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Cultural and Religious Barriers Influencing the Participation of Women in Research: A Study from Jordan

Zeinab Al subeh, MPharm, PharmD*, Karem Alzoubi, PhD

Department of Clinical Pharmacy, Faculty of Pharmacy, Jordan University of Science and Technology, Irbid, Jordan

Abstract

Objective.—To assess the general attitude toward women's participation in research studies in Jordan and determine the various cultural and religious issues that could impact the rate of inclusion of Arab and Muslim women in research studies.

Methods.—A descriptive cross-sectional questionnaire-based survey study was conducted among Jordanian university students using a 17-item opinion questionnaire.

Results.—A total of 1265 students from different professional disciplines completed the questionnaire. The majority of the respondents (69.1%) believed that females in Jordan do not have the full autonomy to make their decision to participate in research studies. Study findings also showed that females are more likely to avoid the participation in research studies that require staying outside home or involve direct interaction between researcher and study participants. Females would prefer to deal with female research assistants when participating in research studies.

Conclusion.—More efforts are required to encourage and enhance the rate of participation in research studies among women in Jordan and, probably, other Middle Eastern societies. When designing and conducting research studies in these countries, researchers should seriously consider the cultural and religious beliefs.

Keywords

Women; research studies; attitude; Students; Jordan

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*Corresponding Author: Zeinab Al Subeh, MPharm, PharmD Lecturer, Clinical Pharmacy Department Faculty of Pharmacy, Jordan University of Science and Technology, P.O. Box3030 Irbid, Jordan., zyalsubeh14@ph.just.edu.jo, zynabalsobh@gmail.com Tel: +962779467523; Fax: + 962 (0) 2 7095123.

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INTRODUCTION

There have been several concerns surrounding the inclusion of women in research studies. Participation in clinical investigations was limited primarily to men rather than women (Mastroianni, Faden et al. 1994, Kwiatkowski, Coe et al. 2013). Treatment of women based on a scientific evidence that were generated from clinical studies based on men subjects leads to suboptimal treatment for women (Beauchamp and Childress 2016, Vitale, Fini et al. 2017). The importance of inclusion of women in research studies has been recognized because of the health issues, diseases, and risk factors that differ between men and women (Bird and Rieker 1999, van der Graaf, van der Zande et al. 2018). In fact, the inclusion of both genders is necessary to enhance the universal application of research outcomes on the general population and to produce valid knowledge on women's health and diseases (ACOG 2015, National Institutes of Health 2015). Moreover, equal representation of both men and women in research studies is important to achieve the principle of justice, which is highlighted by all declarations related to research on human subjects (Panel on Research Ethics 2014, Electronic Code of Federal Regulations 2018).

Several changes in research practices and designs have been made to increase the representation of women in research studies. Among these is the establishment of National Institutes of Health (NIH) Office of Research on Women's Health (ORWH), which was found in 1990 for several purposes among them was to enhance the systematic and consistent inclusion of women in NIH-supported clinical research (Blehar, Clayton et al. 2013). The ORWH began efforts to focus attention on the need to increase the inclusion of pregnant women in research (Blehar, Clayton et al. 2013). In 1993, the NIH required women to be involved in all federally funded clinical studies, unless inappropriate to do so (Mastroianni, Faden et al. 1994). Newly revised NIH grant application and review instructions required applicants to address consideration of sex as a biological variable in the research strategy section of the application. Strong justification is required from researchers planning to study only one sex (National Institutes of Health 2015). Today, more than half of participants in NIH-supported clinical trials are women (Schweinhart and Clayton 2018). Despite these advances, the inclusion of women in research studies is still a problematic issue in the United States and other countries (National Institutes of Health 2015). There is a gap in knowledge of women's health when observing the mortality rate and life expectancy of women compared to men over the past few years. From 1985 to 2010, there was a significant increase in men's life expectancy in 95% of US counties, while women's life expectancy has either remained the same or decreased in 45% of the counties (Wang, Schumacher et al. 2013). Schweinhart had discussed in her paper that factors of sex, gender, race, and ethnicity intersect and change across stages of women life. She stressed the importance of effective communication between clinicians, researchers, and policy makers to ensure that the multidimensional aspects of women's lives are considered appropriately to raise the bar for women's health (Schweinhart and Clayton 2018). To do so, more representation of women in clinical research is vital. Researchers should put more effort in identifying the barriers and obstacles that could prevent women from participating in research trials. Issues related to pregnancy, fetus protection, contraception requirement, and lack of child care have been reported in previous studies as barriers against women

participation in research (Stevens and Pletsch 2002, Blehar, Clayton et al. 2013, Phelan, Kunselman et al. 2016, Rubin 2018).

