Prevention and Management of Cervical Cancer; A Gender-Lens Review of Programmatic and Sociocultural Dimensions

Final Report

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List of Abbreviations

BSMMU	Bangabandhu Sheikh Mujib Medical University
CFE	Client Friendly Environment
CBO	Community-based Organization
DPHI	Department of Public Health and Informatics
DH	District Hospital
DMC	Dhaka Medical College
DGHS	Directorate General of Health Services
DGFP	Directorate General of Family Planning
EPI	Expanded Program on Immunization
FA	Facility Assessment
GNSPU	Gender, NGO, Stakeholder, Participants Unit
GOB	Government of the People's Republic of Bangladesh
GCO	Global Cancer Observatory
HEU	Health Economics Unit
HIV	Human Immunodeficiency Virus
HPV	Human Papillomavirus
IRB	Institutional Review Board
IDI	In-depth Interview
KII	Key Informant Interview
MOHFW	Ministry of Health and Family Welfare
MMCH	Mymensingh Medical College and Hospital
NICRH	National Institute of Cancer Research and Hospital
NGO	Non-Governmental Organization
OPD	Outpatient Department
PPS	Probability proportional to Size
QA	Quality Assurance
STDs	Sexually Transmitted Diseases
SES	Socioeconomic Status
SDG	Sustainable Development Goal
UHC	Upazila Health Complex
UH&FPO	Upazila Health and Family Planning Officer
UNFPA	United Nations Population Fund
VIA	Visual Inspection with
WHO	World Health Organization
WI	Wealth Index

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Executive summary

Globally cervical cancer ranks 4th among females and in Bangladesh cervical cancer is the 2nd most common cancer. Gendered perceptions and health behaviors of both women and men play a significant role in women's ability to access the care that they need. The construction of gender and the position of women in the family and society affect disease process. Literature review suggests that women, who live in rural area, are more affected. Low education, early age at marriage, and early age at first child, higher parity contributes to develop cervical cancer. Early age at first exposure, behavior of male partner, multiple partners are risk factors for developing cervical cancer. The Government of Bangladesh has developed a National Strategy for Cervical Cancer Prevention and Control (2017-2022). One of the focuses of this strategy document is conducting research to develop deeper understanding regarding cervical cancer in different dimensions. The understanding of socio-cultural factors with gender lens is required to address the different group of vulnerable women with cervical cancer to address the SDG 3 and SDG5.

Department of Public Health and Informatics (DPHI) of Bangabandhu Sheikh Mujib Medical University (BSMMU) conducted this study using mixed-Method were used to assess socio-demographic characteristics and knowledge of patients, understand reported risk factors, to examine vulnerability, understand relation of socio-cultural factors, and find out gaps in services and recommendations in Dhaka and Mymansingh from August to November 2020. In total 200 cervical cancer patients, service providers (doctors and nurses), activists for prevention of cervical cancer were interviewed through survey, Key Informant Interview, In-depth Interview, cases study. In addition, two facility assessments were conducted.

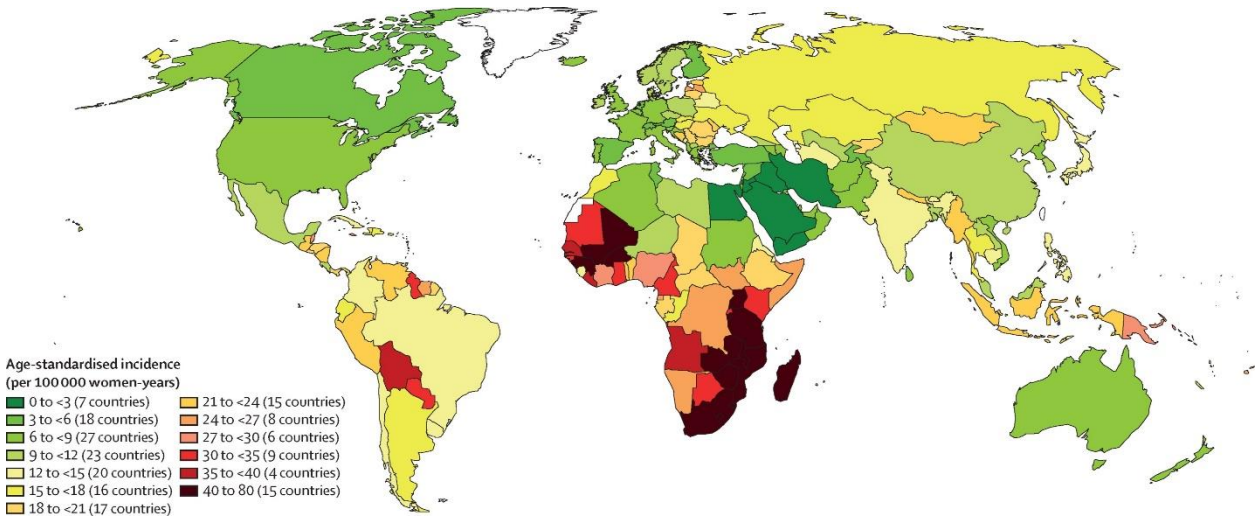
It was found that 33% respondents were in the age between 40-49 years, 73% reside in rural areas, 59%, women were with no formal education, 91% respondents were housewife, 20% were belong to poorest and poor economic background, and 52% respondents were widow, seperated and divorced.

Sixty eight percent were not aware of cervical cancer, 74% not heard about screening. Seventy percent respondents used dirty clothes during menstraution, 83% married before the age of 18 years, 55% of respondents became 1st time pregnant age between 18 and above 18 years. Fifty percent had 3 to 4 children and 22% respondents had 5 and more than 5 children. Fifty seven percent faced obstacle during treatment, 82% continued their treatment, and 47% respondents' treatment expenses was loan and 16% respondent's expenses from savings to continue their treatment. During qualitative interview a close association between poor socio-economic status and development of cervical cancer was found. Usually women from low socio-economic background have limited access to education. Low level of education prevents them to be empowered and to acquire proper knowledge regarding health. They are not aware of screening of cervical cancer and available services in facilities. In addition that gender inequality in our society, polygamy characteristic of men and women, and parents' low education level, etc. contributed to develop the illness expressed by the key informants. Insufficient service providers, gender matched service provider, trained counselor, screening room, medicine supply, lack of referral system, privacy, and trained human resource, long waiting time to get radiotherapy serial, out of order radiotherapy machine were identified as obstacle to get services. Considering these hindering factors respondents' recommended arranging campaigning, awareness program, sharing information through courtyard session and media, ensuring door-to-door vaccination services and VIA test facilities, counseling for service recipients and family members. Based on the study findings it was proposed to Increase awareness on cervical cancer focusing target groups, and create a client friendly environment (CFE) in the facility as part of health system strengthening. This study will be one of the initiatives to understand the scopes and utilization of cervical cancer services across the hierarchy of health facilities.

Background:

Cervical cancer is the second most common cancer in women worldwide and the leading cause of cancer deaths in developing countries. According to Global Cancer Statistics 2018, out of 5,69,847 diagnosed women, 311,365 die annually from cervical cancer. Cervical cancer is the second most common type of cancer in Bangladesh, with approximately 12,000 new cases detected every year, and over 6,000 deaths occur due to severity of the disease (DGHS, 2017). Cervical cancer is the second most common type of cancer in Bangladesh, with approximately 8,068 new cases detected every year, and over 5,214 deaths occur due to severity of the disease (Bruni L et al., 2019). Though cervical cancer remains a global issue, it mainly affects women in low resource settings. According to the Global Cancer Observatory (GCO) of 2012, in Bangladesh, about 19.3% of female cancer patients suffer from cervical cancer. In a study of (Ferdous et al. 2013) reported cancer cervix are approximately 7.8% of all gynecological patients and 70% of all gynecological malignancies admitter in BSMMU, Bangladesh. The incidence rate of cervical cancer in developed countries has been decreasing dramatically while it remains high in developing countries (The CCA Report, 2011). As indicated above, developing countries constitute high percentages; they represent 86 % of the new cases and 88 % of the deaths (WHO, 2010).

Figure 1: Geographical distribution of world age-standardized incidence of cervical cancer by country, estimated for 2018



There are various social, cultural, economic and biological factors involved in the development of the disease. Researchers identified socio-economic factors and behaviors are part of its etiology beside biological characteristics. There are multiple factors involved in cervical cancer etiology, such as: low socioeconomic level, early age at first intercourse, multiple sexual partners, early age at first pregnancy, multiparity, use of hormonal contraceptives and smoking (Biswas L, 1997; Mackillop WJ et al, 1997; Hoffmann D, 1997; Faggiano F et al, 1997; De Sanjose S et al, 1996).

Another factor studied as a cervical cancer initiator is the presence of cervical infections, mainly those caused by human papillomavirus (HPV) (Kjaer SK et ai, 1997; Franco E, 1997; Bosch F, 1997; Chang DY et al, 1997; Mendoza-Alcantar et al, 1997). Based on multiple researches, WHO established Human Papilloma Virus (HPV) as the leading cause for the development of cervical cancer in 1991 (Munoz N, Bosch FX, 1992).

However such characteristics are inadequate to explain sufficiently the role that emotions, family networks and socially-constructed categories such as gender play in the demand and utilization of health services for cervical cancer diagnosis and treatment and neither the timely undertaking of preventive actions, such as getting a Pap smear or seeking adequate and continuous treatment. With a comprehensive approach to prevent, screen and treat, cervical cancer can be eliminated as a public health problem within a generation. A number of high-income countries have shown that with successful and effective implementation of comprehensive cervical cancer prevention and control, incidence and deaths from the disease can be dramatically reduced. This is a story of inequality which the accelerated approach towards elimination aims to change dramatically. Most of the women from low- and middle-income countries will not have had access to the key cervical cancer services which could have saved their lives, nor the palliative care to help them manage pain and safeguard their quality of life. In addition, it is important to note that women who are living with HIV are at high risk of cervical cancer as they are 4-5 times more likely to experience persistent HPV infection and subsequently cervical cancer (WHO, 2020).

A lack of effective screening coverage and access to preventive therapy is the primary driver for the high cervical cancer burden among women in the developing world (Cervical Cancer Control & Prevention, 2020). Bangladesh has a high burden of cervical cancer due to the lack of screening, high prevalence of risk factors like early marriage, early initiation of sexual activity, multiparity, sexually transmitted diseases (STDs) and low socio-economic condition (DGHS, 2017).

Cervical cancer patients face multiple challenges in the process of diagnosis and treatment. The main challenges faced by patients include socioeconomic, cultural, health care based and psychological challenges. These challenges are documented as having an immense impact on the lives of women in various literatures (Waskul and van der Riet, 2002; Arrossi et al., 2007; (Price et al., 2011; Harford, Azavedo and Fischietto, 2008).

However, low financial resources may account for non-compliance with screening guidelines. Other causes of non-compliance include poor implementation of comprehensive cancer control plans (in countries that have them), poor healthcare infrastructure to implement cancer screening program, low levels of health literacy regarding the importance of routine cancer screening and high prevalence of competing health issues (Mvundura and Tsu, 2014). Prior studies in the USA have reported that socioeconomic status (SES) at the individual and parental levels, as well as over the entire life course, strongly influences health outcomes (Senese et al., 2009; Chaparro and Koupil, 2014; Ball and Mishra, 2005; Khang, 2007; Adler and Newman, 2002) and is associated with screening (NCI, 2015; Pruitt et al., 2009; Bigby and Holmes, 2005; (Fukuda, Nakamura and Takano, 2020). The life-course approach to understanding cancer screening recognizes the complex interplay of early life factors, including parental and individual SES in shaping health behavior, either directly through financial resources and healthcare access or indirectly through awareness of cancer screening recommendations (Lynch and Smith, 2005).

Although some studies in LMICs have shown that low individual SES negatively influences cancer screening rates (Chidyaonga-Maseko, Chirwa and Muula, 2015; Gadgil et al., 2015; Yerramilli et al., 2015; Compaore et al., 2015), none to the best of our knowledge have examined SES over the life-course in relation to cervical cancer screening. It remains unclear whether parental SES plays a role in adherence to cancer screening guidelines above and beyond individual SES, or whether this association depends on the measure of SES, that is, education or income measures, or based on maternal or paternal SES measures.

In an un-published cross-sectional survey conducted for a master's thesis, Yehualashet Tadesse, assessed the factors that affect the diagnosis and treatment of cervical cancer in public health institution. It was explored that the awareness of health care providers of the disease and identified the available therapeutic and diagnostic infrastructure for the treatment of cervical cancer. The study surveyed 34 public health institutions (8 hospitals and 26 health centers). The outcome of the research showed the lack of awareness of the disease among the surveyed practitioners. Moreover, lack of equipment, proper documentation for diagnosis and treatment of cervical cancer were seen in the majority of the institutions.

