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## Original Research Article

# Stakeholders' opinion regarding disabled friendliness of obstetrics and gynaecology services in hospitals of North India

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## ABSTRACT

**Background:** Hospitals are part of our society. Barriers faced by people with disability (PWD) in hospitals reflect obstacles in society also. Women with disability (WWD) are at particular disadvantage. Our objective was to explore the domain related to the problems that WWD face in accessing obstetrics and gynecology (OBG) services in government institutes/hospitals of Chandigarh.

**Methods:** This mixed quantitative and qualitative research was done during 2013-2017. Stakeholders included WWD, their families, self-help groups, community-based organisations, NGOs, doctors, nurses, public health experts, research scholars and government bodies involved in disability services. Five major government institutes/hospitals of Chandigarh were purposively selected for the study. In-depth interviews were conducted among different groups to gain an insight into their views regarding the degree to which the reproductive health services were disabled-friendly.

**Results:** Most (80-90%) of the stakeholders emphasized the need of making OBG services disabled-friendly. The majority of doctors and nurses said that no special training was given to them to deal with WWD. They opined that SRH needs of WWD were different from other women. Lack of access was the main barrier to OBG care in hospitals reported by 46% of WWD. Most of the hospitals lacked any special provisions for PWD.

**Conclusions:** There is a lack of concern and apathy for WWD in the society. Hospitals lack a disabled-friendly attitude, design and facilities. Access to OBG services for WWD was barrier ridden.

**Keywords:** Disabled friendliness of obstetrics and gynaecology services, Sexual and reproductive health, Stakeholders' opinion, Treatment seeking behaviour, Women's health, Women with disabilities

## INTRODUCTION

Political, economic, structural and socio-cultural barriers in the external environment constrain the involvement of People with Disability (PWD) in social activities. Access to optimum health care services is vital for every woman. In particular, women with disability (WWD), face multiple discrimination and social exclusion.<sup>1</sup>

Barriers to health care faced by WWD, like the cost of treatment, and lack of appropriate services and equipment

reflect the lack of social support, legal protection, understanding and empathy.<sup>2</sup>

Health care services can accommodate WWD easily. Various stakeholders can together make reproductive health services better. This will help in mainstreaming WWD within society.

The dearth of research on this topic stimulated us to explore the domain related to the problems that WWDs of Chandigarh face in accessing obstetrics and gynecology

(OBG) services by summarizing their experiences and opinions about the issue.<sup>3</sup>

## METHODS

This study done during 2013-2017 used a mixed-method quantitative and qualitative research design. Stakeholders included WWD, their families, self-help groups, community-based organisations, NGOs, doctors, nurses, public health experts, research scholars and the members of various government bodies involved in disability related services. In-depth interviews were conducted among different groups of people to gain an insight into their views regarding the degree to which the reproductive health services were disabled-friendly.

Five major government institutes/hospitals of Chandigarh were purposively selected for the study. In hospitals, staff and their family members and patient visiting hospital were included in the study. From above information, list of WWD aged 15 and above was prepared. Adequate representation of women with different types of disabilities was ensured by choosing different study areas viz- institute for the blind, government rehabilitation centre for intellectual disabilities, colleges and universities. The principle of redundancy was followed. Data collection was continued till no new information emerged.

Clearance was taken to conduct this study from the Institute Ethics Committee of PGIMER, Chandigarh, the host institution. Respondents were explained the purpose of the study. They were assured about the confidentiality of the information obtained. Participants' consent was taken.

Data was entered and analysed in MS Excel and SPSS version 21.0. Textual analysis of qualitative data was done. Data were manually coded and collated into possible themes. Data triangulation was used to draw relevant inferences.

## RESULTS

Overall, 376 stakeholders were interviewed for their opinion regarding status and scope of disabled friendliness of OBG-OPD/ward services in hospitals. It included 261 WWD, 60 persons from DPOs (36 persons from NGOs/self-help groups, 10 from social welfare and other govt. departments, 9 members of various associations for rights of the disabled and 5 PWD). Also, 30 doctors (28 gynecologists and 2 experts from community medicine), 11 research scholars, 12 nursing staff and two social workers were interviewed. Their ages ranged from 15-65 years.

