

## Knowledge and attitude of Women with Special needs towards breast Cancer in Saudi Arabia; A cross sectional study

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**Abstract: Background and Objectives:** Women with disabilities have lower rates of breast cancer screening than other healthy women and often face barriers to preventive health services. The objective of this study was to assess the knowledge and attitude of early breast cancer detection and identify barriers against this detection among this group of women with special needs. **Methods:** This cross sectional study was conducted at Jeddah deaf and mute club, Saudi Arabia during the period from 2011 to 2012. Forty eight deaf and mute women were enrolled in the study. The distributed questionnaire was filled with the help of a nurse certified in sign language and the distributed questionnaire included demographic data, knowledge about breast cancer and its risk factors, beliefs and practice regarding breast self-examination (BSE) and mammography, in addition to obstacles preventing them from going to screening. **Results:** About two third of the participants have heard about breast cancer, physicians and relatives represented the main source of knowledge. Their knowledge about symptoms of breast cancer and its risk factors was poor. About two thirds of them stated that they do not believe in breast examination and its role in early detection of breast cancer. About 56% of them knew about BSE. The importance of mammogram was not known to 85.4%. The main three barriers that prevented participants from seeking for early detection of breast cancer were ignorance of its important (33.3%), shyness (31.3 %) and far distance from places of free mammography. **Conclusions:** Women with special needs can run the same risk of developing breast cancer like other healthy women. It is recommended that sign language be introduced as part of the health services in all aspect of our health care system.

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### 1. Introduction

In Saudi Arabia, breast cancer ranks first among cancers affecting women<sup>1</sup>. It is established that early detection of breast cancer increases survival.<sup>2-4</sup> This is applied for both healthy and disabled persons but in practice, the use of preventive cancer screening services by persons with disabilities and special needs is still not optimal.<sup>5,6</sup> **Roetzheim and Chirikos** reported that women with disabilities are diagnosed with breast cancer at a later stage and have higher mortality.<sup>7</sup> They specified disabilities that include persons who experience limitations or barriers related to vision, hearing or mobility.

Many cancer care providers are not well informed about the care needs and issues of people who experience cancer especially those with special needs like the deaf and mute. Not only that but also health care providers are not trained on sign language and most, if not all, health facilities are lacking the translators of this language. These are health and basic human rights of these women with special needs.

The National Society for Human Rights had stated clearly the rights of this needy group. This is based on international law and Saudi Law in which Alshoura council decision numbered (96/66) and dated 18/1/1429 G in addition to the Ministry decision issued in 21/5/1429 G (26/5/2008) and headed by King Abdullah Bin Abdulaziz had agreed on international law for health rights of those with disabilities, and in agreement with Arab contract for special needs to have sign language in media to provide them with the knowledge they need.<sup>8</sup>

Public awareness that early detection of breast cancer improve the outcomes is critical and efforts are directed towards empowering women with these information. Unfortunately women with special needs are facing many problems and lacking such information because information delivery through the language they use and understand (sign language) is not practiced in the medical field.

The objective of this study was to assess the knowledge and attitude of early breast cancer detection

and identify barriers against this detection among this group of women with special needs (deaf and mute) and emphasize the importance of directing our efforts to study the needs of these women.

## 2. Methods:

This cross-sectional study was conducted at the deaf and mute club in Jeddah, Saudi Arabia during the years 2011 and 2012. The study was approved by the Biomedical Research Ethics Committee at the Faculty of Medicine, King Abdulaziz University. Forty eight deaf and/or mute women had participated in the study. A qualified nurse, trained on sign language at deaf and mute club for 2 weeks and were certified by the director, conducted the translation of the questionnaire to sign language. The participants were consented in sign language.

The questionnaire used in this study included; demographic data, knowledge about breast cancer and its source, beliefs and practice regarding breast self-examination (BSE) and mammography, in addition to obstacles preventing them from going to screening. Data were entered into the computer and analyzed using the Statistical Package for Social Sciences version 15 (SPSS Int. Chicago, IL, USA). The results were presented in the form of number and percentage. Chi-square test was used as a test of significance for quantitative data and significance was considered at *p* value less than 0.05.

## 3. Results:

The total number of the participants was 48 deaf and mute females. Their mean age was  $29.73 \pm 8.51$  with a range from 15 to 50 years. About 35 (72.9%) were Saudi and about half of the participants (58.3%) were non-working. About 81% of them had preparatory and secondary education. About 20% of them were married and the age of marriage varied from 16 to 29 with mean age of  $22.18 \pm 4.12$ . Fourteen of them had children and more than two thirds had children aged from 20 to 30 years (Table 1).