Directorate General of Health Services, Health Services Division, Ministry of Health & Family welfare (MoHFW) released the 'National Strategy for Cervical Cancer Prevention and Control in Bangladesh, 2017-2020' (DGHS, 2017). This strategy has been developed by the Ministry of Health and Family Welfare (MoHFW) with technical support from the Bangabandhu Sheikh Mujib Medical University (BSMMU), the World Health Organization (WHO) and the United Nations Population Fund (UNFPA). Spanning over five years from 2017 to 2022, the strategy is the first step to align agendas and activities among all stakeholders to ensure a coordinated approach in addressing cervical cancer. Though prevention and management of 'Cervical Cancer' through programmatic and sociocultural Dimensions have not yet been explored properly.

Rationale

The social, economic, cultural vulnerabilities, gender issues and the challenges faced by women after their diagnosed cervical cancer have not yet been explored properly in Bangladesh. So, this study examined these variables in an attempt to fill this gap within gender dimension in Bangladesh. This call to action was likeable for an effort to accelerate national action towards elimination of cervical cancer among all socio-economic classes in the society. This is to make a cervical cancer story of the past and to safeguard the human rights of all women everywhere to good health and well-being, no matter where they live.

Objectives

Preliminary Study Objectives:

I. To understand the scopes and utilization of services of cervical cancer across the hierarchy of health facilities

II. To reveal association between cervical cancer and socio-economic factors of the women

III. To find out the gaps in the services in the health facilities and recommend the ways to address them from both provider and beneficiary outlook

Detailed Study Objectives:

I. To assess socio-demographic characteristics of patients with cervical cancer

II. To understand reported risk factors of patients with cervical cancer

III. To examine vulnerability of patients with cervical cancer

   a. Social vulnerability

   b. Biological vulnerability

IV. To assess knowledge of patients with cervical cancer

V. To understand relation of socio-cultural factors with patients of cervical cancer

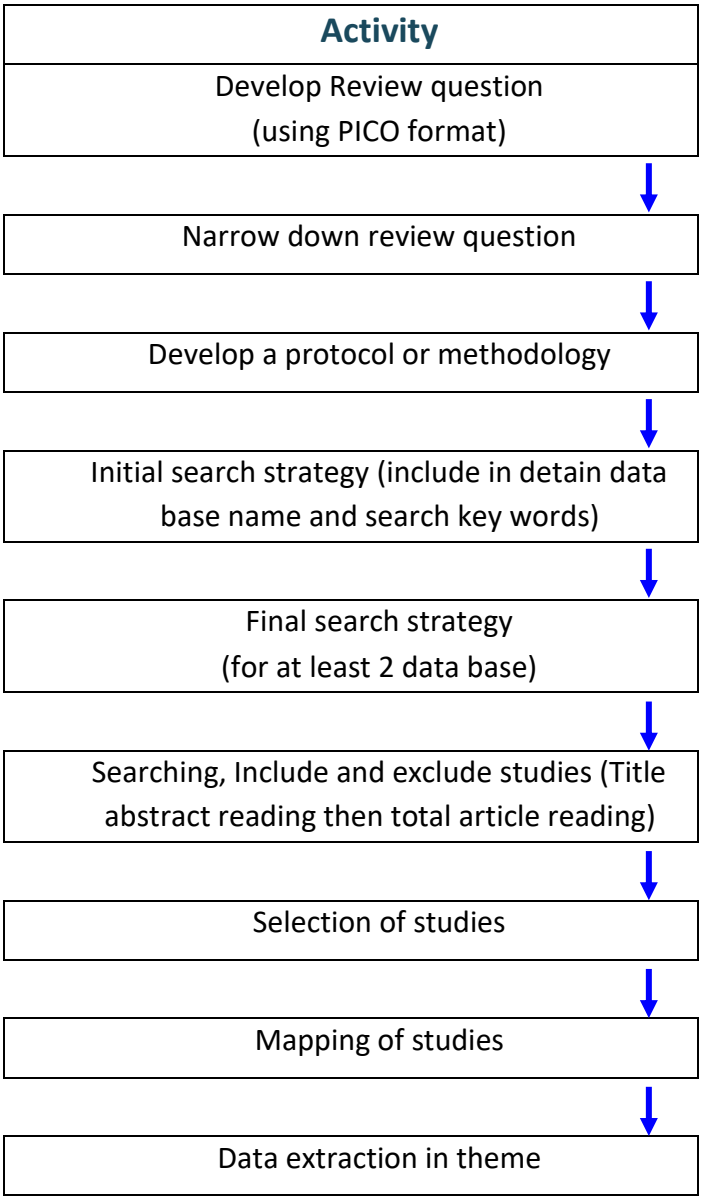
VI. To find out gaps in services and recommendations to address them from both provider and beneficiary perspectives

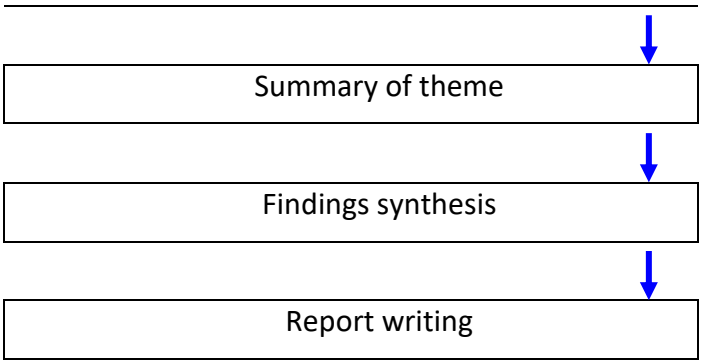
Methodology

Study design: The study employed a mixed approach; it involved a descriptive cross sectional quantitative and exploratory qualitative design.

Rapid Literature Review: A rapid review was conducted according to a pre-defined methodology including clear inclusion criteria. A comprehensive search strategy will be used, including published and grey literature, written in English. Two review authors will independently apply the eligibility criteria. Data extraction will be done by one reviewer and checked by a second. A summary of the results will be presented.

Figure 2: Proposed steps of Rapid Review





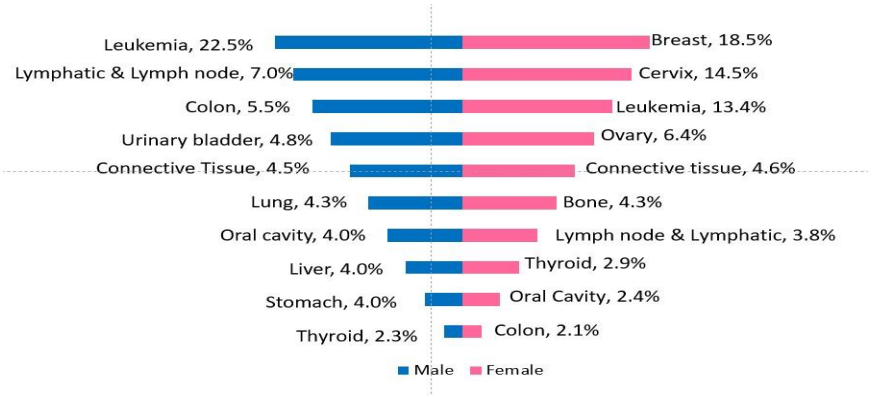
Study sites:

Table 1: Study sites

Sl. No.	Hospitals/NGOs	Tiers in Health System
1.	BSMMU	Super specialized tertiary level facility
2.	National Institute of Cancer Research & Hospital (NICRH)	Specialized Institute for Cancer
3.	Dhaka Medical College Hospital	Tertiary level Medical College
4.	Ahsania Mission Cancer and General Hospital	Private Tertiary Level Institute
5.	Mymensing Medical College Hospital	District Level Institute
6.	Jamalpur 250 Bed General Hospital	District Level Hospital
7.	Upazila Health Complex (UHC)	Upazila Level Hospital
8.	Non-government or volunteer organizations	NGO Sector

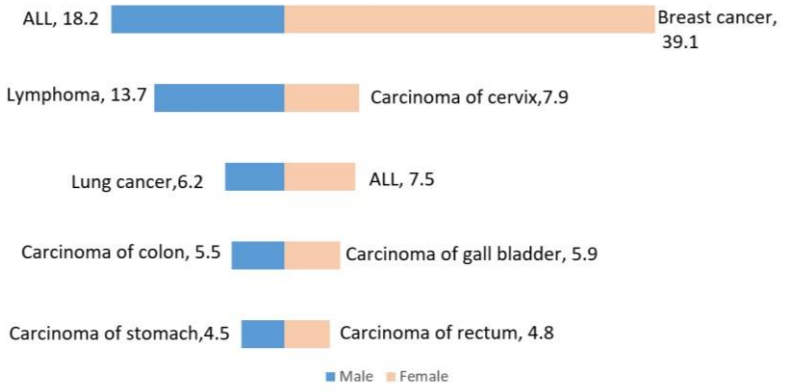
BSMMU serves as the main autonomous public hospital in Bangladesh and accepts referrals from all over the nation. It will be selected as the study site because it is the only center of excellence in Bangladesh that has a Gynecological Oncology department where surgery for the cervical cancer patients have been performed routinely and also has the department of Oncology that provides radiation therapy and chemotherapy treatments for cancer patients. Recently Cancer Registry has started in BSMMU. Types and distribution of cancer patient attending the inpatient departments of BSMMU are given below in figure 1 (Nazifa, 2019).

Figure 3: Top 10 cancers in both sexes at BSMMU in patient department



Types and distribution of cancers among the patients attending at the outpatient departments (OPD) of BSMMU are given below in figure 2 (Sharmin, 2019).

Figure 4: Top 5 cancers among male and female patients by percentage at Out Patient Department of BSMMU



National Institute of Cancer Research & Hospital (NICRH) offers an energetic and dynamic environment and staffed by well trained professionals dedicated to cancer patient management, education and research. This is the only tertiary level center of the country engaged in multidisciplinary cancer patient management. In Ahsania Mission Cancer and General Hospital, there are currently more than 12,00,000 cancer patients in Bangladesh. About 200,000 new cancer patients are added each year and 150,000 die from the disease annually.

There are various Non-Government/Voluntary Organizations which are working for awareness/prevention/early detection/treatment/psychosocial support/rehabilitation of cervical cancer patients. Here are some organizations.

Table 2: List of non-Government/Voluntary Organizations work for awareness/prevention/early detection/treatment/psychosocial support/rehabilitation of cervical cancer patients

Sl. No.	Name of NGO and Voluntary Organizations
1.	Naripokkho
2.	Cancer Pratirodh Gobeshona Kendra
3.	Gynae Oncology Society of Bangladesh
4.	Young Women' Christian Association
5.	Oporajita (Society for Survivor)
6.	Public Health Foundation of Bangladesh
7.	Community Oncology Foundation of Bangladesh
8.	The Blue-Sky Charitable Foundation
9.	Cancer Awareness Foundation of Bangladesh
10.	Bangladesh Cancer Aid Trust (BANCAT) (formerly known as Bangladesh Cancer Aid Foundation)
11.	Diganto Memorial Cancer Foundation
12.	Child and Mother Care (Projayini)
13.	Marie Stopes

Study Participants:

i. Cervical Cancer patients

ii. Service providers: Treatment Expert, Medical Officer and Nurse

iii. Administrators: Departmental Head/Chairman, UH&FPO

iv. Specialist/Experts: Gynecologist, Oncologist, Gender Specialist, Social Scientist

v. Activist/Survivors: Women Activist, Cancer Survivor

Inclusion criteria: Clinically diagnosed, subsequently confirmed, willing and physically able cervical cancer patients

Exclusion Criteria: Severe ill patients will be excluded from the study.

