Saudi female university employee self-determination in their own health-related issues

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Received: December 14, 2017
Accepted: March 11, 2018
Online Published: March 20, 2018
DOI: 10.5430/jnep.v8n8p12
URL: https://doi.org/10.5430/jnep.v8n8p12

ABSTRACT

Introduction: To date, there have been no studies located investigating Saudi women’s self-determination in their own health-related issues. This study aims to investigate how women in Saudi Arabia see their ability and willingness to decision making in this matter.

Methodology: The study design is ethnonursing and Leininger’s Sunrise model was utilized as background theory; qualitative data analysis method was used. 12 Saudi women worked at a large University in Saudi Arabia were interviewed in-depth.

Results and discussion: Seven universal Saudi Arabian cultural themes were identified: customs and traditions, women’s decision-making denied, shared decision-making, informed women and empowerment rise, financial status matters, emerging changes in the society, and impact from the Western world.

Conclusions: One of the major findings in the interviews was that all research participants observed themselves as more independent and empowered than in the accounts reflecting other women they knew. They saw other women, whom they met at the hospital or who were their friends or relatives, were without equal rights for independent decision making. Mainly, men are interested in reproductive health and are willing to dominate women’s independent decision making in healthcare. The main conclusion, according to this study, the Saudi women research participants who are educated, are more independent in their health-related decision making than the previous literature suggested. The result may be different in villages and among less educated women and their husbands.

Key Words: Saudi women, Self-determination, Health, Ethnonursing, Leininger, Sunrise model

1. INTRODUCTION

The world is facing new challenges in the Muslim societies that have gradually emerged in the research; and one of those challenges is women’s self-determination. The status for self-determination in the modern era and the challenging issues for gender equality in the Muslim world require more academic research. The importance of this study stems from the lack of research studies related to Saudi women’s self-determination in relation to their own health. The study aims to reveal the existence, importance, and manifestations of this issue. This study also aims to investigate how women in Saudi Arabia view their ability and willingness for decision making about health-related issues in practice. The importance of this study is that nurses and other healthcare professionals will be better informed about the women’s ability and willingness to make autonomous decisions about their own health-related issues.

According to the present published documents, although lacking academic research, there is an assumption that women in Saudi Arabia, who are almost all Muslims, do not have
full rights to healthcare and cannot provide consent for their own medical treatment or medical procedures. In the published articles, although somewhat outdated, the discussion is usually on rights, whereas in this study, the discussion will focus on Saudi women’s ability and willingness to make healthcare decisions for themselves. Walker[1] reported that officials regularly request permission from the woman’s legal guardian, even when it is not mandatory or stipulated under the government guidelines. In the Patient’s Bill of Rights and Responsibilities in Saudi Arabia,[2] it is clearly stipulated that patients should be able to make informed choices. In addition, it states that the legal guardian, who is responsible for the patient by law or religion, is entitled to sign on his/her behalf when he/she is incapable of acting in his/her own interests due to infancy, incapacity or disability.[2] However, the legal rights of a woman are ignored in Saudi hospitals, where healthcare workers require a guardian’s permission before women are admitted or allowed to consent to medical procedures for themselves or their children. A guardian may also be consulted before the woman is discharged, despite the fact there are national regulations to the contrary.[1]

According to Al-Amoudi,[3] the misconception of Saudi women’s full rights to health exists not only in Western countries, but unfortunately, also among Saudi women themselves and, more importantly, among some healthcare providers in the Kingdom of Saudi Arabia. This is a very important issue in health care because enhancing patients’ personal autonomy will empower and help them to make meaningful decisions.[4]

However, it must be taken into consideration that in Muslim countries, families play a major role in medical decisions. The patient must listen to the opinion of close family members about the treatment he or she is going to accept.[5]

