the participants' response was positive. This study finding is consistent with the existing literature on self-care behavior in chemotherapy

Table 3: Patient perception regarding effectiveness of counseling sessions

Counseling session	Agree (%)	Neutral (%)	Disagree (%)
Physical symptoms			
Q32. Increased knowledge	14 (82.4)	2 (11.8)	1 (5.9)
Q32.1. Helpful	13 (76.5)	3 (17.6)	1 (5.9)
Psychological			
Q33. Increased knowledge	15 (88.2)	2 (11.8)	-
Q33.1. Helpful	15 (88.2)	2 (11.8)	-
Sexual health			
Q34. Increased knowledge	13 (76.5)	2 (11.8)	2 (11.8)
Q34.1. Helpful	9 (52.9)	3 (17.6)	5 (29.4)

⁻ No response received

patients. [17-18,22] However, mixed responses were received for alleviating the feeling of powerlessness and hopelessness. It could be because of the religious beliefs of the study participants; as in Islam, the feeling of hopelessness or despondence is considered as a lack of trust in Allah's mercy. The said belief could have been the reason of participants' mixed feelings of being hopeful. In addition, a previous study conducted among Pakistani women suffering from breast cancer also reported an optimistic attitude of Muslim women toward breast cancer. [23] This affirms the association of religious belief in shaping participants' perceptions toward terminal diseases.

Similar to the self-care behavior, participants gave a high rating for the satisfaction outcome. This study finding concurs with previous studies. Likewise, participants rated counseling sessions highly in terms of knowledge enhancement and helpfulness in practical life, except for the sexual health counseling session, which received the lowest score for practical helpfulness. The reason for this could be participants' lack of understanding of the term sexual health. Studies conducted on health-care professionals have also reported a lack of understanding of the term sexual health as the term is interchangeably used with sexual functioning and dysfunction. However, in the current study, sexual health was viewed broadly, which includes sexual self-concept, sexual relationship, and sexual functioning. [26]

To further evaluate participants' satisfaction with the patient help group program, their views were sought about each mind diversion activity (comedy movie, natural scenes movie, guided imagination, and prayer) on a Likert scale. Prayer received the highest score, whereas comedy movie received the lowest rating. This study finding coincides with the findings of studies conducted among other Muslim patients, in which the participants reported observing religious practices as an important source of coping during the illness trajectory.^[3,27]

A possible reason for why comedy movie was less appreciated by the participants could be that conversational activities are preferred more in the Eastern culture^[16] compared to the Western culture, where people like television watching, listening to music, and reading activities more.^[28] Moreover, the conduciveness of the environment and the higher concentration demand in movie watching might have undermined its effect.

Participants were also provided with the opportunity to comment on various aspects of the patient help group program. Most patients gave positive responses about the supportive care interventions and the principal investigator's role, and their comments were consistent with the published literature regarding nurse–patient relationship in cancer care.^[29]

Mind diversion activity	Fair, n (%)	Good, n (%)	Very good, n (%)	Excellent, n (%)
Q35. Comedy movie	3 (17.6)	5 (29.4)	3 (17.6)	6 (35.4)
Q36. Natural scene slide show	2 (11.8)	4 (23.5)	1 (5.9)	10 (58.8)
Q37. Guided imagination	-	3 (17.6)	4 (23.5)	10 (58.8)
Q38. Prayer	-	-	3 (17.6)	14 (82.4)

⁻⁼No response received

Strengths and limitations of the study

This study offered comprehensive care via physical and psychosocial counseling and mind diversion activities to female cancer patients undergoing chemotherapy. Benefits of this study are not limited to patients but have also illuminated the role of a nurse, within a multidisciplinary team, as a significant contributor in improving cancer patients' well-being. Only women with breast and gynecological cancers receiving weekly chemotherapy were part of the study. This limits generalizing the study findings to women receiving chemotherapy treatment on shorter or longer duration and with other cancer types. Moreover, participants were exposed to supportive care for 5 weeks, and then in the 6th week, data were collected for outcome variables, which might have resulted in recall bias. Moreover, principal investigator herself applied supportive care interventions and collected data because of logistic reasons. Therefore, there are chances for researcher-led biases. Small sample size and one-point data collections are other limitations of this study. The responses on the questionnaire were taken on a three-item scale, which can be converted to a five-point Likert scale to avoid bias.

Conclusion and Recommendations

Self-care behavior initiatives by cancer patients hold potential of averting physical and psychosocial distress caused by cancer diagnosis and chemotherapy and in turn improve their quality of life. Patients require knowledge and self-commitment for these behavior initiatives. Therefore, health-care professionals can play a crucial role in providing knowledge to cancer patients about these strategies. Moreover, increased utilization of these approaches in nursing care and reinforcement of these approaches by the health-care team can further influence patient utilization of these self-care strategies in daily life. The study findings have clearly highlighted the significance for psychological counseling of cancer patients. The study has also highlighted the benefits of an advanced role that oncology nurses can perform in health-care settings such as patient care coordinators, case managers, and nurse navigators, as well as the benefits of these roles in patient care. Finally, cancer patients undergo different phases during illness trajectory starting from diagnosis to treatment and to recovery or survivorship phase. Each one of it gives rise to unique challenges and supportive needs. Hence, cancer patients entering in survivorship phase still require health-care professional support. Therefore, further studies on cancer survivors can explore their distinctive needs and offer support to them. Future studies in similar context with large sample size are required to support the findings of the current study.

Acknowledgment

We would like to acknowledge the nursing and medical staff of Aga Khan University Hospital, chemotherapy day care unit, for their co-operation during the research work. We are also grateful to study participants; without their support and cooperation this study would not have been possible. Moreover, we are thankful to Aga Khan University school of Nursing and Midwifery for funding the study.

Financial support and sponsorship

We would like to acknowledge Aga Khan University School of Nursing and Midwifery for funding the study.

Conflicts of interest

There are no conflicts of interest.

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