Table 3: Operational Definitions:

Variables	Definitions
Cervical Cancer	Cervical Cancer is the cancer of woman's cervix (the entrance to the uterus from the vagina) (WHO)
Staging of Cervical Cancer	**Stage I** The carcinoma is strictly confined to the cervix uteri (extension to the corpus should be disregarded). **IA:** Invasive carcinoma that can be diagnosed only by microscopy with measured deepest invasion <5.0 mm (involvement of vascular/lymphatic spaces does not change the staging) ○ **IA1** Measured stromal invasion <3 mm in depth ○ **IA2** Measured stromal invasion ≥3 mm and <5 mm in depth **IB:** Invasive carcinoma with measured deepest invasion ≥5.0 mm, limited to the cervix uteri ○ **IB1** Invasive carcinoma ≥5 mm depth of stromal invasion and <2 cm in greatest dimension ○ **IB2** Invasive carcinoma ≥2 cm and <4 cm in greatest dimension ○ **IB3** Invasive carcinoma ≥4 cm in greatest dimension
	Stage II Cervical carcinoma invades beyond the uterus, but not to the lower third of the vagina or to the pelvic wall. **IIA** Involvement limited to the upper two-thirds of the vagina without parametrial involvement • **IIA1** Invasive carcinoma <4 cm in greatest dimension • **IIA2** Invasive carcinoma ≥4 cm in greatest dimension **IIB** With parametrial involvement but not up to the pelvic wall

	Stage III The carcinoma involves the lower third of the vagina and/or extends to the pelvic wall and/or causes hydronephrosis or non-functioning kidney and/or involves pelvic and/or paraaortic lymph nodes. **IIIA** Carcinoma involves the lower third of the vagina, with no extension to the pelvic wall **IIIB** Extension to the pelvic wall and/or hydronephrosis or non-functioning kidney (unless known to be due to another cause) **IIIC** Involvement of pelvic and/or paraaortic lymph nodes, irrespective of tumor size and extent (with r and p notations) • **IIIC1** Pelvic lymph node metastasis only • **IIIC2** Paraaortic lymph node metastasis
	Stage IV The carcinoma has extended beyond the true pelvis or has involved (biopsy proven) the mucosa of the bladder or rectum. **IVA** Spread of the growth to adjacent organs **IVB** Spread to distant organs (Bhatla et al., 2018)
Screening	It is a test done to find a condition before symptoms begin and help find diseases and conditions early, when they are easier to treat
Cervical Cancer screening	It is the process of detecting and removing abnormal tissue or cells in the cervix before cervical cancer develops
Pap test	The Papanicolaou test is a method of cervical screening used to detect potentially precancerous and cancerous processes in the cervix
VIA	The percent of cervical cancer screenings using visual inspections with acetic acid (VIA) (also referred to as direct visual inspection), within a given timeframe (e.g. monthly, quarterly, annually), that test positive for precancerous lesions.
Age	In years

Marital status	Married, Unmarried, Separated, Divorced, Widow
Education	Primary, Secondary, Graduate, Above
Occupation	Working, Retired, Housewife
Monthly income	In taka
Family type	Extended family Other than extended family- Single person household, Nuclear family etc.
Gravidity	The total number of confirmed pregnancies that you have had regardless of outcome or the number of times the a women has been pregnant.
Parity	The total number of birth (after 24 weeks of gestation) that you have had, regardless of the outcome
Still birth	A baby born with no signs of life at or after 28 weeks' gestation.
Abortion or miscarriage	The spontaneous or unplanned expulsion of a fetus from the womb before it is able to survive independently.

Sample size:

Sample size calculation:

$$n = \frac{{Z_{\alpha/2}}^2 pq}{d^2}$$

$Z_{\alpha/2} = 1.96$ for 5% level of significance

p= prevalence of cervical cancer [5-year prevalence (all ages)] = 21.46%=0.21

(WHO Bangladesh, 2019)

q= 1-p=1-0.21= 0.79

d=level of absolute precision =0.05

$n = \frac{1.96^2 \times 0.21 \times 0.79}{0.05^2}$

=254.92

=255

Before Institutional Review Board (IRB) and COVID-19 pandemic in the beginning of March 2020 it was planned and finalized to interview participants from BSMMU, NICRH, Dhaka

Medical College (DMC) and Mymensing Medical College Hospital using probability proportional to size (PPS) sampling technique.

- Survey : 174 (Patient)
- Key Informant Interview : 11 (Service Provider : Physician and Nurse)
- In-depth Interview : 11 (Patient)
- Cases study : 4 (Patient, Activist for Cervical cancer)
- Facility assessment : 2

Data collection tools:

I. **Survey Questionnaire:** Structured questionnaire will be used for the survey of cervical cancer patients.
II. **In-depth Interview (IDIs) Guideline** will be used with selected cervical cancer patients.
III. **Key Informant Interviews (KIIs) Guideline:** It will be conducted with service providers who provide services to cervical cancer patients, experts on cervical cancer, gender specialist, NGO Leaders who deal with cervical cancer patients, women rights Leaders.
IV. **Facility Assessment Checklist** will be used for health facilities at national level, district level and in upazila level.
V. **Case Study guideline** will be used to understand a patient's course of disease and role of gender

Development of data collection tools:

a. Development of tools:

The Research Team Members have conducted thorough literature review for the development of the data collection tools i. Survey Questionnaire, ii. KII Guideline, iii. IDI Guideline, iv. Facility Assessment Checklist, and v. Case Study Guideline to understand and explore the relevant indicators, issues and questions. The draft tools were presented within Research Team and several zoom meetings were done to finalize the tools among investigators. The draft tools were presented and shared with funding partners and experts in the Methodology Validation

Workshop in March 10, 2020 to discuss the appropriateness of tools according to the objectives of the research and gain their opinion and feedback.

b. Pretesting of the data collection tools:

The tools will be pre-tested to ensure clarity, comprehension and that questions are eliciting the intended information, the process works smoothly, to explore any difficulties that may occur in the actual data collection process, to observe the interaction of data collectors with the respondents, identify gaps in the questioning of the questions. Corrections on the questions as well as overall data collection procedure will be made accordingly after completion of the pre-testing. Due to COVID-19 pandemic in Bangladesh if situation does not allow doing pre-testing the tools by face to face interview, we will also go of telephonic pre-testing of tools besides face to face pre-testing.

c. Tool finalization

After process examination the tools will be finalized by the research team through internal meeting and consultation with experts and funding agency.

Methodology validation workshop:

i. A workshop was held on 29th July at 11am-1pm in GNSPU, Dhaka.

Table 4: Data collection approach

Data Collection Activity	Research Domains	Type of Respondents	Study site
Survey	Reveal relation between cervical cancer and socio-economic factors find out gaps in the services and recommend ways to address them from both provider and beneficiary outlook	Service recipient (cervical cancer patients)	BSMMU NICRH Ahsania Mission Cancer Hospital
In-depth interview (IDI)	Reveal relation between cervical cancer and socio-economic factors Find out gaps in the services and recommend ways to address them from beneficiary outlook	Service recipient (cervical cancer patients)	BSMMU NICRH Ahsania Mission Cancer Hospital MMCH Jamalpur 250 Bed General Hospital UHC
Key Informant Interview (KII)	Reveal relation between cervical cancer and socio-economic factors Find out gaps in the services and recommend ways to address them from provider outlook	Administrators Service Providers, Cervical Cancer Treatment Expert, Gender Specialist, Women Leader, NGO/ CBO Leaders, Right-Based Activist	DGHS, DGFP, MOHFW, DMCH, Ahsania Mission Cancer and General Hospital NGO/Volunteer Organization
Case study	Understand a patient's course of disease and role of gender	Service recipient (cervical cancer patients)	BSMMU
Facility Assessment	Understand the scopes of services across the hierarchy of Health facilities.	Service facility assessments using observation checklist	BSMMU, Ahsania Mission NICRH, MMCH Jamalpur District Hospital, UHC

Patient Source:

- Patient Register:

- We collected list of cervical cancer patients from Gynecological Oncology Department, Oncology Department and Palliative Care Department.
- Listing was prepared.
- Team communicated with patients over phone and asks about their follow- up schedule.
- On their selected follow-up date face to face interviews were conducted with them by the trained data collectors.
- Written informed consent was taken from the respondents before data collection.

- Outdoor patients: Data were collected from outdoor patients after taking written informed consent by face to face interview by data collector.
- Indoor patients: Data were collected from admitted Indoor patients after taking written informed consent by face to face interview
- In-depth Interviews were recorded for transcription. Consent was taken for recording from the participant.

Key Informant Interview: After selection of KII participants. Permission letter was given to the organizational authority. After permission date and time were taken from participants. On the fixed date KIIs were done with the participants by using guideline and tape recorder.

Case Study: The cases were single case: Holistic (extreme or Unique). The cases were collected from multiple sources. A chain of evidence was maintained from research question to conclusion.

Facility Assessment: Team has taken permission from responsible authorities of the institutions. After taking permission the day will be fixed. On the fixed day facility assessment will be done by checklist by direct observation.

Data analysis:

Survey: Quantitative data was analyzed using statistical software (Stata). The analysis plan for data included summary statistics of distribution indicators using the appropriate test for significance. Descriptive statistics (mean, median, percentage, frequency, standard deviation), cross tabulation, p value (0.05 level), chi square test etc.

KII and IDI: data analysis was beginning with the first piece of information. For every interview, a full listing, whether of interviews, field notes or other items have been drawn up. Each item, e.g. transcript carries a unique identifier. As soon as data is collected, data processing was started. Researchers initiated reviewing the data and processing it for themes or patterns. A skeleton coding structure was developed to ensure consistency in the broader thematic concepts. Researcher's applied thematic codes systematically to the data and examine for patterns. The qualitative data were analyzed under pre-determined themes and emerging themes. Data analysis was conducted manually. Any particularly noticeable or curious findings may be probed as part of the qualitative component of the study, time permitting.

Case Study: Descriptive case studies were done. Data was mapped. Categorical aggregation of the data will be done. Themes, subthemes and contradictory evidences was found and documented.

Facility Assessment: Findings of summary statistics of distribution of indicators were presented in tables.

Data triangulation: Both qualitative and quantitative data will be analyzed regularly. By using data triangulation, we will produce valid results that will broaden our views and enhanced our understanding and we will prepare a result with more comprehensive pictures. The summary findings will be included in reports, shared with stakeholders for feedback and comments. If required, additional qualitative data will be collected to help interpretation of data obtained in quantitative research.

Data Collection: Survey and facility observation information were done using questionnaire and observation checklist by data collectors. IDIs, KIIs and case studies were done via face-to-face interviews following guidelines. Research coordinator supervised the whole process.

Data validation workshop:

i. A workshop was held on October, 19th at 2pm to 4pm in GNSPU, Dhaka.
ii. A workshop was held on October, 28th at 10am to 2pm in MMCH, Mymensingh.

Data storage: Filled up data collection sheets were kept in a specific file cabinet of Principal Investigator's Office in BSMMU under lock and key. Data manager had written permission from Principal Investigator (Dr. Fariha Haseen) and Study Advisor (Professor Syed Shariful Islam) to access the file cabinet. A register book was maintained with date and time by Data Manager and Principal Investigator.

Ethical Issues to be addressed:

Potential risks-physical, psychological, social, legal or other risk:

No invasive procedure was used during data collection. If any participant seems distressed due to interview or study participation, they had the option of refuse/stopping the interview and were offered necessary counseling and supports, if any occurs. Participants were informed that they may opt not to respond to questions or they may terminate the interview at any time.

Methods of confidentiality or protecting anonymity:

We took protected the information of the participants. Information which identifies her/him will be kept secured and restricted with a code number. The information was only be used for research purpose. Anonymity and confidentiality were maintained in all stages of the study.

Ethical Consideration:

Permission and ethical clearance was taken from the BSMMU Institutional Review Board (IRB). The research objectives and procedure were explained to every study individual and their guardians before start of interview. Authorized permission letter was issued from all the

departmental head of all the institutions. Informed written consent from participants was obtained before interview. Confidentiality was maintained at every stage of data collection for every individual. The final report will not contain the names of the participants.

Every attempt was made to limit harmful effect of the study either on the family or on the individual. In order to document the consent from illiterate individuals, Bengali version of consent form was read out, after that be signed by respondent. The uneducated respondent or guardians were asked to put their thumb impression. Interviews were conducted at times and locations suitable to the study individuals and privacy will be maintained during assessment.

Process of obtaining Informed Consent:

The respondents were informed about the objective, purpose of the study and other relevant information of the study. The participation was voluntary.

Quality assurance: This study was implemented with a team of researchers (Health System and Gender Specialist, Qualitative Research Expert, Cervical Cancer Specialist, Statistician, Quantitative Data Analysis Expert). To ensure standardization and good quality of data, 6 (Six) days training was given on consent forms, survey questionnaire, KII, IDI, Case Study Guideline and Facility Assessment Check List. Data collection and supervision were carried out by Data Manager who had previous data collection experience. Supervision was done by PI, Co-investigators and Research Officer throughout the data collection time.

Result

Literature Review: In Bangladesh approximately 8,068 new cases are detected every year, and over 5,214 deaths occur due to severity of the disease. Ferdous et al. (2013) reported cervical cancer is approximately 7.8% of all gynecological patients and 70% of all gynecological malignancies admitter in BSMMU, Bangladesh.

Disparities exist in cervical cancer incidences between different subgroups of women. Men and women cannot be divided into two homogenous groups, and people's group memberships such as gender, age, ethnic background, sexual orientation, religious affiliation redefine each other. (Ivan et al, 2013).

Intersectionality is an approach that addresses the way gender and other social identities affect life, and refer to mutually constitutive relationships that influence each other. (Crenshaw, 1993). The construction of gender and the subordinate position of women in the family and society affect disease process. (Learmonth et al, 2015). Cervical Cancer occurs worldwide, but most women who die from cervical cancer live in less developed countries. Every year, more than 270 000 women die of cervical cancer, 85% of them in low- and middle-income countries. (WHO, 2014).