1.1 Literature review
The first literature review of this study was conducted using keywords such as Saudi women, human rights, self-determination, female autonomy, autonomy, female autonomy in Islam, female empowerment, human rights, right to health, decision making in health care, and individual freedom, ethics, and Islamic ethics. The second literature review was conducted using method keywords such as ethnography in nursing and ethnonursing. The King Saud Abdul Aziz University for Health Sciences Medical library, as well as the Finnish National Library and Helsinki University Library for Health Sciences in Finland, were utilized. The literature review was conducted between October 2012 and September 2016, and the years between 1992 and 2016 were included. The databases that were used were EbscoCINAHL, ScienceDirect Research, ScienceDirect Nursing, OvidMedline, Medic, PsycLit (psychology), Eric (education) and PubMed Humanities. Additionally, certain Arabic newspapers, such as Arab News, Saudi Gazette, and Al Arabiya News, were consulted to get a clearer picture of the present study problem. The first literature review yielded 3 peer-reviewed articles discussing women’s status in Saudi Arabia. In addition, 10 articles on women’s autonomous decision making in healthcare were reviewed. These came from various countries. Three articles from the Arabic newspapers were also retrieved. Furthermore, four other articles discussing the general civil right issues in Saudi Arabia also referred to women’s rights. From the library, one book of Muslim women’s self-determination and two books of Islamic ethics were utilized.

1.2 Self-determination and autonomy
If secular Western bioethics can be described as rights-based, with a strong emphasis on individual rights, Islamic bioethics is based on duties and obligations (e.g., to preserve life and seek treatment), although rights (of God, the community, and the individual) do feature in bioethics, as does a call to virtue.[5]

Islamic bioethics is an extension of Shari’ah (Islamic law), which is itself based on 2 foundations: The Qur’an, the holy book of all Muslims, whose basic impulse is to release the greatest amount possible of the creative moral impulse,[5] and is itself “a healing and a mercy to those who believe”, and the Sunna, which are the aspects of Islamic law based on the Prophet Muhammad’s words or acts.[5] Several authors have claimed that the roots of Western bioethics principles are clearly identifiable in Islamic teachings. However, there are some differences in the applications of these principles.[5]

Van Bommel[6] stated: “For a Muslim patient, absolute autonomy is very rare, there will be a feeling of responsibility towards God, and he or she lives in social coherence, in which influences how the relatives play their roles”. Consequently, Personal choices are only accepted if they are the “right” ones.[6] However, Hammami et al.[7] concluded in their survey study with 488 Saudi patients (both male and female) that their results showed a strong sense of individual autonomy orientation, a strong sense of self-efficacy, and reduced trust in the healthcare system. However, Marrone,[8] argued that Saudi women usually will defer to their husband’s or father’s decision making.

The Permanent Committee (PC) for Issuing Religious Edicts restricting women’s role, rights and freedoms in the Kingdom of Saudi Arabia[9] has an effect on this issue. As a conclusion, it looks like women in Saudi Arabia have been seen as a group of persons who have been deemed non-autonomous because of their social role, which means that they are re-
quired to fulfil certain criteria in line with their religious and cultural constraints.

1.3 Informed consent
Informed consent is also related to autonomy. If a patient has enough information, she or he can make informed choices. According to Jamjoom et al.,[10] Kingdom of Saudi Arabia surgeons tend to view informed consent not only as an ethical and legal obligation but also as a benefit to patients. However, the Saudi Arabia surgeons are more likely to adopt a paternalistic attitude in informing patients and felt that information about harmful risks may dissuade their patients from undergoing the operation.[10] They admit that the amount of information they give is related to patient characteristics such as age, gender, level of education and social class. In this study, it was not mentioned how gender affected the physician’s information-giving.

Abolfotouh and Adlan[11] investigated the quality of informed consent for invasive procedures in Saudi Arabia, and in their cross-sectional study, they concluded that patients are not aware of their rights or that physician paternalism is practised in Saudi Arabia. They suggest that further studies should focus on how the value of autonomy can be appreciated in Saudi culture. This study also aims to address Abolfotouh’s and Adlan’s[11] study recommendation.

2. Materials and methods
2.1 Study design
The study design, called ethnonursing, is derived from ethnography. Ethnography aims to describe the cultural phenomena. One of the goals of ethnography is to make explicit what is implicit within a culture and especially in aiming to investigate non-Western cultures (Streubert and Carpenter[12]).

Ethnonursing, according to its founder M. Leininger,[13] is the study and analysis of the local indigenous people’s viewpoints, values, beliefs, and practices. The primary function of Leininger’s[13] approach to ethnography is to focus on nursing and related health phenomena.

2.2 Sunrise Model: a conceptual research enabler
In general, the Sunrise Model is an invaluable guide to discovering new knowledge or to confirming knowledge of cultural informants. The researchers decided to use female individuals as research participants. The three overlapping circles in the Leininger’s[14] Sunrise Model (see Figure 1) illustrate three different care perspectives, but the aim at this stage is to explore and reveal the Muslim women’s perceptions and associated practices.