Mothers (28%) or husbands (17%) escorted most of the respondents to the hospital. Few (9%) respondents went alone to the hospital. Most of the WWD (88%) had visited a government hospital for their last consultation, despite

many barriers, as indicated by their responses: "Priority should be there for us. We were called for admission. But the doctor spoke rudely and sent us back. If we could afford a private hospital, we would never have come here". "Nobody allows us to enter the lift". "In the parking reserved for PWD, non-disabled people also park their cars. We parked the car far away and came here on foot". "I came to the emergency unit, but no doctor bothered despite the fact that I was crying with pain. Condition of government hospitals is very pathetic". "It is very difficult to stand in the crowd. We come in the morning and keep on waiting till evening".

Most (80-90%) of the stakeholders emphasized the need of making OBG services disabled-friendly. The majority of doctors and nurses said that no special training was given to them to deal with WWD. They opined that SRH needs of WWD were different from other women, e.g., "WWD can conceive, but delivery is not normal. WWD have deformed anatomy. More Caesarean sections are done in them. WWD need more counselling, care, guidance and support. But, no significant steps to understand SRH issues among this segment have been taken so far".

Table 1 shows that the lack of access was the main barrier to OBG care in hospitals reported by 46% of WWD. Most of the hospitals lacked any special provisions for PWD. Proper ramps, stairs or toilets were not present in hospitals.

One respondent reported, "We both have polio. Who will drive or push the wheelchair? Even ramps are not of proper height. Without handrails, ramps are of no use". Another respondent highlighted multiple problems like- lack of proper toilets, equipment and assistance- "I bring my own toilet seat; wheelchair too pinches. I have to be lifted to be put on the ultrasound machine. No hospital attendant helps while I am being examined. My relatives come with me". Others said, "It would have been better if there was an escalator, lift or ramp". "It is difficult to go up and down". "At least we should get space in the lift". "In foreign countries, facilities and infrastructure are very good; not in India". "Here floors are slippery. Many changes need to be done; but who cares? Even the buildings are not disabled friendly". "We waited for 1/2 hour to get a wheelchair".

There was no special equipment in the OBG department to examine WWD. At times, patients had to struggle to get onto examination tables. They had to be lifted manually by their family members- "I cannot climb the examination bed. I cannot adopt the position asked for by the doctor and hence, I did not get myself examined". A 35-year-old married respondent with locomotor disability told, "The ultrasound machine in the hospital is too high. So, I have to call my husband. The staff objects to this". Another respondent reported that she had a problem holding urine for getting an ultrasound done; so, she did not go for the diagnostic procedure.

Most women with speech and hearing impairments reported difficulties in explaining their problems to the

doctors- “We were unable to explain to the doctor, who left us without listening to our problem”. “There should be some interpreter”. “We cannot understand the instructions given by doctors”. “Everybody talks fast. I cannot understand and get tense”. “We came in a special autorickshaw. I cannot come on the bus due to pregnancy. Here, my mother stands in the queue. A full day is wasted when we come here”. A 60-year-old married respondent said, “I am not able to board a bus. I wish there were steps or a ramp on the bus”.

Mother of a WWD highlighted- “Because of physically lifting her every now and then, my uterus has dislocated”.

There were no special lifts for PWD- “I feel suffocated in the lift. So, I prefer stairs”. Long waiting hours and lack of priority in treatment force them to postpone their visit to the hospital- “Though we reach here in the morning, we are never free before 2-3 pm”. “No doctor examines us as a special case. Therefore, we did not come for treatment for the past 5-6 years”.

Some (6%) respondents reported that doctors and other hospital staff were rude and indifferent to their special needs- “Doctors did not take my bedwetting problem seriously. Doctors do not understand my suffering. Everywhere, I search for the washroom. I use diapers while going anywhere”. “Doctor said- why did you marry a deaf and dumb? How will he understand your feelings?”. “When I conceived, the nurses were furious and said: when you cannot walk, why did you conceive? They advised me

not to have another child”. “When we repeatedly ask something, doctors become angry”.

The mother of a 15-year-old mentally retarded respondent told, “The doctors said: she is alright and did not admit her saying that they have other sick patients to look after. They started treatment only after an argument”. “I had come to get the blood test done. I said I have polio. Staff asked me to bring my disability card. Am I pretending? People sympathize with us. But doctors did not”. “It is difficult to stand and wait for such a long time. Nobody vacates a seat for us. The doctor said: every Tom, Dick and Harry comes to Gynaecology. I will not visit the hospital again”.