Other behavioral factors include: multiple sexual partners, early age at first sexual practice, early marriage, polygamy, multiple births (high parity), co-infection with other sexually transmitted infection, tobacco and alcohol consumption (Munoz N, Bosch FX, 1992).

Assessment of the socio-demographic characteristics of patients with cervical cancer

Figure 5 : Distribution of Respondents' age (N=174)

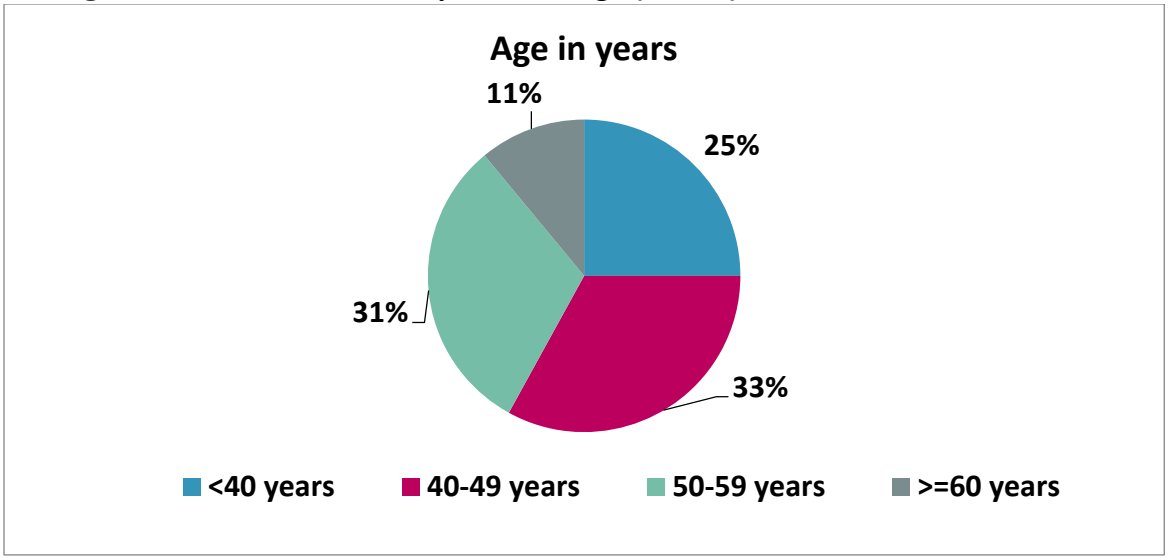


Figure 5 shows that around 33% respondents aged between 40-49 years.

Figure 6: Distribution of Respondents' Residence (N=174)

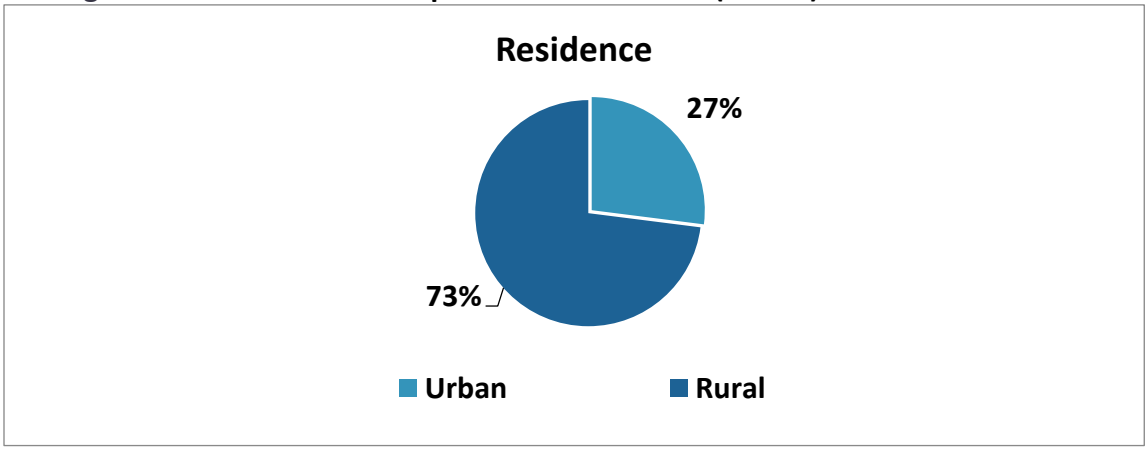


Figure 6 shows that around 73% respondents reside in the rural areas.

Figure 7: Distribution of Respondents' Educational Status (N=174)

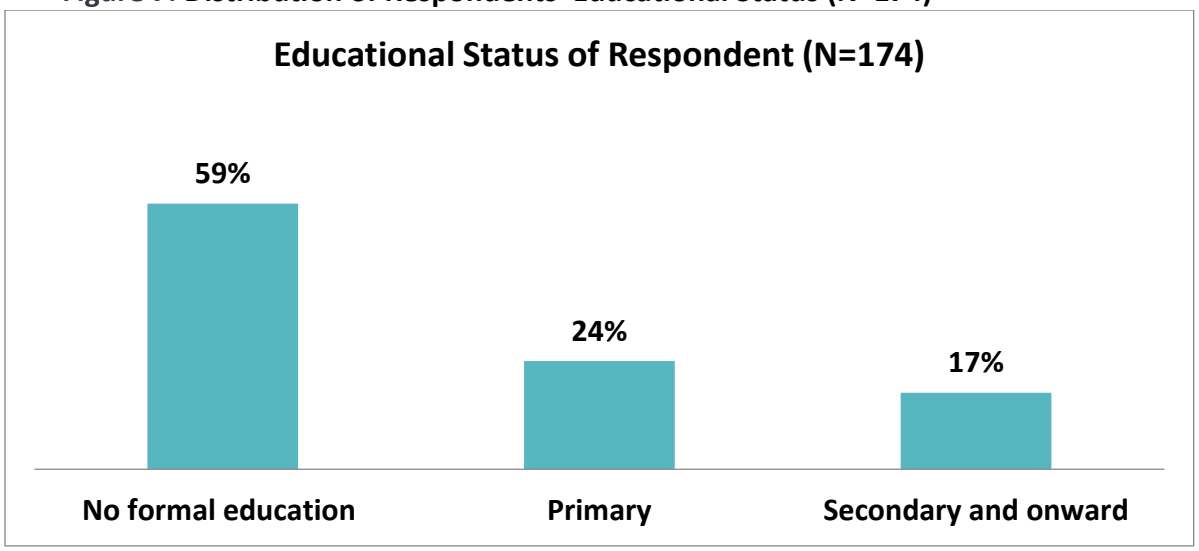


Figure 7 show that the percentage of women with no formal education around 59% and the percentage of women with primary education had around 24%.

Figure 8: Distribution of Educational Status of respondents' Husbands (N=174)

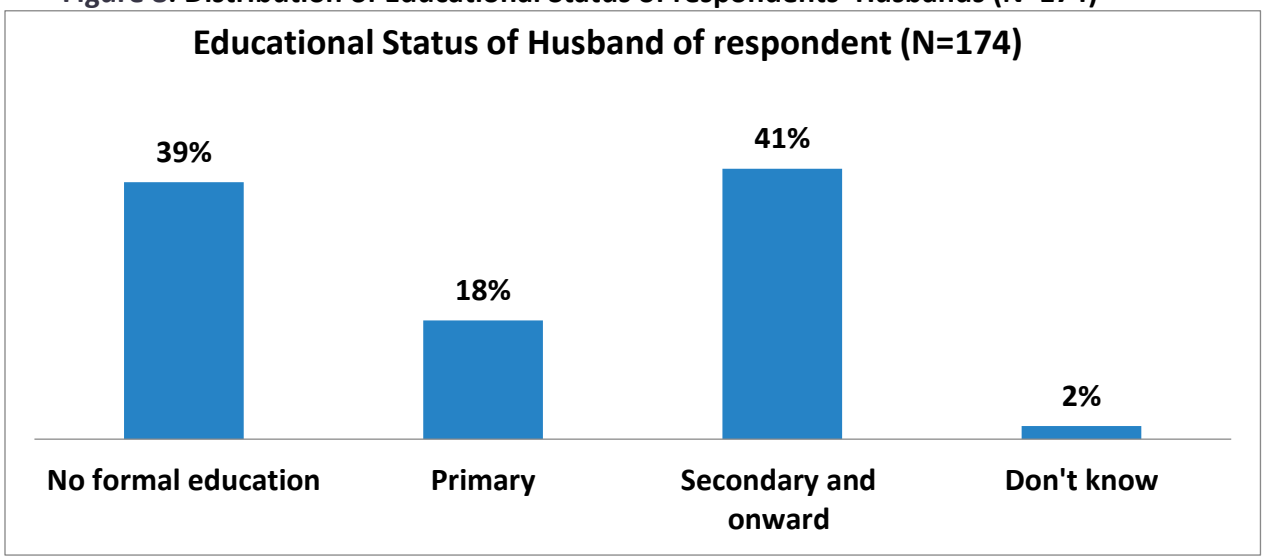


Figure 8 show around 39% respondents' husbands were illiterate and around 41% were completed secondary or higher education.

Figure 9: Distribution of respondent's working status (N=174)

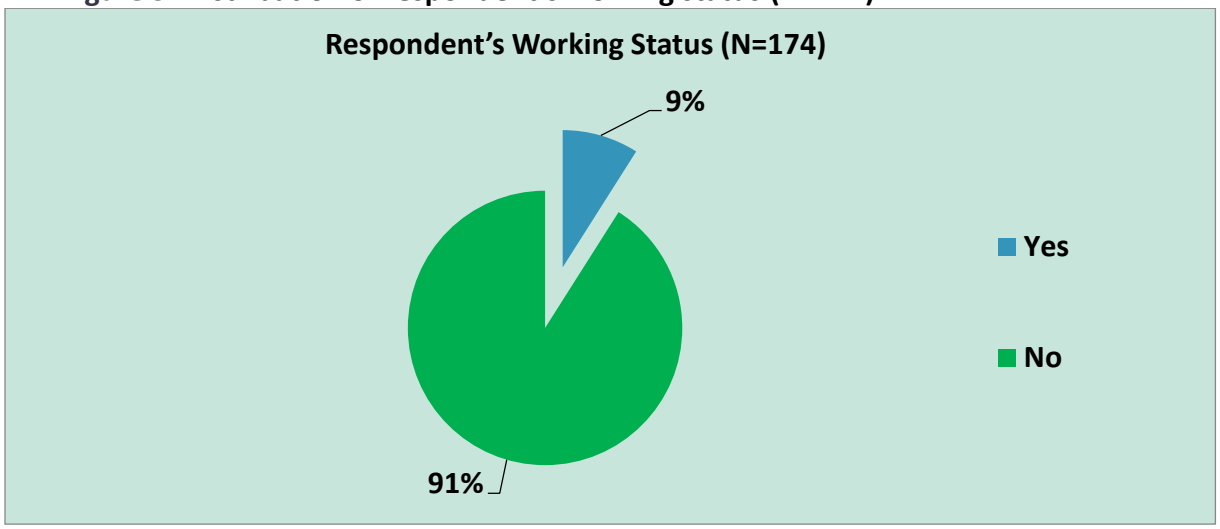


Table 9 shows almost 91% respondents were not currently doing any earnable work they were housewife, around 9% were currently doing work.

Table 5: Cross-tabulation between Age (in years) and Marital status of the respondents (N=174)

Marital status	Age (in years)	
	Less than and equal 40 years (%)	More than 40 years (%)
Living with husband	12%	88%
Widow/Separated/Divorced	38%	62%

Table 5 shows that percentage distribution between age of the respondents within their Marital status where, around 88% respondents aged >40 years who lived with their husband and around 62% respondents aged >40 years who were widow/divorced/Separated.

Table 6: Wealth Index of respondents (N=174)

Wealth quintile	Frequency	Percentage
Poorest	35	20

Poor	35	20
Middle	35	20
Rich	35	20
Richest	34	20

Wealth index (WI) is a composite measure of a household's cumulative living standard. WI is calculated using a household's ownership of selected assets, such as TV, mobile phone; materials used for housing construction; types of water access and sanitation facilities. WI is constructed following the guidelines of Filmer and Pritchett (2001). In this study WI will help to compare influence of wealth on respondents' cervical cancer prevention and treatment.

Table 6 shows that around 20% of the respondents were belong from poorest and poor economic background.