In Arab countries, including Jordan, there are additional cultural and religious considerations that could negatively impact the inclusion rate of women in clinical trials and their participation in other research studies. For example, Muslim women are required by religion to cover their entire body, except face and hands, and men other than their first-degree relatives are neither allowed to observe nor touch any part of their body. A woman can refuse to participate in a research study if she has to deal with male researchers, particularly when the research requires withdrawing a blood sample or performing a physical examination. Furthermore, most Arab women try to avoid discussing sensitive topics, such as those related to menstrual cycle or sexual intercourse, with male individuals. Some habits, like smoking cigarettes or exercising in public areas, are not socially acceptable for women in many Arab communities (Islam and Johnson 2003). Obviously, there is a real need for researchers in these regions to adequately address such barriers and challenges towards the participation of women in research studies. New approaches and practices should also be developed to ensure adequate representation of women in research conducted in Arab countries. In this survey-based study, different cultural and religious issues associated with Jordanian population that could limit the participation of women in research studies were investigated. The results of this study can help researchers in this area achieve effective representation of women in their research in a manner that adopts cultural and religious beliefs of the population.

METHODS

This study was a descriptive cross-sectional questionnaire-based survey. A 17-item opinion questionnaire was specifically designed through a multi-step process to best achieve the objectives of the study. The questionnaire was used to explore the opinion of students at Jordan University of Science and Technology from both genders regarding the inclusion of women in research investigations. As the available information on this literature topic is limited, the initial draft of the questionnaire was developed based on the customs and traditions that were most common in Jordan. A panel of researchers with expertise in research ethic and responsible conduct of research performed a content validation of the developed questionnaire. The questionnaire was then piloted among some participants to assess its clarity and comprehension. Several modifications to the questionnaire items and overall language were applied at different stages of development before the final version emerged. The questionnaire was developed in Arabic, the native language for population of Jordan.

All questionnaire items were close-ended and fell under three main sections: (1) socio-demographic and professional characteristics (7 items); (2) students' opinions towards the participation of women in research studies (6 items); (3) the general attitudes of students toward major issues related to the participation of women in research studies (4 items).

This questionnaire was distributed in a paper-based version along with a consent form, as it was the most convenient method to enhance the response rate. Well-trained research

assistants invited the undergraduate students to participate in this study by visiting popular areas at the Jordan University of Science and Technology (JUST) campus at different times per day between May 29 and July 18, 2017. We targeted the JUST population in this study, as JUST hosts more than 20,000 undergraduate students who come from all Jordanian cities. The questionnaire was completely anonymous, and the consent forms of the participants could not be linked to their respective responses attached to the questionnaire. The ethical compliance of the study was approved by the Institutional Review Board at JUST.

The Statistical Package for Social Sciences, version 22 (IBM SPSS® Statistics for Windows; IBM Corp, Armonk, New York, USA) was utilized for the analysis of collected data. Frequencies and percentages were predominantly used to present and summarize the data generated through this study. Inferential statistics and chi-square test were utilized to identify significant differences between male and female respondents. *P* value of less than 0.05 indicated statistical significance.

RESULTS

Students from different professional disciplines at JUST ($n=1265$) filled out the questionnaire. Most of the respondents were female (79.8%), single (96.9%), Jordanian (91.1%), Muslim (96.8%) students with age that ranges between 18–25 years (98.5%) as shown in Table 1. Table 2 shows the students' distribution based on their majors and academic year. Students with a major in healthcare were more interested in participating in this study than those in non-healthcare majors (68.9% vs. 31.1%, respectively). Although the inferential statistics were not shown in Table 1 and 2, no statistically significant differences were found between the responses of male and female students.