Figure 1. Leininger’s Sunrise Model (Leininger and McFarlane[14])

2.3 Ethnonursing
Ethnonursing has been used for many decades in many nursing research studies as a theory and as a research design. The second literature review was conducted in February 2013 and March 2016 by using the keywords ethnonursing and research and by utilizing CINAHL. This search yielded 35 nursing studies altogether in which the people’s actions, world views and opinions were understood through the cultural phenomena affecting their daily living. The conclusion was that these studies provided evidence that the ethnonursing study design was applicable for this current study.

2.4 Study objectives
The qualitative ethnonursing approach derived from ethnography and the utilization of Leininger’s Sunrise Model was used to describe how Saudi female university employees feel they are able or willing to decide their own health-related issues.

2.5 Data handling
Population and sample
Ethnonursing requires two categories of participants,[13] namely, key informants that are Muslim Saudi women working in female colleges. Interviews were held on
university premises. To obtain these informants, the snowball technique was used, which means that one informant found another[12]. The search for research participants continued until the researcher felt the saturation point was met. In qualitative research, saturation means that the data show redundancy, meaning that no new information is emerging.[15]

In the study, 9 key informants and 3 general informants were interviewed. The key informants had personal experiences with their own self-determination in health-related issues. The other category of research participants was general informants who were also Saudis but described the phenomenon under investigation as a general issue and not as personal experience. It was understood that female patients in a healthcare setting may be in a vulnerable position and, therefore, may be unable to express their free will, and subsequently, the female patients within healthcare institutions are excluded.

A purposive sample was used and, therefore, information-rich individuals were needed. The study sample was biased because the interviewees were young (23-38 years old), and 10 of 12 research participants had a bachelor’s degree. Four research participants were single and 8 were married. None of the research participants lived within extended families.

Research participant inclusion criteria were that the interviewees had experience in using healthcare services in Saudi Arabia, they were adults (not less than 18 but not those whose safety and ethical protection could not be assured), they were able to understand the consent form and they were willing to participate voluntarily.

2.6 Data collection

The themes for the semi-structured interviews have been derived from the existing literature. The most suitable units for this study were the whole interviews of Saudi women’s accounts. Interviews conducted in Arabic or in English depended on the research participant’s ability to express herself better in either of the languages. All interviews were tape-recorded and transcribed, those conducted in Arabic first into Arabic and then translated into English by the researchers. Both researchers had been living and working in Saudi Arabia for several years, and one of the researchers was Muslim and from the Middle-East.

2.7 Ethical considerations

Ethical issues are related to the protection of research participants as persons and to the protection of the data they have revealed and other persons involved in their stories. In-depth interviewing offers great advantages, but it also entails certain risks and dangers as well as distinct ethical considerations. Information shared by female research participants will inevitably involve participants’ personal feelings and reflections as well as their perceptions of others, for instance, research participants’ family members.[16] Therefore, the interviews were conducted by experienced faculty members who had been trained to conduct sensitive interviews.

The ethical approval was obtained from the Scientific Committee the King Saud Bin Abdulaziz University, College of Nursing Jeddah, Saudi Arabia.

2.8 Data analysis

The inductive content analysis was used to analyse the interview transcripts to gain in-depth knowledge of the topic under investigation.

All interviews were tape-recorded and transcribed, first into Arabic and then translated into English by the researchers. All interviews were first read question by question, and then the emerging meaning units of the texts were identified for further analysis. For clarification, Graneheim and Lundman[17] considered a meaning unit as words, sentences or paragraphs containing aspects related to each other through their content and context of the research questions.

As a summary of data analysis, it also followed Leininger’s[13] phases:

1. collecting, describing and documenting raw data;
2. identification and categorization of excerptors and components;
3. pattern and contextual analyses; and
4. major themes, research findings, theoretical formulations, and recommendations.

2.9 Trustworthiness

According to Lincoln and Guba[18] (in Siegle[19]), valid inquiry in any sphere must:

1. demonstrate its truth value,
2. provide the basis for applying it, and
3. allow for external judgements to be made about the consistency of its procedures and the neutrality of its findings or decisions.