Table 7: Cross-tabulation between Age (in years) of cervical cancer patients and wealth quintile of the respondents (N=174)

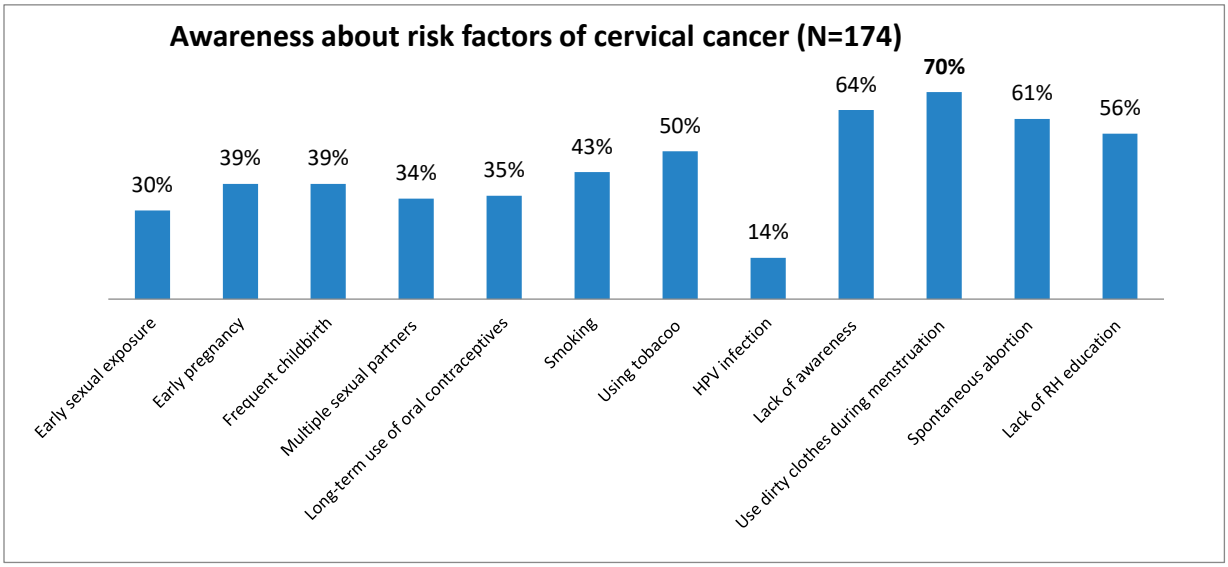
Wealth quintile	Age (in years)	
	Less than and equal 40 years (%)	>40 years (%)
Poor	29%	71%
Middle	29%	71%
Rich	17%	83%

Table 7 shows that percentage distribution between age of the respondents within their wealth quintile where, around 83% respondents aged >40 years who belong from poor economic background.

Qualitative findings also revealed that most of the respondents (service recipients) were older age people, House wife, lived in rural area, had poor education background, experienced early marriage, early, and frequent pregnancy. Considering marital status most of them were widow.

Assessment of the risk factors of patients with cervical cancer

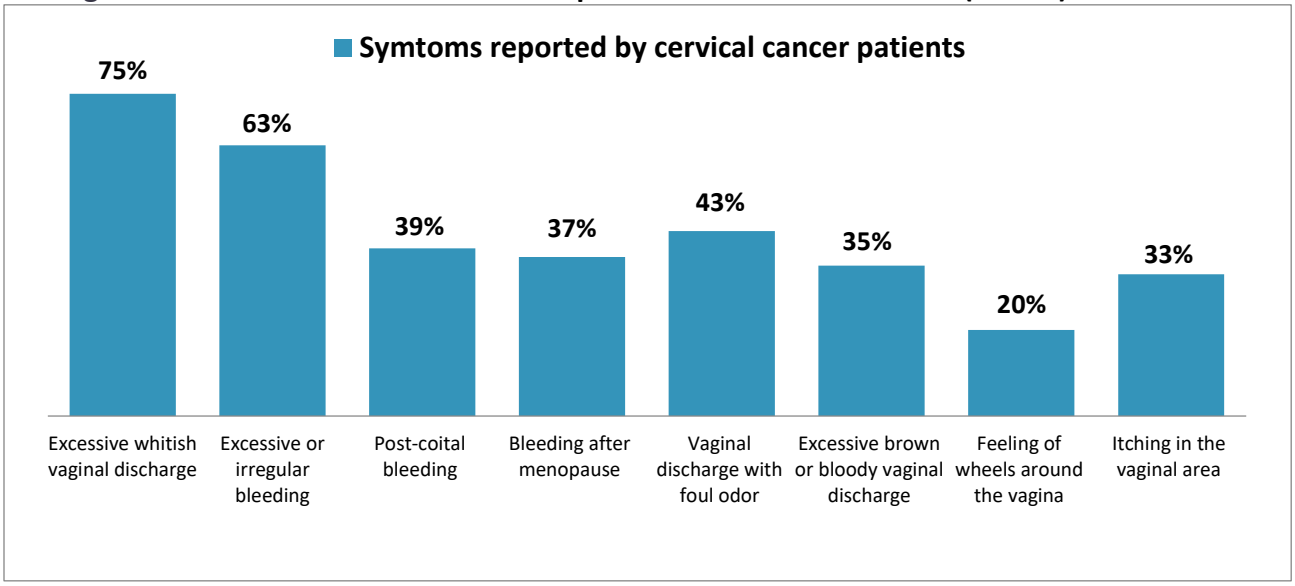
Figure 10: To assess the risk factors of patients with cervical cancer (N=174)



*Multiple responses

Figure 10 shows that a bar chart of multiple response where 70% respondents said use dirty clothes during menstraution is a rist factor of cervical cancer around 64% respondents said lack of awareness is another risk factor for cervical cancer.

Figure 11 : To assess the risk factors of patients with cervical cancer (N=174)



*Multiple responses

Figure 11 show that excessive whitish vaginal discharge and excessive or irregular bleeding were one of the symptoms of cervical cancer in approximately 75% and 63% of respondents, respectively.

During qualitative interview with physicians it was found that there is a close association between poor socio-economic status and development of cervical cancer. Usually women from low socio-economic background have limited access to education. Low level of education prevents them to be empowered and to acquire proper knowledge regarding health. Most of the women from poor socio-economic background are not knowledgeable about hygiene maintenance during intercourse, and menstruation. They are not aware of screening of cervical cancer and available services in facilities.

Respondents shared that early marriage is very common in families of low socio-economic background. Early marriage prevented girls to continue education, and led to early onset of sexual exposure and early pregnancy. Frequent pregnancy is also observed among women from low socio-economic status. All factors increase the chance to develop cervical cancer.

> ***"Women who get married at a young age are more likely to be infected and usually we get more patients like that."*** **Medical Officer, Mymensingh**

In addition that gender inequality in our society, polygamy characteristic of men and women, and parents' low education level, etc. contributed to develop the illness expressed by the key informants. We have also interviewed sisters who are closely involved with cervical cancer screen and treatment. According to them women from low-socio-economic status are belong to extended family, and their scope of education is little.

Assessment of the vulnerability of patients with cervical cancer

i. Socio-cultural vulnerability

Figure 12 : To assess the risk factors of patients with cervical cancer (N=174)

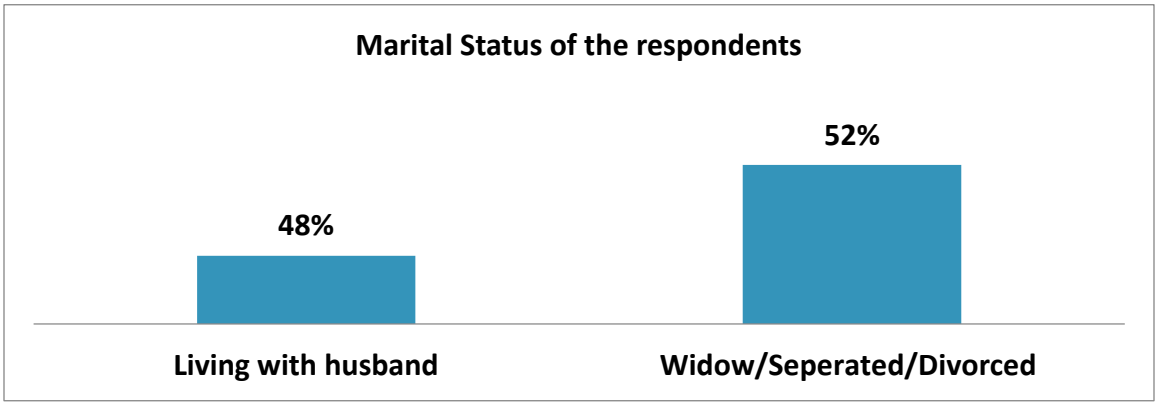


Figure 12 show that 52% respondents were widow, seperated and divorced, they were not living with their husband.

Figure 13: To assess the risk factors of patients with cervical cancer (N=174)

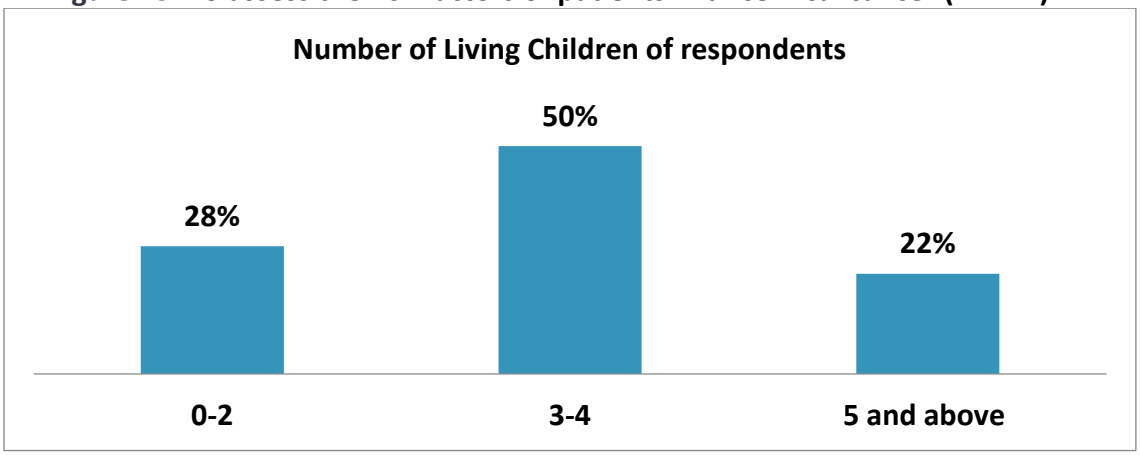


Figure 13 show that around 50% of the respondents had 3 to 4 children and around 22% respondents had 5 and more than 5 children.

Figure 14: Percentage of those with whom respondents first shared their problem (N=174)

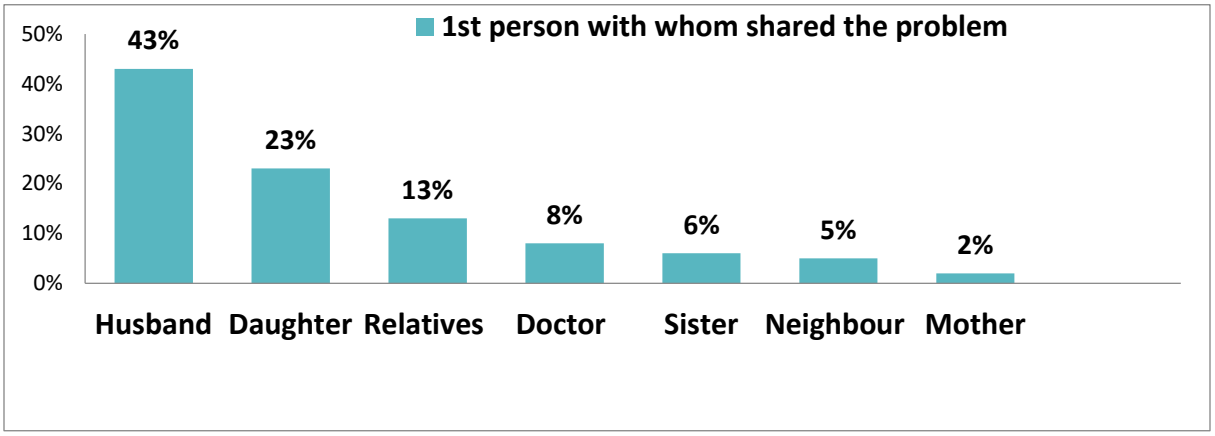


Figure 14 show that around 43% respondents shared their problem with their husband.