The results of the study showed that about 32 (66.7%) of the participants have heard about breast cancer. Physicians and relatives represented the main source of their knowledge in (31.3% and 33.3% respectively) (Table 2a).

Their knowledge about Symptoms of breast cancer were poor as pain, change in the nipple and bloody discharge were chosen as presenting symptom by 50%, 31.3% and 20.8% of the participants respectively while only 10.4% mentioned breast mass as a presenting symptom. Regarding the risk factors of the breast cancer, the participants showed also low knowledge as genetic factor, age and late pregnancy were nominated as risk factor by 41.7%, 12.5% and 10.4% of them respectively. Regarding the protecting

factors, 32.6% and 34.8% of the participants nominated absence of stress and healthy lifestyle respectively.

When asked about their beliefs of breast self-examination (BSE), about two thirds of them stated that they do not believe in breast examination and its role in early detection of breast cancer while 20.8% confirmed their belief that holy water Zamzam can prevent cancer. Regarding their feelings when they hear the word "breast cancer" 60.4% stated they feel afraid and 18.8% feel shy and ashamed (Table 3).

It was found that 27 of the participants (56.3%) knew about BSE and 41.7% have learned how to perform it. Nineteen (70.3%) of those who knew about BSE were not sure about the proper time to perform it. More than 90% of them had learned BSE from lectures and campaigns. About 18 (37.5%) of the participants have practiced BSE and 12 (88.8%) found their experience easy. The importance of Mammography was not known to 41 (85.4%) of the studied group and only 10.4% and 4.2% know that it detects tumors and improves survival respectively.

The main three barriers that prevented participants from seeking for early detection of breast cancer were ignorance of its importance (33.3%), shyness (31.3%) and far distance from places of free mammography (16.7%). Unavailability of female physician and refusal of the family were stated by 8 (16.7%) and 5 (10.4%) women respectively (Table 5).

## 4. Discussion:

Public awareness that breast cancer outcomes are improved through early detection is critical to improving participation in early detection programs. This study has focused on the basic essential knowledge that would affect screening and the practice and common beliefs about cancer among a group of women with special needs (deaf and mute). It was not possible to compare our results to others as such studies that dealt with women with special needs are lacking in Saudi Arabia. To the best of our knowledge this is the first study in Saudi Arabia and in the Arab countries.

Knowledge is power and the key to any successful program is to educate women about cancer nature and importance of early detection. In Saudi Arabia there are several public awareness programs and educational campaigns targeting health women yet different studies showed the knowledge of female regarding breast cancer and its screening still low.<sup>9-11</sup>

**Table 1: Demographic characters of the studied groups (n=48)**

Variables	N	(%)
<b>Age</b>		
Mean ± SD	29.73 ± 8.51	(15-50)
<b>Nationality</b>		
Saudi	35	(72.9)
Non-Saudi	13	(27.1)
<b>Occupation</b>		
Housewife	10	(20.8)
Employee	15	(31.2)
Not working	28	(58.3)
<b>Education</b>		
Primary or less	4	(8.3)
Preparatory/Secondary	39	(81.3)
University	5	(10.4)
<b>Marital Status</b>		
Married	10	(20.8)
Single	33	(68.8)
Divorced	4	(8.3)
Widow	1	(2.1)
<b>Age of Marriage (years)</b>		
Mean ± SD	22.18 ± 4.12	
Range	(16-29)	
<b>Having children</b>		
0	1	(2.1)
One	13	(27.1)
Two	1	(2.1)
<b>Age of First Delivery(years)</b>		
	N	(%)
< 20	2	(14.2)
20-30	10	(71.4)
More than 30	2	(14.2)

**Table 2a: Knowledge of the studied group about Breast Cancer and its risk factors**

	N	(%)
Did you hear about breast cancer?	32	(66.7)
<b>What are the sources of knowledge?</b>		
Physicians	15	(31.3)
Nurses	1	(2.1)
Support team	-	-
Alternative Media	1	(2.1)
Survivors	1	(2.1)
Relatives	16	(33.3)
Books	1	(2.1)
Internet	6	(12.5)

**Table 2b: Knowledge about breast cancer of the studied group**

	N	(%)
<b>Early symptoms for seeking medical care</b>		
Change in the size	7	(14.6)
Blood discharge from nipple	10	(20.8)
Change in the nipple or the areola	15	(31.3)
Pain	24	(50)
Mass in the breast	5	(10.4)
Mass in the axilla	4	(8.3)
<b>Risk Factors</b>		
Age	6	(12.5)
Ovarian stimulator	5	(10.4)
No breast feeding	7	(14.6)
Genetic	20	(41.7)
Oral contraceptive	2	(4.2)
Hormonal replacement therapy	6	(12.5)
Late pregnancy	5	(10.4)
Socio-economic	1	(2.1)
<b>Factors to protect from breast cancer</b>		
Healthy diet	9	(19.6)
No use of chemicals & cosmetics	6	(13)
Healthy life style	15	(32.6)
No stress	16	(34.8)