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<th>Table 1. Trustworthiness in research[19]</th>
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<td>Construct</td>
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Credibility refers to the direct sources of evidence or information from the people within their environmental contexts of their truths, which are held firmly as believable to them.[20]
Transferability refers to whether the findings from a completed study have similar (not necessarily identical) meanings and relevance to be transferred to another similar situation, context, or culture. Dependability means reliability and is demonstrated if the research processes follow accepted standards as described in the chosen analysis method. The dependability of this study was assured by strictly following the etnonursing research procedure.

2.10 Validity and reliability in this study in summary
The validity of the study method and data collection instrument has been tested in previous studies, and feedback for the relevance of the method and instrument was sought from the Scientific Committee members in the College of Nursing, Jeddah.

The reliability of the study was assured by strictly following the etnonursing research procedure, and both interviewers and data analysis investigators were properly trained for data collection. All interviews were tape-recorded and translations were conducted by experts in both Arabic and English languages, and all data were analysed by the experienced researchers themselves, including a Muslim member, to avoid personal biased views.

3. DISCUSSION OF RESEARCH FINDINGS’ MAJOR THEMES
In this section, the findings are presented. Seven universal Saudi Arabian cultural themes were identified in this research study when analysing the data obtained from key informants (KI) and general informants (GI). Saudi cultural values seemed to be strongly influenced by Islam.

3.1 Customs and traditions
Customs and traditions strongly affected the norms within people, which are expected to be used to perform their daily activities and, more importantly, their interaction with other members in the society. A very strong statement that shows how deeply the cultural values are rooted in women was given by one woman:

“Women often shy away in our society, especially with the local norms, customs and traditions, and particularly the Bedouins; for instance, the man would not be pleased with his wife to go to the male doctor. He considers it shame and dishonour that his wife is exposed to a male doctor. Yes, I feel here in Saudi Arabia women cannot make decisions. Women grow with the shame.” (KI)

This is a very strong statement and shows how deeply the cultural values are rooted in women if they have to ‘grow’ with the shame. It must be difficult to get over this kind of obstacle, which is shadowing all womanhood. Another woman said,

“Men grow to the responsibility of their mother, wife, and sisters, and they feel that this is a heavy issue because they have to decide for someone who is valuable to them. However, in general, they (men) are happy with that because they have grown to that, and women will wait for someone else to make my decision because my culture told me to do it this way.” (GI)

This statement again shows that women in Saudi Arabia may also find it easier to give the decision-making power to someone else. Men, husbands, have also been educated to decide for their wives, and men may also be struggling with this issue but again have accepted the situation. This quote shows that some women have adopted their role to follow the cultural norms and do not see it as a problem.

“We have people here in Saudi Arabia who have negative thoughts indicating that a Saudi woman does not understand, which makes her not able to make a decision, and therefore, this is why he has to make the decision about her life. The concept among Saudi men (not all of them) is that Saudi women’s minds are short (deficient with no effective brain), and therefore, she is unable to make decisions, and he will make the decision for her even if the decision was a life and death decision.” (KI)

This quote shows how women can be seen as even intellectually inferior to men. This may be seen as a strong statement of underestimating the women in Saudi Arabia, yet many women have academic degrees and are working in demanding jobs.

3.2 Women’s decision making denied
In the following quotes, the research participants described how husbands have taken or have been given the power to make decisions over their wives. Additionally, it must be noted that the healthcare personnel feel obliged to follow the cultural norms and not question their husband’s authority.

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then decides on her behalf. Sometimes women do not want to make the decisions, and they are accustomed to that.” (KI)

It can be understood that healthcare personnel find themselves between legislation and traditional pressure and, therefore, find it easier to follow tradition and let others decide for women.

“I have always taken my husband’s approval of laboratory tests I take. Even though I am educated, but this applies to all women in Saudi Arabia, meaning if my husband says no, I would never go. However, if the matter is important and he insists the rejection I would go without his knowing.” (KI)

Here, we can see that sometimes women do take the decision into their own hands, but they must do it secretly.

Are women in Saudi Arabia able to take contraceptives without their husbands’ knowledge? One woman states,

“No, they are not; if they do that, it will be a huge, huge issue if the husband finds out that his wife is taking contraceptives behind his back because they (men) always seek children. However, I have a friend that is taking contraceptives without her husband’s knowledge because she has a baby, and she is studying and cannot meet those responsibilities of another baby.” (GI)

As we can see, the responsibility of reproductive health is seen to be the husband’s prerogative, whereas in Western societies, reproductive health is a shared responsibility, and women can decide how their bodies are used for this purpose.