Figure 15: To assess the risk factors of patients with cervical cancer (N=174)

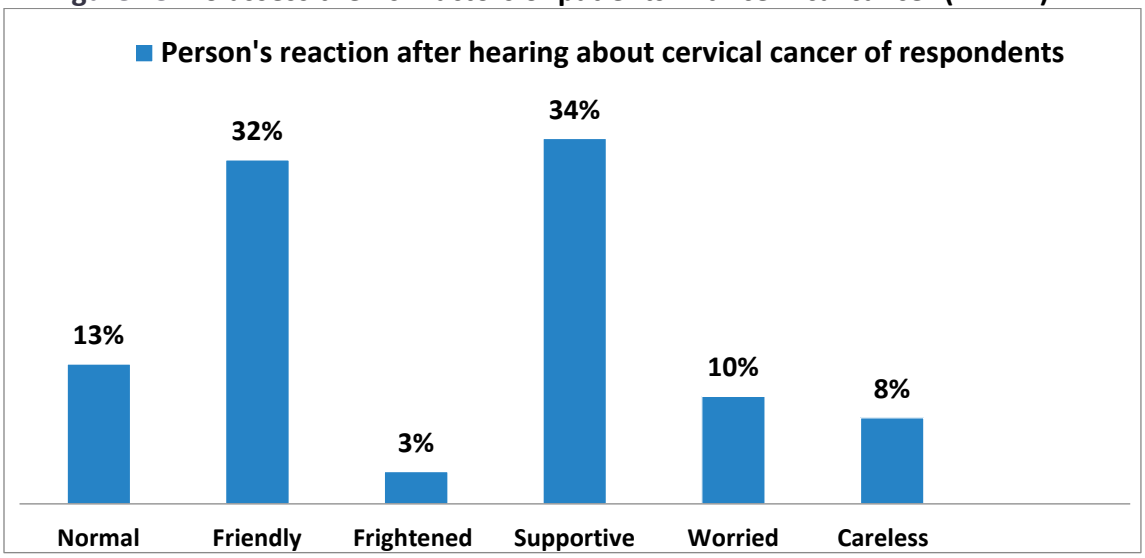


Figure 15 show that 34% persons were supportive to the respondents after hearing about cervical cancer.

Figure 16: Distribution of respondents who start treatment immediately after diagnosis (N=174)

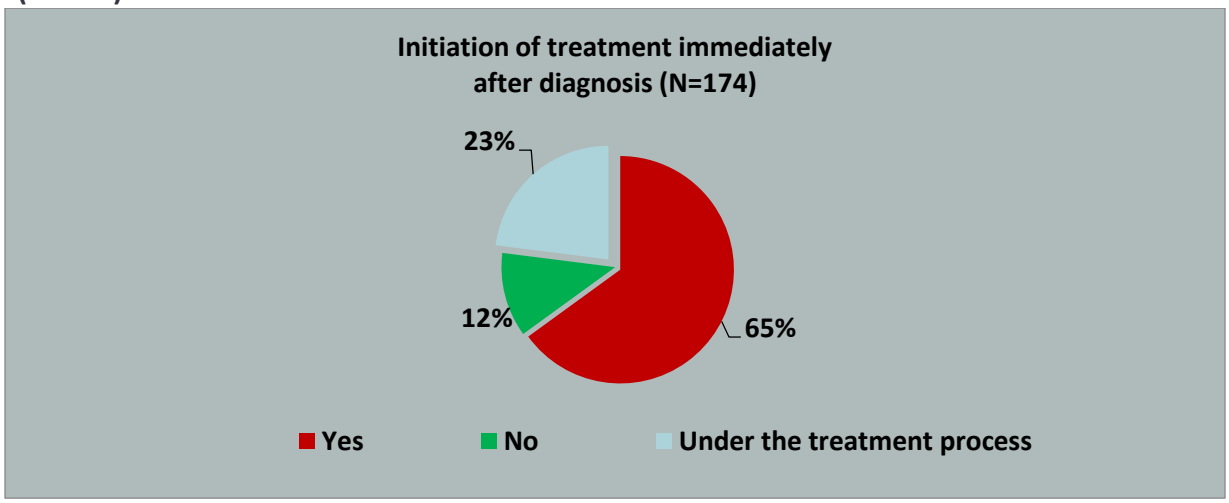


Figure 16 show that around 65% respondents start treatment immediately after diagnosis, around 12% respondents were not start treatment immediately after diagnosis and around 23% respondents were under the treatment process.

Figure 17: Distribution of respondent's cause of delay to initiation of treatment (N=20)

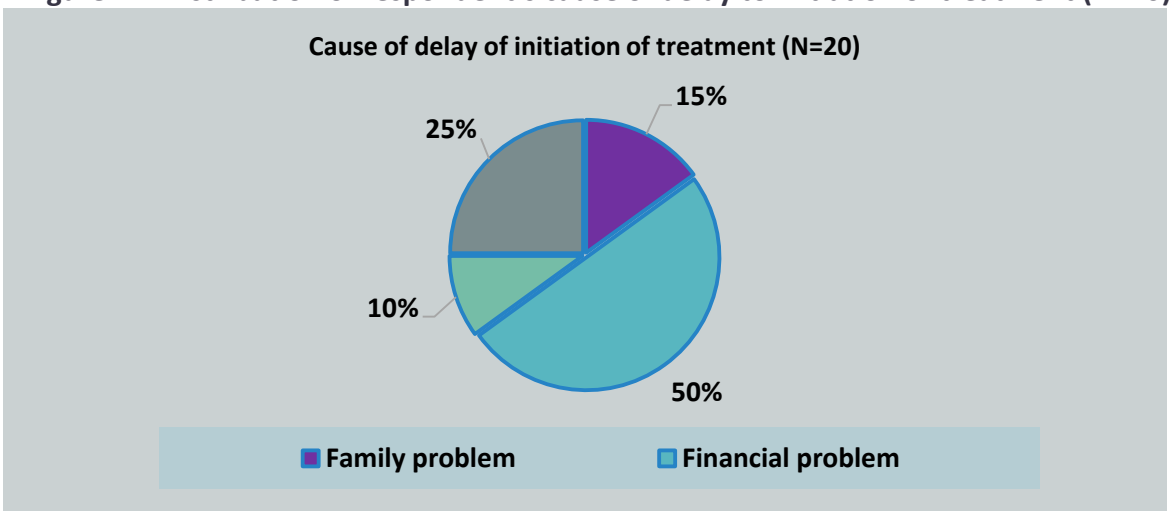


Figure 17 show that around 50% respondents said they didn't start treatment immediately due to financial constrain.

Figure 18: Distribution of respondents who faced obstacle during treatment (N=147)

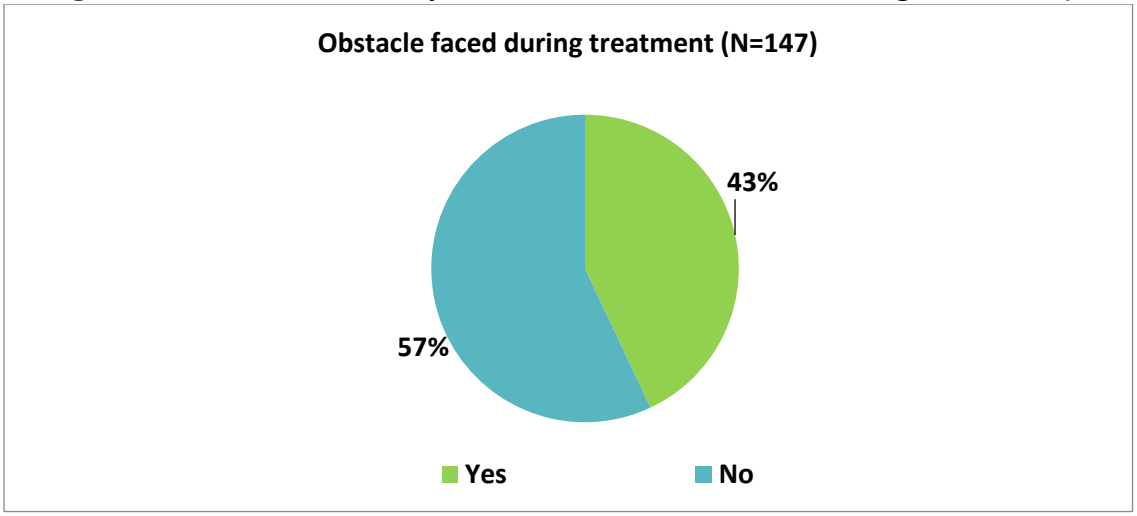


Figure 18 show that 57% respondents faced obstacle during treatment.

Figure 19: Distribution of respondent's types of obstacle during treatment (N=147)

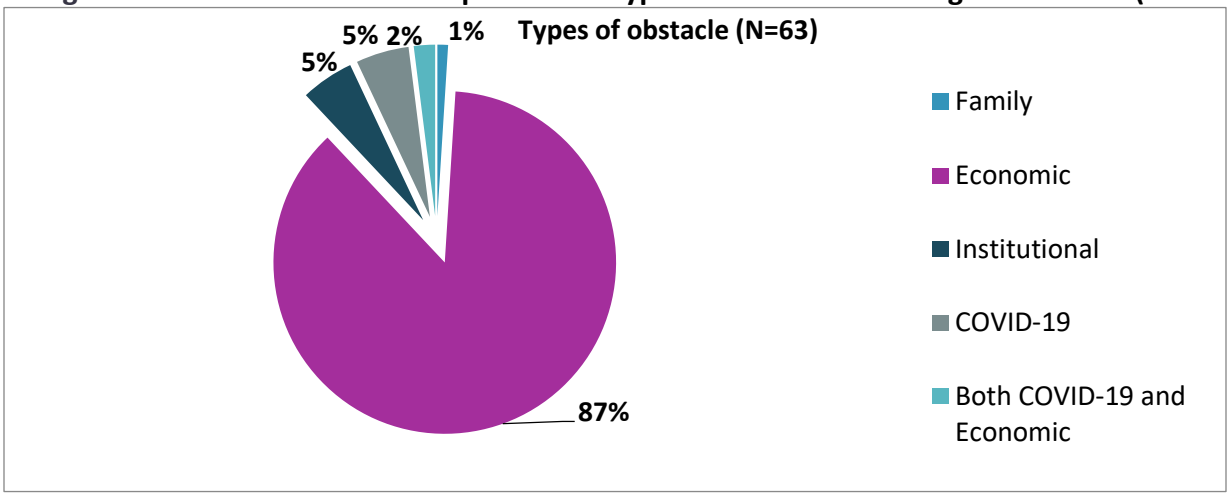


Figure 19 show that around 87% respondents faced economic obstacle during their treatment.

Figure 20: Distribution of respondent's discontinuation of treatment (N=147)

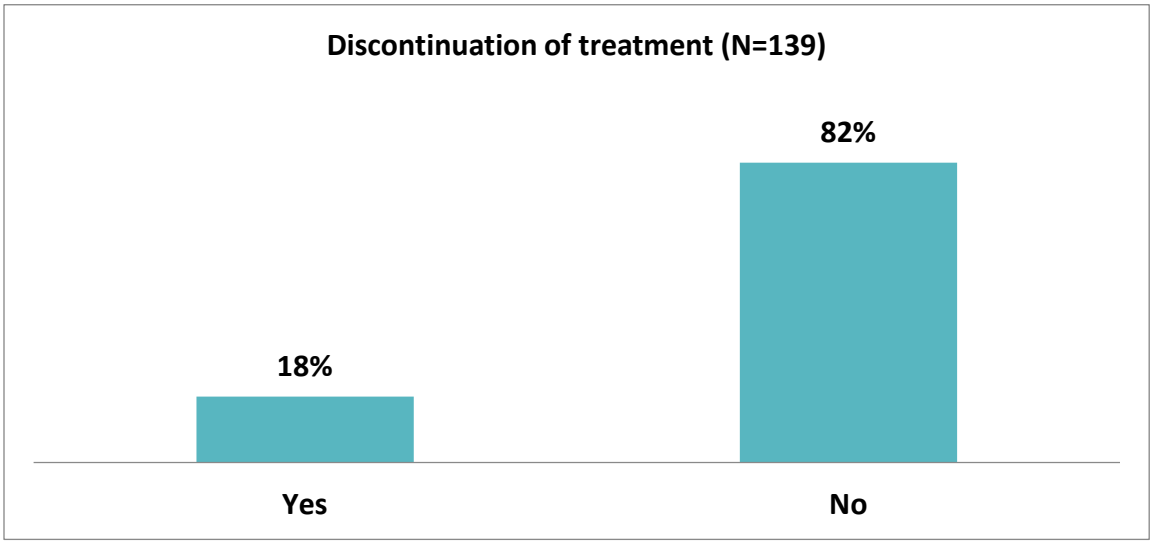


Figure 19 show that around 18% respondents discontinue their treatment during their treatment process.