Other problems were also reported- “Doctors sometimes get angry due to my hearing problem”. “My husband was pushed out of the lift saying that he can use stairs as he can walk on his own”. “There is no special toilet in the hospital. In the 8<sup>th</sup> month of pregnancy, the staff did not allow me to enter the lift. Even security people ignore us lest we may ask them for help”. “Toilets are not clean. Special toilets should be there”. “It is difficult to sit on Indian style seat”. “We reach at 6 a.m. and the staff opens the toilet at 9 a.m.”. “I fear using the toilet since I am pregnant. I could not urinate in a sitting position and a Western seat was not available”. “I find it difficult to get up from the toilet seat. There is a lot of water splashed on the floor due to poor drainage. I am afraid of falling. I avoid using the toilet here and try to hold my urine”. “I bring my own toilet seat. The sweeper threw it out saying that they have to clean the toilets. They kept the toilet closed for one hour”.

**Table 1: Different barriers faced by WWD in the hospitals as per the opinion of various stakeholders.**

Barrier reported	WWD (%)	NGOs (%)	Doctors (%)	Research scholars	Nursing staff	Social workers
<b>Lack of access (infrastructure/ equipment/communication/ transport)</b>	121 (46.36)	15 (25)	17 (56.67)	1 (9)	3 (25)	
<b>Lack of assistance in hospital</b>	30 (11.49)	-				
<b>Overcrowding</b>	30 (11.49)	-	1(3.33)		5 (41.67)	
<b>Long waiting hours/lack of priority</b>	20 (7.66)	-				
<b>Bad attitude of health care providers</b>	16 (6.13)	16 (26.67)	-		2 (16.67)	1
<b>Unfriendly toilets</b>	15 (5.75)	-				
<b>Repeated visits</b>	10 (3.83)					
<b>Limited resources (money/ manpower/ attendants/trainings)</b>	6 (2.30)	-	4 (13.33)	-		
<b>Lack of awareness/confidence/ compliance among WWD themselves on SRH</b>	6 (2.30)	11 (18.33)	3 (10)	5 (45.45)		1
<b>Lack of policy enforcement</b>	-	11 (18.33)	-	1(9)		
<b>Bad attitude of family/society</b>	5 (2%)		2 (6.67)			
<b>Limited surgical options</b>	-	-	1 (3.33)	-		
<b>Others (lack of care/female doctors etc.)</b>	2 (0.77)	-	-	-		
<b>Don't know</b>		7 (11.67)	2 (6.66)	2 (36.36)	2 (16.67)	
<b>Total</b>	261	60	30	11	12	2

Lack of finances affected treatment compliance among a few respondents- “We had no money and hence took no treatment”. “I can’t come daily because of excessive bus fare”. “Battery of hearing aid should be cheaper”.

Few (2%) WWD were themselves not aware of the special provisions for them- “Nobody told that there is a separate queue for disabled”. Often, the barriers in hospitals were accepted by them as their fate. “In the queue for special people, everyone quarrels and pushes us out and says: ‘all are handicapped. It is better not to quarrel and stand quietly in the queue for normal people’”.

Lack of guidance in hospitals led to confusion among WWD- “There should be some guide, there is a lot of confusion here”. Mother of the respondent with mental illness- “Today, when we came to the hospital and she was not traceable. I was tense, thinking that she might be lost”. “Parents kept on running around arranging for blood. My husband is disabled too. We faced a problem at the time of delivery”. “Because of trouble during pregnancy, I stopped coming here. The fee counter is different from the vial counter and then the sample is taken somewhere else. Being disabled and pregnant, it was difficult for me. Some assistance should be provided to patients like me”.

Lack of policy enforcement was also reported by some DPOs (18%)- lack of will- Government is working in this field. But officers and bureaucrats do not work properly to solve the problems of PWD. Government had made PWD Act. But its implementation is poor, as highlighted by a WWD. “All Acts are the same. Nobody listens to us”.

Many (57%) doctors felt that lack of access was the major barrier- hospitals have just built ramps. Nothing else is there. Doctors expressed their limitation to deal patiently with WWD as hospitals generally remained overcrowded- “A single doctor cannot deal with 20 patients per hour and also be able to deal adequately with WWD. Less time and more patients; what can we do?”.