3.3 Shared decision making

Women felt they needed to have shared in the decision, as one woman put it,

“Sometimes, the woman benefits when she hears other people’s experiences, especially when she does not have enough education and awareness, and then, if she is hit by the disease, the family will make the decision on her and her children’s behalf and decide to take her to the operation.” (KI)

In many paternalistic societies, the family plays big role in the decision making for a woman. This is seen as in the best interests of an individual. This is also a matter discussed in the Western world when patients are recommended to discuss medical treatment matters with their next of kin.

3.4 Informed women and empowerment rise

The legislation related to healthcare and the bill of patient rights in Saudi Arabia are giving women the right to decide their own health-related issues. The only difference from the similar documents in Western world is the clause related to reproductive health: “The conscious adult woman has the right to give consent to any medical interventions that are related to her, including surgical operations, except for what is related to reproduction, such as the use of family planning methods, hysterectomy or other procedures. In such procedures, the acceptance of the husband must be obtained too. In emergency and life-threatening conditions, the woman’s consent is sufficient”[21] See also the Decision of the Supreme Council of Ulama (Sharia Scholars): Decision Number 93.[21] This was expressed in some women’s statements,

“The healthcare personnel do know the legislation, and we (healthcare personnel) tell the women that they can decide, but the women prefer the culture. The men want to be dominant, and women are not aware of their rights.” (GI)

In the following statement, the research participant said that some women are finding information about their rights and are more independent.

“Everyone became aware of their rights even in the villages (my aunt drives a car and cultivates land in a village). Women became aware of their rights. Here, one important thing that gives women power is to know their rights. To take full rights, women have to understand that as long as I have got the education and my degree and I have confidence in myself, and I have my work and my pocket is full as the man, here thanks to Allah, I can have my house (family), and I can spend on my children, and I can live my life without a man. If the woman knew this thing, she could make a man respect her and cannot hit or beat her and see that the woman is weak and tell himself I’m in control of her. If she knew these things, her problems will be resolved.” (KI)

This account makes a statement that women’s independent decision making could be resolved only by increasing awareness among women when the bigger picture of the results clearly show cultural underpinnings. However, some of the informants observed themselves as very independent.
3.5 Financial matters

“Saudi women are capable to make decisions with respect to their own health, but I can say that everyone is not able to do so; some husbands want to know about her health. Her husband can affect her decisions about a surgery if the surgery is expensive and he cannot afford it or if he wants to see if the problem is serious. Financial independence is important because then women will have more control over their decisions.” (KI)

Financial issues arise in these quotes, and it somehow shows the status of a woman in a family as an investment; however, if the Saudi woman is financially independent, she has more opportunities, even to take care of her own health. The experience of lack of money can also be a factor to opt for independence,

“When my mother married my father, she wanted to continue her education; she was very interested in chemistry and physics, but my father stopped her right there: you are pregnant, and you stay at home, and there is not such vocation suitable for ladies. My father died when I was seven years old, and we ended up with no money. My eldest sister worked so hard and supported the whole family of 8 people.” (GI)

3.6 Emerging changes in society

The following quotes are very positive expressions of the rise of a new generation in Saudi Arabia who want to take their lives and health in their own hands.

“Women are getting more independent. Ten years ago, women were not allowed to do anything. She was restricted at home, to cook and clean, wash and so on. Now we have our own drivers, we have our own cars and our own jobs. We can reach out and not get married without getting ashamed. However, previously it was a huge shame, but now we can see families who are supported by their daughters.” (GI)

“The new generation now believes in contraceptives and family planning, and we see them in the clinics, and they are happy with 2 babies because they are then financially able to take care of them. I see now many new generation ladies in their twenties and they say ‘I have my first baby and that is enough now’ and will have the second one later on.” (GI)

3.7 Impact from the Western world

Many of the Saudi women, in the study of Lefdahl-Davis and Perrone-McGovern, reported being changed by their time of study in the United States and reported increased confidence, independence, intellectual growth, and acceptance of others as some of the results of their academic sojourn. Additionally, the research participants who themselves had studied or travelled in Western countries see a brighter future for independence among Saudi women; yet, they see the changes as very slow and wonder how they are still in the situation that many women, after all, cannot decide for themselves.