Half of the respondents had the chance to participate in research studies (53.1%). An interesting finding of this study is that most women in Jordan did not have full autonomy in making their decision to participate in research studies. According to students' responses, most women have to obtain the approval of another family member in order to participate in research studies; this family member was reported to be the father (30.9%), the mother (17.2%), the husband (14.2%), or the brother (4.2%). Only 30.8% of respondents believed that women could make their own independent decision to participate in research studies without referring to another family member. In this regard, some differences in responses were found according to students' gender. For example, requiring the approval to participate in research studies from the woman's husband or woman's brother was reported as significantly higher among male students compared to female students (43.8% vs. 15.9%; $p < 0.001$ for husband, and 12.1% vs. 5.0%; $p < 0.001$ for brother), while those who believed that it is a personal decision for a woman to participate in research study were reported as significantly higher from female students than male students (48.0% vs. 41.0%; $p < 0.046$).

When exploring the students' opinion regarding women participation in research studies, more than half thought that women in Jordan prefer to deal with female research assistants (RA) when the study requires measuring vital signs, drawing blood samples, conducting interviews to discuss sensitive or general topics, administration of IV or IM medications, performing clinical examination, or having cigarette or waterpipe smoking experimental

sessions. Significantly more male students believed that women prefer to deal with female research assistants when the study involves drawing of blood samples or filling a general questionnaire. Moreover, the highest percent of students believed that women are less likely to participate in studies that require staying outside the home (57.9%), performing physical exercise (45.8%) or smoking in non-private room at a research center (42.2%; Table 3). Again, inferential analysis showed that male students were more restrictive, as a higher percent of male students believed that women are more likely to decline to participate in research studies that require direct contact with participants, conducting interviews, or filling questionnaires.

Another issue was found concerning is studies that require participants to stay outside the home overnight. The largest proportion of respondents said that women are more likely to refuse to participate in such kinds of studies (64.8%). In cases women agreed to participate, the hospital was the most preferred place to conduct these studies. Interestingly, the majority of respondents (84.1%) agreed that it is a common practice among researchers in Jordan to respect the privacy of women when drawing blood samples, giving injections or performing clinical examination as shown in Table 4. The largest proportion of participants also agreed that researchers in Jordan usually hire female RAs when the research involves women participants; there was no significant difference between of male's and female's responses. Regarding the participants' right to decide whether they would like to deal with a male or female RA, 84.1% of respondents supported this right with a significantly more support from female compared to male students (85.2% vs. 79.3%; $p=0.004$; Table 4). Finally, only 22.3% of respondents disagreed that women in Jordanian society have the freedom to decide to participate in research studies, and the percentage of male students who disagreed to this statement was significantly higher than the percentage of female students (31.3% vs. 20.0%; $p<0.001$).

DISCUSSION

Recruitment of study participants to meet the required sample size is always a major challenge when conducting a human research study. Successful recruitment begins with learning about the study population and identifying barriers that will most likely be issues for members of that population. The cultural background of the study population can influence recruitment approach, particularly when trying to recruit women to participate in research studies. Researchers' awareness of cultural and social barriers to participation is essential.

Findings of this study showed that a large proportion of participants agreed that women in Jordan generally tend to avoid the participation in research studies that require direct contact with participants or discussion of sensitive issues, and in case of participation, they would prefer to deal with female research assistants. This could be attributed to various reasons. First, the religious beliefs of Jordanian population, where women are expected to avoid the direct contact with males other than their first-degree relatives unless necessary. Second, women in Middle Eastern societies usually prefer to deal with females rather than males. Finally, Middle Eastern Arab men do not usually allow women in their family to be in direct contact with other foreign men. This could justify the significant differences between

responses of female and male participants. Male participants who believed that women are more likely to refuse to participate in studies that involve direct contact with participants were significantly higher than female ones. It was previously reported that Arab Muslim mothers would not feel comfortable being alone with men and answering their research-related questions (Aroian, Katz et al. 2006, Purnell 2013). It was also suggested that women and minorities were less likely to trust researchers, which can lead to lower participation rate in research studies (National Institutes of Health 2015). Therefore, hiring research assistants and data collectors who are able to establish personal and culturally appropriate relationships with study participants is important in gaining their trust. This was reported as the most recommended strategy to successfully recruit Arab Muslim mothers in research studies (Aroian, Katz et al. 2006).