**Table 3: Some beliefs regard breast cancer of the studied group**

	N	(%)
Examination does not prevent breast cancer	31	(64.6)
Breast cancer is a punishment	1	(2.1)
Zamzam prevent breast cancer	10	(20.8)
Rukia prevent breast cancer	4	(8.3)
No treatment for breast cancer	1	(2.1)
Chemotherapy leads to death	1	(2.1)
<b>How do you feel when you hear about breast cancer</b>		
Pain	2	(4.2)
Disease	1	(2.1)
Death	2	(4.2)
Stigma	-	-
Stress	2	(4.2)
Afraid	29	(60.4)
Shyness	9	(18.8)

**Table 4: Perception of the Studied Group about Breast Self-Examination (BSE) (n=48).**

	N	(%)
Do you know about BSE?	27	(56.3)
Did you learn how to perform BSE?	20	(41.7)
<b>Who learn you? (n=20)</b>		
Lecture or campaign	18	(90)
Obstetrician	2	(10)
Primary health Care Physician	-	-
Relative	-	-
Do you do practice BSE before?	18	(37.5)
<b>How did you find the experience? (n=18)</b>		
Easy	16	(88.8)
Difficult	2	(11.2)
<b>What is the best time to do BSE? (n=27)</b>		
Before cycle	3	(11.1)
During cycle	1	(3.7)
After cycle	4	(14.8)
I am not sure	19	(70.3)
<b>What is the importance of the mammogram</b>		
Discover tumor	5	(10.4)
Improve survival	2	(4.2)
I do not know	41	(85.4)zzz

**Table 5: Obstacles and barriers preventing the studied group from going to early detection of cancer breast**

	N	(%)
Shyness	15	(31.3)
Health insurance	2	(4.2)
Cost	1	(2.1)
No female physician	8	(16.7)
I didn't know it is important	16	(33.3)
Refusal of family	5	(10.4)
I do not know where to go	6	(12.5)
Transportation	3	(6.3)
I do not need to search for unknown	4	(8.3)
Free services is away	8	(16.7)
Laziness and looseness	3	(6.3)

For those with special needs the situation is more challenging. Existing health services research has largely ignored this population and the current healthcare system may be unprepared to respond to the special needs of this underserved group. In this study; pain was thought to be one of early symptoms of breast cancer as perceived by about half of the participants and only 10% of them recognized mass in the breast as

a presenting symptom. These findings are reflecting the poor knowledge about breast cancer among this group.

Risk factors also were not clear perceived by the participants to this study. Physicians, internet and Television/radio were reported as best source of information for cancer among healthy women in Saudi Arabia.<sup>10,12,13</sup> This was not the case of course among these women with special needs as sign language is not used routinely in media in general. In our study physicians and relatives represent the main source of information at about one third of the studied group.

As these women with special needs are not equipped with enough information they have many misconceptions and they believe examination does not prevent breast cancer in about two thirds of the studied group and about one fifth believed that Holy water Zamzam can prevent breast cancer. These false beliefs are consistent with other findings of studies in minority groups like Hispanic and African American populations where the beliefs that traditional therapies (namely natural herbal remedies) are better than standard cancer treatments.<sup>14</sup>

Among the studied group about 40% have learned how to perform BSE but about 70 of them were not sure about the proper time. The more serious issue is that about 85% of the participated women did not know what mammogram is and what its value is. These findings could explain those of the previous studies on disabled persons which revealed that people with pre-existing disabilities including people with barriers to hearing may be at greater risk of certain cancers, are often less likely to be screened for cancer, may not receive the most effective treatments and have poorer prognoses and survival rates.<sup>7</sup> Women with disabilities showed less compliance with breast and cervical screening programs<sup>(15)</sup>.

Existing health services research have largely ignored this population.<sup>16</sup> The current health care system in Saudi Arabia may be unprepared to respond to the special needs of these women particularly in the area of preventive cancer screening.

In conclusion women with special needs can run the same risk of developing breast cancer like other healthy women. Women's health rights are human right and by international law and by Law in Saudi Arabia they have the right to all facilities and services and to empower them with knowledge in their understandable language which is the sign language. We recommend that sign language to be introduced as part of the health services in all aspect of our health care system.

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