Figure 21: Distribution of respondent's discontinuation of treatment (N=147)

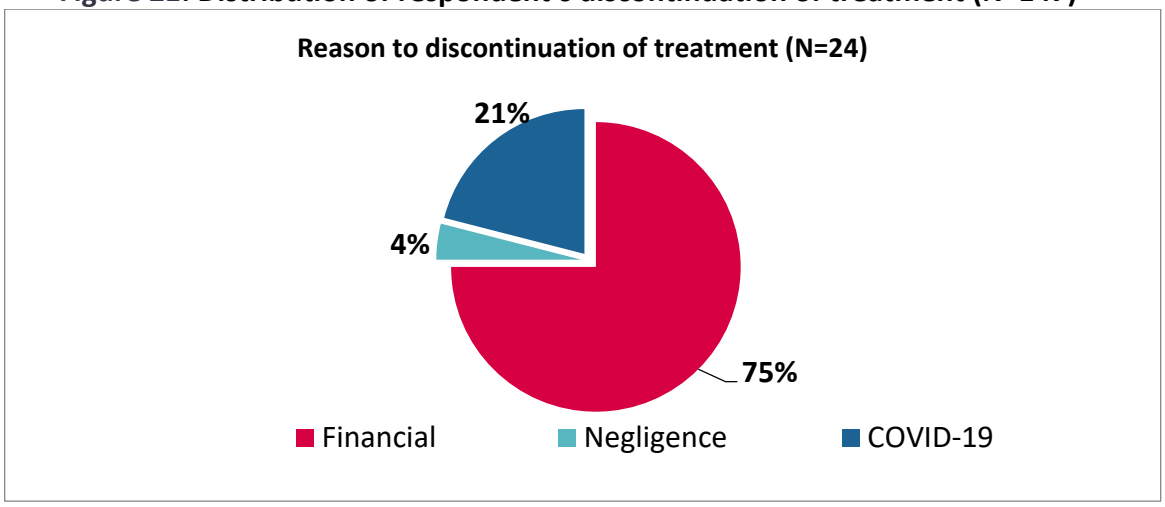


Figure 21 show around 75% respondents faced financial obstacle during their treatment and around 21% respondents were discontinue their treatment due to COVID-19.

Figure 22: Distribution of source of expenses for treatment of the respondent's (N=147)

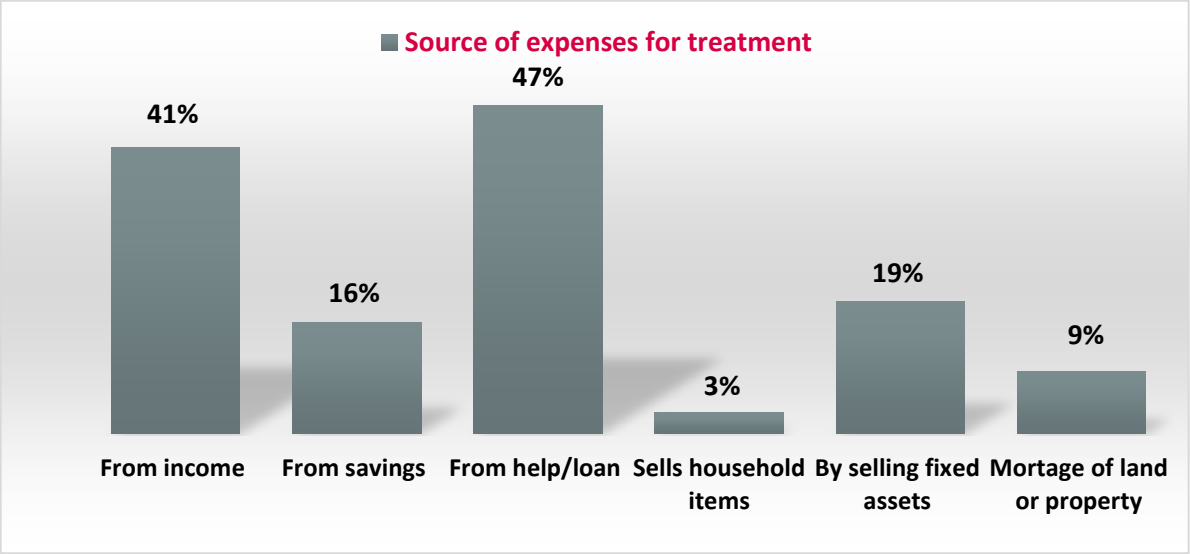


Figure 22 show around 47% respondent's source of expenses for treatment was loan and around 16% respondent's expenses from savings to continue their treatment.

ii. Biological vulnerability

Figure 23: Distribution of age at marriage of the respondents (N=174)

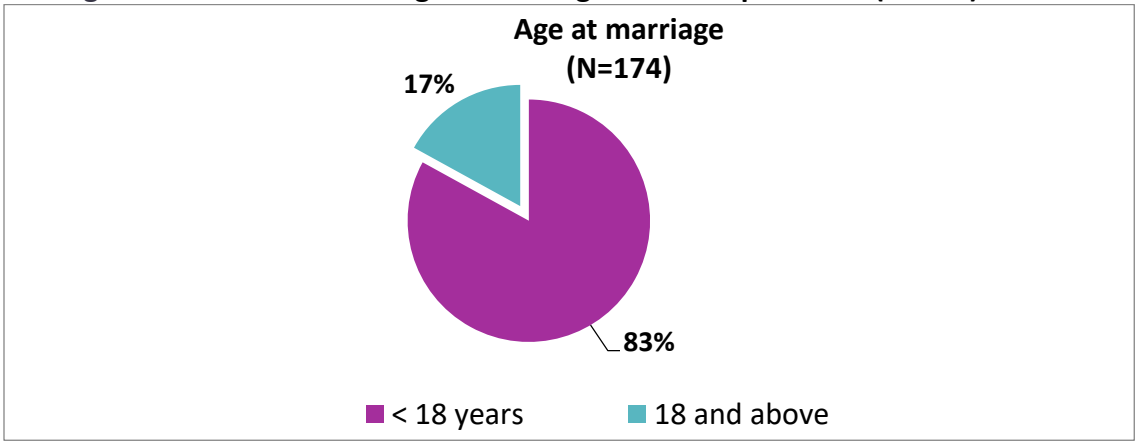


Figure 23 shows around 83% respondents married before the age of 18 years and around 17% respondents married 18 and above 18 years.

Figure 24: ***Distribution of age at 1st pregnancy of the respondents (N=174)***

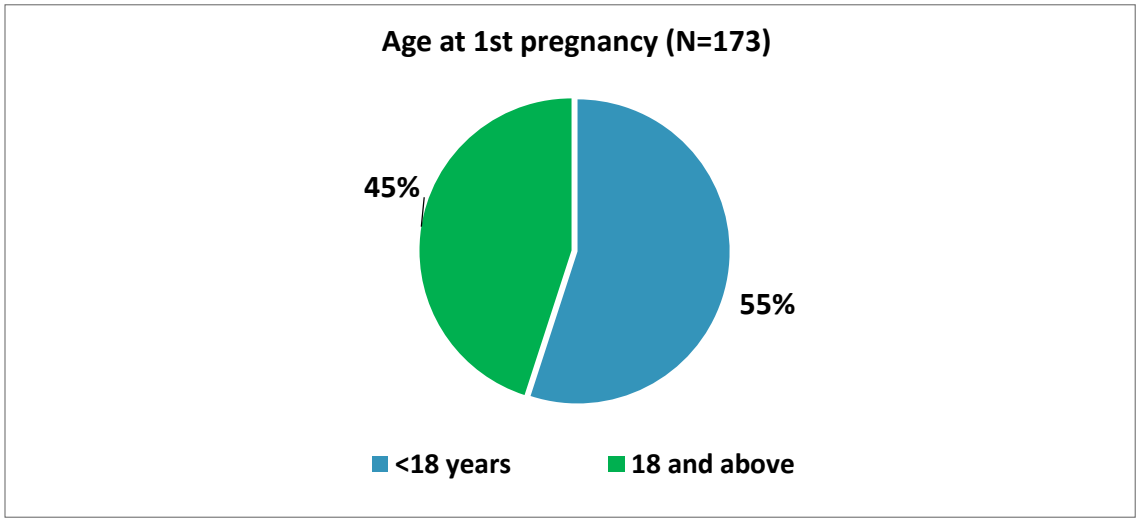


Figure 24 shows that 55% of respondents became pregnant for the first time between the ages of 18 and above 18 years and about 42% of the respondents became pregnant for the first time <18 years.

Figure 25: Distribution of total number of pregnancy of the respondents (N=174)

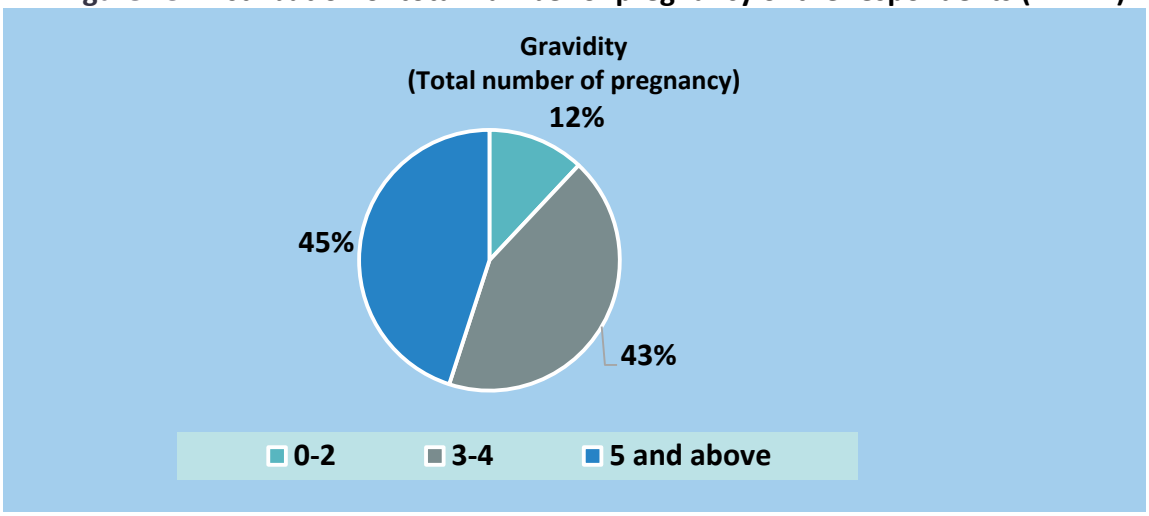


Figure 25 shows that around 43% respondent's total number of pregnancy was 5 and above in number.

Figure 26: Distribution of total number of delivery of the respondents (N=174)

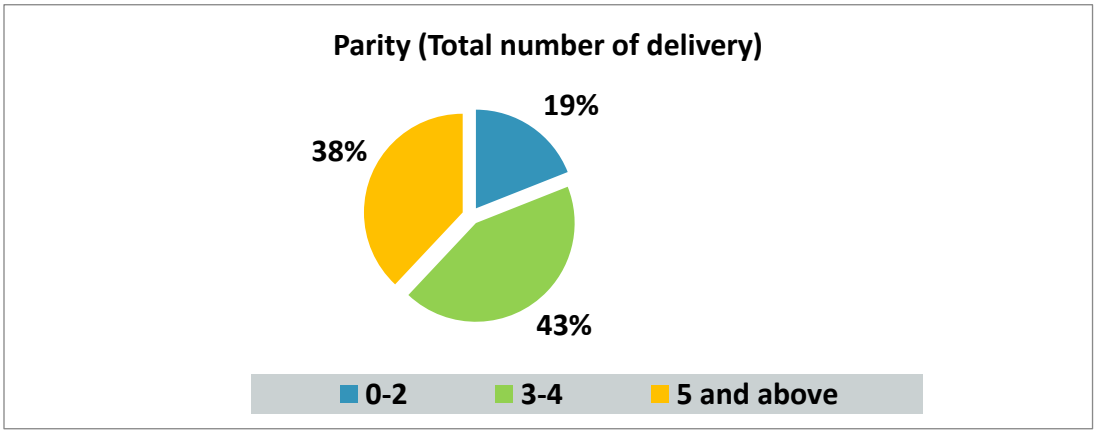
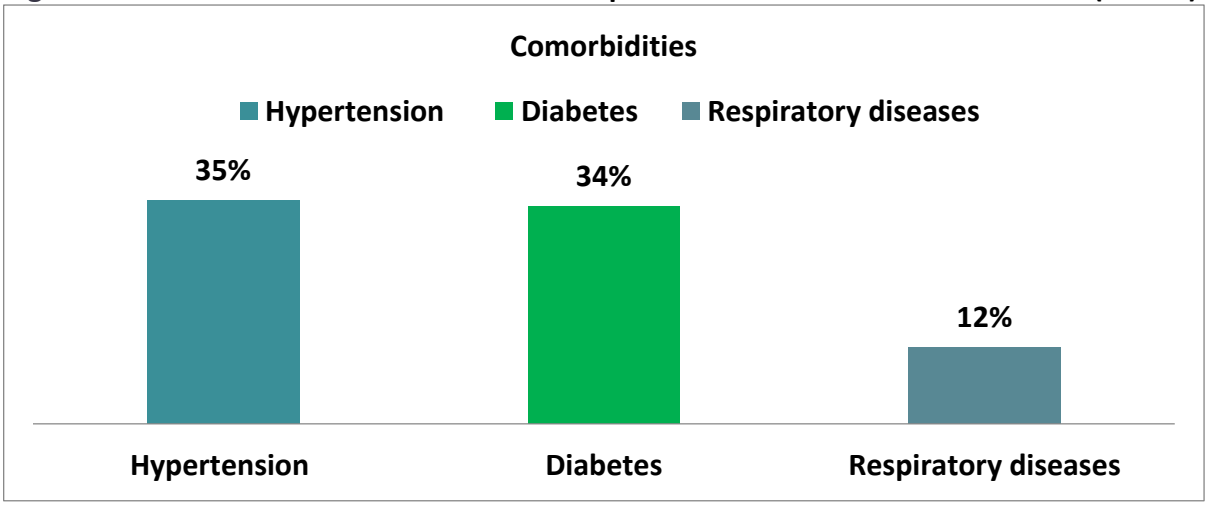


Figure 26 shows that around 43% respondents' total number of delivery were 5 and above and around 38% respondents' total number of delivery were 3-4 in number.