Students believe that women in Jordanian society could not make their own decision to participate in research studies without obtaining the permission of another family member. Although we used the general term of “research studies” in the questionnaire upon the investigation of this concern, we believe that the opinion of the respondents is more related to participation in clinical studies than in survey-based studies as all respondents filled out our questionnaire without obtaining the permission of any of their family members. People in Jordan, as in most Islamic Arab countries, have their own norms and beliefs that should be respected by researchers when conducting research studies. Strong family relationships usually exist between family members in Jordan. Younger family members are required to respect older family members, while elders are required to protect younger family members. Culturally, it is the responsibility of male family members to protect and take care of female family members. The head of the household, which is usually the father or the husband, is responsible for taking care of his mother, wife, and daughters. Middle Eastern men are typically the heads of households and dictate what behaviors and activities are permissible for their wives and children. It has become part of the culture for women to consult the head of the household before making important decisions in their life, such as marriage, applying for job, or even staying outside the home. That could explain why most participants (69.2%) believed that women in Jordan could not participate in research studies without obtaining the approval of the head of the household. Study findings suggest that special attention should be considered in studies involving female participants conducted in Jordan. It is worth mentioning that significantly more male than female students reported that women have to obtain the permission of the husband or the brother, which could indicate that males in Jordan expect women in their family to obtain their permission before participating in research studies. A similar result was previously reported in Egypt, where 90% of Egyptian men agreed that men should have the final word about decision in the home (El Feki, Heilman et al. 2017). In Qatar, some women preferred to consult their husbands when deciding whether to participate in an interview-based study (Killawi, Thurston et al. 2014). The high refusal rate among Hispanic women to participate in clinical research studies was attributed to some husbands forbidding their wives to participate (Daunt 2003, Martin, Negron et al. 2013). Although the institutional review board (IRB) requires researchers to obtain a consent form from each participant, the researchers might need to seek the consent of the husband, father, or brother when they try to recruit women to participate in clinical research studies.

Another issue that could be common among Jordanian families is that it is generally not acceptable for women to stay outside their homes in the absence of a reasonable cause. Otherwise, the woman and her family would be stigmatized. However, one acceptable reason for a woman to stay outside the home is to get admitted to hospital to receive treatment. That could explain why the largest portion of respondents considered the hospital as the most convenient place to conduct research studies. Although some may argue that participation in a clinical study is a reasonable cause for woman to stay outside home, most of the Jordanian population may not be fully aware of the importance of clinical research and participation in clinical studies because it is not a common practice for them.

According to study findings, women in Jordanian society generally prefer to deal with female research assistants when participating in research studies. This could be attributed to religious and cultural reasons. Researchers are highly encouraged to put more effort in facilitating the participation of women in research studies by respecting the norms and traditions of the specific population. Researchers who are not familiar with the cultural norms are highly encouraged to seriously consider the barriers discussed in this study to enhance the rate of women participation in research.

The majority of the student respondents were young Jordanian and Muslim students, which could allow them to be a representative sample population at JUST because the demographic characteristics are similar. JUST is now hosting more than 20,000 undergraduate students in 42 different undergraduate programs, and it is considered one of the region's leading universities in Jordan and Arab countries. The large population of JUST students and its wide diversity make it a good target in this survey-based study. Obviously, the percentage of female participation was higher than male participation, which could be attributed to the nature of this study that focuses on a female-related issue. It also reflects the actual percentage of female and male students at JUST, which is about 75% and 25%, respectively.

Study findings add significant value to current literature, as very limited studies were conducted in this field. Yet, this study has some limitations. One of them is the number of students who participated in this study, which is 1265 students, while JUST involves more than 20,000 students. However, the number of participants exceeded the minimum effective sample size required to represent the large population of students. The generalizability of findings should be handled with caution inside and outside Jordan, and further investigation is required to identify the general practice of researchers in the Middle East while conducting research studies that involve female participants. Other limitation were the sampling of students population, and the fact that the questionnaire used was a 17-item questionnaire, only 10 of which were directed towards perceptions, other were demographics. Future studies are recommended to avoid such limitations via sampling general population and the development of a more comprehensive questionnaire, which should be largely based on the results of the current study.