“I have also observed that students and people who go abroad to study and come back with another culture (Western) will think about family planning and how to raise children well and not just fulfilling basic needs.” (GI)

Another woman explained,

“I see that the cultural changes get to us very slowly. I mean people in other places have developed a lot over the time and for long time, while here in our country, Saudi Arabia, they develop in a very, very slow manner. I do not speak for all Saudis, but for a large proportion of them.” (KI)

Here, again, the research participants felt that even though the changes in women’s independence are rising, they are still restricted by local values, and the families are afraid of local opinion over their women that can negatively affect all family members, even the younger generation’s marriage prospects.

“The society is changing, and I believe that the scholarships that went abroad out of Saudi Arabia during the past ten years and more have changed their thinking and culture and will change the current generation completely. Our grandmothers could not make decisions and when they get sick, their husbands decide whether to take them to the doctor or not. The men feel that they are more aware and can make the best judgement and not because it is a dictatorship.” (KI)

“The media plays a big role even for the lower classes that are uneducated; they can see and hear news of new treatments and so on. My grandmother, who cannot read or write, follows the TV programmes and teaches herself about
health-related issues” (KI). Social media is acknowledged for some of the changes, “There has been cultural openness through the Internet and Twitter, and we have more than the limited information we had before. We can read other people’s opinions.” (KI)

The interesting discussions with Saudi women as informants shed a light on this important question under investigation, and showed that some women see a future of more independent, bright women,

“Therefore, I believe that people in Saudi Arabia are more open, and the problem is that people abroad in the West believe that women in Saudi Arabia do not have rights, but it is the contrary: women in Saudi Arabia are opened up and know their rights and obligations fully.” (KI)

4. CONCLUSION AND RECOMMENDATION
One of the major findings in the interviews was that all research participants observed themselves as more independent and empowered than in the accounts reflecting the other women they knew without equal rights for independent decision making, whom they met at the hospital or who were their friends or relatives. This result was expected in general informants’ accounts, but the same result also emerged in key informants’ accounts. Mainly, regarding women’s independent decision making in health, men are interested in reproductive health and are willing to dominate. Clearly, women in this research study were educated and wanted to make a statement of independence. The main conclusion is that, according to this study, where the research participants were all educated, the Saudi women are more independent in their health-related decision making than the previous literature suggested. The result may be different in villages and among less educated women and their husbands. We need to acknowledge that the family members involved in shared decision making are also a resource to women. We do not know whether the future of Saudi women will give them more degrees of freedom in their own decision making or whether the restrictions and discrimination towards women will increase. The most serious assumption in research participants’ accounts is that women are sometimes seen as intellectually inferior to men. Maybe the Western cultures and more moderate Islamic cultures are affecting the mind-set in Saudi Arabia, which may not please everyone in Saudi Arabia. It should be acknowledged that concepts of self-determination and autonomy are sometimes used interchangeably in the literature. Generally, they are all related to individual decision making. In this study, the concepts are strongly bound to informed consent in healthcare, although female patients in a healthcare setting have not been investigated. One of the missing aspects of the results was that the research participants, Saudi women, did not stress religious aspects in their own decision making. All participants referred to modern secular media or health professionals to find help with their own decision making in health-related issues.

The main suggestion for future investigation of this topic is to interview Saudi women who live in rural areas and are not educated. The female patients within healthcare settings might be approached as research participants since the phenomenon is now better understood. The research topic is sensitive in Saudi culture among Muslim women. The recommendation to nursing practices is that nurses who work in clinical settings should try their best to involve female patients in their own decision making. The recommendation to nursing education is to place women’s rights issues on the agenda in every course specification. Lastly, the recommendation to nursing management is that nurse managers at all levels in healthcare should ensure that their practitioners are aware of women’s rights. This study served to make the Ministry of Health’s memorandum of women’s rights more widely known among Saudi women and healthcare workers in the Kingdom of Saudi Arabia, and they will all be better informed on how self-determination is viewed and applied; this understanding will promote culturally congruent care.

CONFLICTS OF INTEREST DISCLOSURE
The authors declare that there is no conflict of interest.

REFERENCES