Figure 27: Distribution of comorbidities of respondents other than cervical cancer (N=174)



*Multiple responses

Figure 26 shows that about 35% of respondents had high blood pressure and around 34% had diabetes along with their cervical cancer.

Table 8: Cross-tabulation between Age (in years) of cervical cancer patients and number of living children (N=174)

Number of living children	Age (in years)	
	Less than and equal 40 years (%)	More than 40 years (%)

<2	48%	52%
3-4	23%	77%
5 and above	3%	97%

Table 8 shows that percentage distribution between age of the respondents within their number of living children where, around 97% respondents aged >40 years who had 5 and more than 5 number of children.

Qualitative interviews identified social, cultural, economic, and geographical vulnerabilities. During qualitative interviews it was found that most of them felt shame to share illness with family members, and service provider. In addition that poor education, unemployment, lack of awareness about preventive measure and available services at facility make them vulnerable. Male dominated society is also linked with delayed family decision regarding treatment. One of the respondents stated that

My marriage was done when I was maybe at the age of 15 years. I arranged my elder daughter's marriage at the age of 14. Now she is 19 years. Service recipient

According to a physician

"The squamo-columnar junction is mainly vulnerable part of the girls and have premature cell in the early age. Later, these premature cells make them vulnerable to cervical cancer due to early sexual exposure." Physician

All most al of the respondents both from poor and well off families faced financial constraint to continue treatment because of expensive treatment procedure. Besides it was found that awareness, hygienic life maintenance are also influenced by the financial solvency.

"……..there is a link between poverty and sanitization, as poor people have low income & lack of health awareness; they use dirty clothes instead of pads due to lack of money …which leads to cancer in future." Nurse

Additionally distance from home to health facility was found as another vulnerability. Living in remote area is linked with limited facility visit.

"Patients are not able to take therapy, cannot maintain schedule properly as their residence is far from health center." Physician

Table 9: Cross-tabulation between age (in years) and total number of conception (Gravidity) (N=174)

Total number of conception (Gravidity)	Age (in years)	
	Less than and equal 40 years (%)	More than 40 years (%)
<2	57%	43%
3-4	34%	66%
5 and above	9%	91%

Table 9 shows that percentage distribution between age of the respondents within their total number of conception where, around 91% respondents aged >40 years who had total the number of conception was 5 and more than 5 in number.

Case study finding revealed that different issues e.g. gender inequality, education, patient's family's economic status, women's position in the family, negative attitudes towards women in the society influences treatment procedure. In addition that distance from home to health facility, availability of female doctors, privacy maintenance in facility, proper screening, and referral system are linked to the treatment procedure.

Assessment of the knowledge of cervical cancer patients

Figure 28: Awareness about cervical cancer, screening and HPV vaccination (N=174)

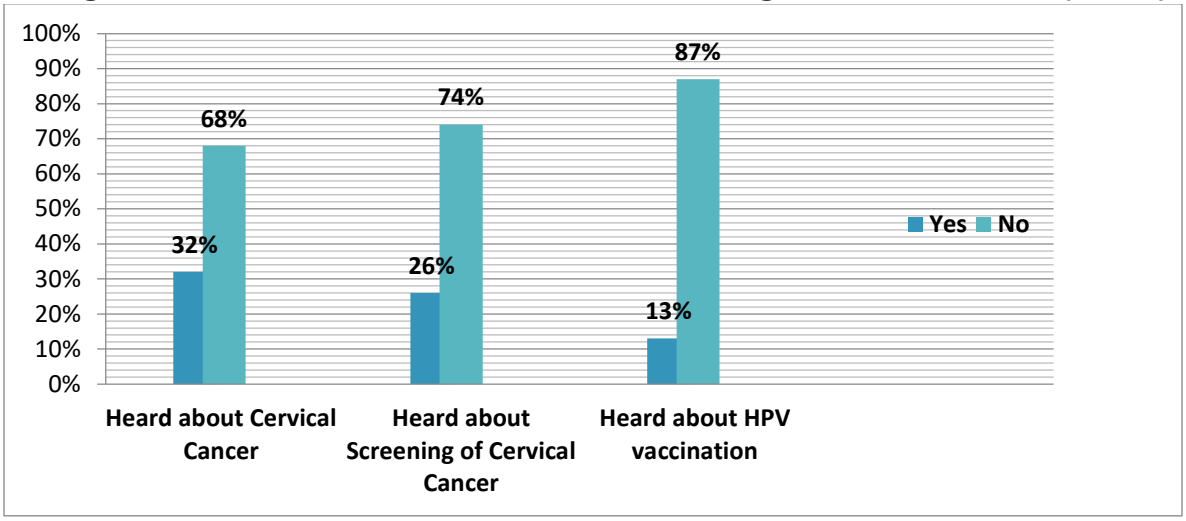


Figure 28 shows that 68% respondents were not heard about cervical cancer and around 74% not heard about screening and around 87% never heard about HPV vaccination before their diagnosis of cervical cancer.

Table 10: Cross-tabulation between Age (in years) and knowledge about cervical cancer of the respondents (N=174)

Heard about cervical cancer before diagnosis	Age (in years)	
	Less than and equal 40 years (%)	More than 40 years (%)
Yes	31%	69%
No	23%	77%

Table 10 shows that percentage distribution between ages of the respondents within their knowledge about cervical cancer of the respondents where, around 77% respondents had no knowledge about cervical cancer before diagnosis of cancer.

Table 11: Cross-tabulation between Age (in years) and knowledge about the screening of cervical cancer of the respondents (n=174)

Heard about the screening of cervical cancer before diagnosis	Age (in years)	
	Less than and equal 40 years (%)	More than 40 years (%)
Yes	36%	64%
No	22%	78%

Table 11 shows that percentage distribution between ages of the respondents within their knowledge about the screening of cervical cancer of the respondents where, around 77% respondents had no knowledge about the screening of cervical cancer before diagnosis of cancer.

Qualitative finding shared that the entire respondent had no knowledge about preventive measure of cervical cancer before diagnosis.

Gaps and recommendations to address them from both provider and beneficiary perspectives

We have asked key informants' opinion regarding Gaps in the services "gaps in cervical cancer" related services. They focused on different issues. According to them major gaps are -

- Insufficient service providers
- Insufficient gender matched service provider
- Insufficient trained counselor
- Insufficient Screening room
- Lack of proper referral system
- Insufficient medicine supply
- Long waiting time to get radiotherapy serial
- Lack of trained human resource to operate machine
- Some of the radiotherapy machine were out of order
- Lack of privacy

To minimize gaps key informants suggested

- Campaigning all over the country to raise awareness about prevention, treatment.
- Arrange awareness program during school health program
- Share information in DGFP organized courtyard session, through media
- Ensure door-to-door vaccination services including free vaccine

  "If HPV vaccine can be included in the Government's immunization schedule, then it will help a lot." Medical Officer, **Mymensingh**
- Ensure VIA test facilities in upazila sub center.

They also focused on counseling. According to them

- Counseling should be considering patient's local culture e.g. using local language
- Appoint counselor at VIA center
- Pre and post counseling for personal level, family level, and community level

Beside counseling need to motivate women for screening, motivate both husband and wife to maintain personal hygiene, use condom. Take initiatives to prevent early marriage.

Ensuring ***women friendly environment at facility*** through ensuring privacy during service delivery, arranging separate toilet for women,

Case study: To prevent cervical cancer need to focus on women empowerment e.g. ensures women's education, economic

gender matched service provider, all services in one specific place, separate cervical cancer unit, and separate radiation services for cervical cancer patient.

One of the respondent stated that
"If a women will give radiotherapy then it will be comfortable for us" Service recipient

freedom, raising awareness, decision making power at family level.

Besides need to take initiatives to make health facilities **"Women friendly".**

"Cervical cancer can be prevented through making all hospital women-friendly and creating the mentality of going to the doctor among women." Women Leader

Case Study 1: Old Aged woman with cervical cancer

A woman aged 73 years lives in rural area. She got married at 15 years & conceived after 2 years of marriage. She conceived 13 times. After having symptoms shared her problem with daughter. She was diagnosed during primary stage. She had no idea about prevention of cervical cancer before diagnosis. She visited doctor after starting white discharge & bleeding. After that she visited different cancer treatment specialists. She had an operation in Dhaka. Now she is feeling better. She expressed her satisfaction about present treatment.

Case Study 2: Young aged Woman Cervical

A 35 years old cervical cancer patient got married at 15/16 years of age, and conceived during 1st month of marriage. She was not aware of cervical cancer before diagnosis.

Initially she was diagnosed as pregnant, later she had miscarriage and wen to govt. hospital. But problem continued, after few months, from private facility she came to know that she has tumor, & suggested to go to Rajshahi or Dhaka. Her family quickly moved to Dhaka & admitted her at NICRH. Patient's brother & husband jointly took decision regarding treatment. She visited doctor immediately after starting heavy bleeding. Although she had no idea about her problem. Patient's family faced financial problem to continue treatment.

She expressed her satisfaction about present treatment at NICRH. But she suggested to make the facility women friendly e.g. ensure privacy, separate ward and separate toilet for female.

Case Study 3: Social Activist

She thinks women's low socio-economic status increases chance to develop cervical cancer. She added, usually women from low socio-economic background got marriage at early age.

It reality a huge number of them are failed to continue education. As a result they have poor knowledge about preventive measure e.g. maintaining menstrual hygiene etc. of cervical cancer. As well as poor economic condition also prohibited them to maintain hygiene. Poor knowledge about available cervical cancer services, women's vulnerable status in the society etc.

Policy matrix on "Prevention & Management of Cervical Cancer; A Gender-Lens Review of Programmatic & Sociocultural Dimensions" study findings

Action Points on Policy recommendations

Recommendation	Key/Major Activities (What to do)	Strategies (How to Do)	Responsibilities		Timeline			Resource Intervention		Objectively Verifiable Indicators (OVIs)				Means of Verification (MOV)
			Lead	Support	Short	Medium	Long	HR	Finance	Process	Output	Outcome	Impact	
Increase awarenes s on cervical cancer focusing target groups	Intensify the existing awarenes s program	Mappin g of relevan t person nel Gap analysi s to identify the area of existing awaren ess progra m Review and revise the awaren ess strateg	MOH FW	MoPA DGH S DGFP DG Medic al Educ ation HEB	✓ ✓	 ✓			✓	Mappi ng of releva nt perso nnel Gap analys is to identif y the area of existin g aware ness progra m Revie w and revise the	List of people identifie d Consult ative Worksh op & Expert meetin gs	Increas e awaren ess increas e knowle dge Revised strategy in effect	Incre ase utility of servi ces	List availa ble Works hop report availa ble Revis ed strate gy availa ble

		y								awareness strategy				
Create a client friendly environment (CFE) in the facility as part of health system strengthening	Create a client friendly environment (CFE) in the facility and structural renovation of facilities	Orientation on client friendly environment (CFE) Structural renovation of facilities by facility mapping on priority basis	MOH FW	MO Finance MO Planning	✓	✓	✓		✓	Training and orientation Facility survey	Training report List of facilities	Sensitization of service providers Improvised existing health facility	Service Providers more oriented HFs more client friendly	Training report available HFs improvised

Timeline:

- **Short Timeline refers to period not exceeding 12 months**
- **Medium Timeline refers to period between 1 to 3 years**
- **Long Timeline refers to period between 3 to 5 years**

Conclusion:

Cervical cancer is unique among cancers in that it can largely be prevented through screening and removal of precursor lesions. We have tried to expose vulnerabilities to cervical cancer, challenges faced by cervical cancer patients, and recommend ways to address them in Bangladesh. So far we have analyzed the data; we found there is a relationship of women with cervical cancer with social, economic, gender position in the society. Additionally, women's' age, education, occupation of her and her husband, residence, make the women vulnerable for having the cervical cancer. Lack of awareness about cervical cancer leads to lack of accessibility of screening program and also to access the treatment facilities. The preliminary analysis also observed some gap in the service provision for example, shortage of trained human resource, out of order machines, lack of separate screening room, limited access of cancer drug etc. This study will be one of the initiatives to understand the scopes and utilization of cervical cancer services across the hierarchy of health facilities.

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