PUBLIC POLICY IMPLICATIONS

The findings of this study signify the need for developing an integrated policy regarding the main ethical considerations surrounding women's participation in research studies in Islamic

societies. Populations could have their own religious, cultural, and traditional beliefs that differ from those in western society. Failing to take these issues into account when conducting research studies could dramatically reduce the recruitment rate of women for said studies.

Based on the findings of this study, we suggest that researchers need to understand the culture and address the barriers that could affect the recruitment of Arab Muslim women in research studies. Being flexible in scheduling study times or locations, conducting study interviews by telephone, or offering home-based study assessments can make it easier for women to participate. It is also recommended to involve investigators and staff who reflect the study population and understand its behaviors, language, customs, and beliefs. Hiring Arab Muslim women as data collector would help in establishing culturally appropriate connections with women participants. Having clear communication and open discussion with study participants can improve women recruitment in research studies and address issues of mistrust and fears that they might have. The strong relationship between family members in Arab countries requires researchers to develop a recruitment method that focuses more on family involvement. Researchers should be willing to communicate with the father or husband when trying to recruit women participants.

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Table 1

Demographic characteristics participants (n = 1265)

Variable	Students N=1265
n (%)	
Age in years	
Less than 18	4 (0.3)
18–25	1246 (98.5)
More than 25	15 (1.2)
Gender	
Female	1009 (79.8)
Male	256 (20.2)
Marital status	
Single	1226 (96.9)
Married	31 (2.5)
Divorced	2 (0.2)
Widowed	5 (0.4)
*Nationality	
Jordanian	1157 (91.1)
Other	113 (8.9)
Religion	
Islam	1225 (96.8)
Christianity	28 (2.2)
Other	12 (0.9)

* This question allows for multiple responses

Table 2

The distribution of participants according to major and academic year

Variable	Total N= 1265	Health care majors N= 871	Non-health care majors N= 394
	n (%)	n (%)	n (%)
Study level			
First year student	368 (29.1)	248 (67.4)	120 (32.6)
Second year student	228 (18.0)	151 (66.2)	77 (33.8)
Third year student	258 (20.4)	169 (65.5)	89 (34.5)
Fourth year student	238 (18.8)	172 (72.3)	66 (27.7)
Fifth year student	121 (9.6)	80 (66.1)	41 (33.9)
Sixth year student	52 (4.1)	51 (98.1)	1 (1.9)

Table 3

Participants' opinions toward women participation in research studies

Variable	Students N=1265	Female Students N=1009	Male Students N=256	P value
	n (%)	n (%)	n (%)	
Previous voluntary participation in research study				
Yes	672 (53.1)	538 (53.3)	134 (52.3)	0.780
No	593 (46.9)	471 (46.7)	122 (47.7)	
*In Jordanian society, women could not provide a consent to participate in research study without taking the approval of the:				
Father	592 (30.9)	471 (46.7)	121 (47.3)	0.867
Husband	272 (14.2)	160 (15.9)	112 (43.8)	<0.001
Mother	330 (17.2)	268 (26.6)	62 (24.2)	0.446
Brother	81 (4.2)	50 (5.0)	31 (12.1)	<0.001
It is a personal decision	589 (30.8)	484 (48.0)	105 (41.0)	0.046
Other	50 (2.6)	37 (3.7)	13 (5.1)	0.301
*Women participants prefer to deal with female research assistant if the study involve:				
IV or IM drug administration	664 (52.5)	519 (51.4)	145 (56.6)	0.136
Blood sampling from the arm	740 (58.5)	574 (56.9)	166 (64.8)	0.021
Collection of urine or feces sample	520 (41.1)	406 (40.2)	114 (44.5)	0.212
Vital signs Measurement	741 (58.6)	594 (58.9)	147 (57.4)	0.674
X-Ray imaging	604 (47.8)	471 (46.7)	133 (52.0)	0.131
Clinical examination	654 (51.7)	522 (51.7)	132 (51.6)	0.961
Physical exercise sessions	649 (51.3)	517 (51.2)	132 (51.6)	0.926
Cigarette or waterpipe smoking sessions	457 (36.2)	355 (35.2)	102 (39.8)	0.166
Interview to discuss any general topic	653 (51.7)	528 (52.3)	125 (48.8)	0.317
Interview to discuss sensitive topic	735 (58.1)	581 (57.6)	154 (60.2)	0.456
Filling a questionnaire about any general topic	435 (34.4)	330 (32.7)	105 (41.0)	0.012
Filling a questionnaire about sensitive topic	463 (36.6)	348 (34.5)	115 (44.9)	0.002
None	40 (3.2)	27 (2.7)	13 (5.1)	0.050
*In Jordanian society, women are more likely to decline their participation in the studies that involve:				
IV or IM drug administration	264 (20.9)	196 (19.4)	68 (26.6)	0.012
Blood sampling from the arm	147 (11.6)	95 (9.4)	52 (20.3)	<0.001
Collection of urine or feces sample	307 (24.3)	228 (22.6)	79 (30.9)	0.006
Vital signs measurement	126 (10.0)	83 (8.2)	43 (16.8)	<0.001
X-Ray imaging	169 (13.4)	125 (12.4)	44 (17.2)	0.044
Clinical examination	261 (20.6)	194 (19.2)	67 (26.2)	0.014
Performing physical exercise in non-private room at the research center	580 (45.8)	456 (45.2)	124 (48.4)	0.352
Cigarette or waterpipe smoking in non-private room at the research center	534 (42.2)	427 (42.3)	107 (41.8)	0.880
Staying outside home overnight	733 (57.9)	577 (57.2)	156 (60.9)	0.277
Audio-recorded discussion session	187 (14.8)	138 (13.7)	49 (19.1)	0.028
Audiovisual-recorded discussion session	353 (27.9)	282 (27.9)	71 (27.7)	0.946