Some WWD raised other demands- “Forms in the hospital should be in braille”. “There should be an announcement system in every room so that we may know what is going on and we don’t have to wait for long”. “There should be such a system that enables us to go everywhere independently”. “Everything should be in order”. “Doctors should understand our problem. Our condition is not in our control”. “There should be more good doctors in general hospitals.” “Special days should be allotted to us so that we don’t have to wait. It is very difficult to wait for such a long time”.

Few WWD (10%) suggested that interpreters should be there in every department to improve communication. Doctors were insensitive, as they told one WWD- “Bring somebody along, how will we talk to you”.

The majority (60%) of doctors suggested creating awareness among the society- “Educate WWD about

sexual exploitation. Proper pre- and post-marriage counselling should be given to them. Society needs to change the attitude towards them and understand them”. In order to improve the quality of care for WWD in hospitals, some (23%) doctors suggested special arrangements- special staff, telemedicine and a sensitization program. Few others suggested empowering WWD- “Involve WWD in SRH programs. They will be safe if made aware of the issues”.

## DISCUSSION

In India, the health of the WWD is not considered a priority. They are viewed as helpless, incompetent, asexual and intellectually challenged. They have been isolated from social and political participation.<sup>4</sup> WWD face stigma and discrimination in society through stereotyping, separation, status loss, dislike and being ignored. It forces them to internalize negative thoughts, psychosocial consequences and low self-worth. In Zimbabwe, nobody shared information on sexuality and child-bearing with WWD.<sup>5-7</sup> Negative experiences of WWD while accessing SRH services are common.<sup>8,9</sup> In Sierra Leone, access to hospital services was low for PWD.<sup>10</sup>

WWD are discriminated against by health professionals right from the onset of pregnancy right through to motherhood.<sup>11,12</sup> WWD were assumed to give birth to children with disability.<sup>13,14</sup> WWD felt cheated that doctor did not support their idea of bearing children.<sup>15,16</sup>

In the US, WWD were refused care by physicians. They faced discrimination from health care providers, support staff, policymakers and even facility and equipment design.<sup>17</sup> PWD faced transportation problems, financial barriers, inaccessible buildings, lack of knowledge and a bad attitude from health care providers.<sup>18</sup> In Malaysia, none of the hospitals satisfied 100% accessibility criteria. Parking was reported to be the least friendly for PWD. Toilet facilities were also found to be unsuitable for use by PWD. Private hospitals scored higher than public hospitals.<sup>19</sup>

Providers lacked knowledge on how to treat disability-related health problems and assumed that PWD did not require the full range of health-care services, as they were asexual and incapable of reproduction.<sup>20</sup> In Uganda, physical inaccessibility was the major challenge reported by PWD in hospitals, e.g., adverse attitudes of providers, long queues, high costs, lack of ramps, help in climbing stairs; wheelchairs and disabled-friendly beds.<sup>21</sup> In Ghana, insensitivity and ignorance of providers and unfriendly infrastructure discouraged them from seeking SRH care.<sup>22</sup>

WWD in our study and elsewhere reported that the transport system was not friendly to them. They resented being dependent upon others.<sup>3,10,21,23</sup> They were denied care as they were considered to be a burden by the providers.<sup>24</sup> Providers’ attitudes affected WWD’s perception of the quality of services.<sup>25</sup>



Limitations were that the WWDs and other respondents were not randomly selected.

## CONCLUSION

Most stakeholders recommended that OBG services need to be made disabled-friendly. Health care providers lacked knowledge or training about dealing with WWD and their disability-related health problems. They were rude and indifferent to their special needs of WWD. The overcrowded hospital scenario further aggravated this problem. Barriers to SRH care faced by WWD reflect lack of social support, legal protection, understanding and empathy. WWD are discriminated against by health professionals and by the society, for their general as well as SRH care related problems.

## Recommendations

A sincere effort is needed to ensure a better quality of life for WWD. Transformative changes in laws, social norms, social institutions and public policies are urgently required for the empowerment of WWD. A freely accessible health care system for WWD without any obstacles is a prerequisite for this. Though solo efforts have been made, continuity in these efforts is lacking.

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