Variable	Students N=1265	Female Students N=1009	Male Students N=256	P value
	n (%)	n (%)	n (%)	
Interview to discuss any general topic	121 (9.6)	78 (7.7)	43 (16.8)	<0.001
Filling a questionnaire about any general topic	101 (8.0)	65 (6.4)	36 (14.1)	<0.001
Filling a questionnaire about sensitive topic	331 (26.2)	229 (22.7)	102 (39.8)	<0.001
None	180 (14.2)	146 (14.5)	34 (13.3)	0.627
Could women in Jordanian society agree to participate in the research studies that require participants to stay outside home overnight				
Yes	445 (35.2)	366 (36.3)	79 (30.9)	0.105
No	820 (64.8)	643 (63.7)	177 (69.1)	
The most convenient place if the study requires participants to stay outside home				
Research center for clinical studies	298 (23.6)	223 (22.1)	75 (29.3)	<0.001
Hospital	637 (50.4)	533 (52.8)	104 (40.6)	
Health center	34 (2.7)	27 (2.7)	7 (2.7)	
No specific place	254 (20.1)	201 (19.9)	53 (20.7)	
Other	42 (3.3)	25 (2.5)	17 (6.6)	Other

* This question allows for multiple responses

Table 4

Attitudes of participants toward issues related to women participation in research studies

Attitudinal statement	S.A or A (N%)		Neutral (N%)		S.DA or DA (N%)		P value
	F (%)	M (%)	F (%)	M (%)	F (%)	M (%)	
It is common practice in Jordan to respect the privacy of women when drawing blood samples, giving Injections or performing clinical examination	1064 (84.1)		162 (12.8)		37 (2.9)		0.876
	847 (83.9)	206 (84.7)	131 (13.0)	31 (12.1)	29 (2.9)	8 (3.2)	
In general, researchers should hire female research assistant (RA) if the research will target women participants	1154 (91.3)		94 (7.4)		16 (1.3)		0.311
	925 (91.7)	229 (89.4)	73 (7.2)	21 (8.2)	10 (1.0)	6 (2.4)	
In research studies that require direct contact with the participants, each participant should be asked whether he/she would like to deal with a male or female RA	1063 (84.1)		154 (12.2)		47 (3.7)		0.004
	860 (85.2)	203 (79.3)	120 (11.9)	34 (13.3)	28 (2.8)	19 (7.4)	
Women in Jordanian society have the freedom to decide to participate in research studies without reference to anyone	575 (45.4)		404 (31.9)		282 (22.3)		<0.001
	463 (45.9)	112 (43.8)	342 (33.9)	62 (24.2)	202 (20.0)	80 (31.3)	

S.A: Strongly Agree, A: Agree, DA: Disagree, S.DA: Strongly Disagree, DA: Disagree, F: Female Students, M: Male Students