Original Research Article

Pathways to care and diagnostic delay among cervical cancer patients attending a tertiary care hospital in Puducherry: a cross-sectional study

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ABSTRACT

Background: The high mortality among cervical cancer patients in India can be attributed to presentation at advanced stages. The varied and lengthy pathway taken up to diagnosis could be a major reason for advanced stage at presentation. Hence, we aimed to describe the care pathways and diagnostic delay among cervical cancer patients.
Methods: A hospital-based cross-sectional study was conducted among 101 cervical cancer patients attending a cancer clinic at a Regional Cancer Center. The histo-pathologically confirmed cases of cervical cancer, who registered in July to October 2018 were approached. Data were collected through personal interviews using a semi-structured questionnaire. Descriptive statistics were used to describe the number of providers visited and diagnostic delay.
Results: The median (range) number of providers visited by the patients up to diagnosis was 2 (1-5). As the first point of care, 14% of participants approached sub-center or primary care facilities, 27% approached secondary care facilities, 49% participants approached tertiary care facilities and 11% came directly to a regional cancer center. Diagnosis was made only in 24% of participants at secondary and tertiary care levels. The median (IQR) number of days to get diagnosed was 66 (30-130) days and three fourth of the patients had a diagnostic delay.
Conclusions: The diagnostic delay was higher among patients who consulted multiple providers. Implementing a protocol to be followed at all three levels of health care delivery system may enhance the early diagnosis.

Keywords: Diagnostic delay, Health care levels, Navigation pathways, Referral pathway

INTRODUCTION

Globally, cancer is the second most leading cause of death after cardiovascular diseases. The incident cases of cancer have increased by 28%, from the year 2006 to 2016. The cases of cancer and death by cancer has increased from 12.7 and 7.6 million in 2008 to 18.1 million and 9.6 million in 2018.[1] Cervical cancer is the second most common cancer among women in India, with an age-standardized incidence rate of 14.7 and a mortality rate of 9.2. The disability-adjusted life years (DALYs) of cervical cancer in India has shown a vast increase from the year 2001 to 2016 (i.e. 3.4 to 5.4 lakhs).[2] Among Indian states, Karnataka has the highest-burden in terms of DALY's, followed by Tamil Nadu.[3]

The progression of cervical cancer from normal to pre-cancer to invasive cancer is slow. Effective tackling of the cancer is possible by raising awareness, human papilloma virus (HPV) vaccination, regular screening, early diagnosis and efficient treatment.[4] However, the proportion of women who present with advanced stages of cervical cancer in India is estimated to be 70%.[5] The government of india launched the national program for

prevention and control of cancer, diabetes, cerebrovascular diseases and stroke (NPCDCS) program in 2010, to tackle the rising burden of noncommunicable diseases (NCD) including cancer. The program proposed strategies for different levels of care. Screening at primary care level, using frontline workers like accredited social health activist (ASHA) and auxiliary nurse midwives (ANM), NCD clinics at secondary and tertiary care level and district hospitals and capacity building at all levels of health care, for early diagnosis and management of NCD's are the strategies.[6]

The present study aimed to track the care pathways followed by cervical cancer patients until the diagnosis and to estimate the diagnostic delay. We tried to observe whether the pathway is at par with the strategies followed by the NPCDCS program i.e. screening and detection at primary care level, diagnosis and referral at secondary care level and treatment at tertiary care level. Identifying the pattern of pathways and quantifying the diagnostic delay can help to identify the gaps in health system. This information can be used to evaluate the effectiveness of NPCDCS strategies and to frame amendments if required, for better and efficient cancer care.

METHODS

This hospital-based cross-sectional study was conducted at a cancer clinic, Puducherry, South India, from September to October 2018. The clinic is run jointly by gynaecology wing of Department of Obstetrics and Gynecology (OBG) and medical oncology wing of regional cancer center. The hospital provides services free of cost to the poor and caters to the patients from Puducherry and surrounding districts of Tamil Nadu. Histopathologically confirmed (HPC) cervical cancer patients registered in July to October 2018 were included in the study and all terminally ill patients among them were excluded. A semi-structured questionnaire was prepared and pre-tested among ten patients before the study. The socio-demographic, behavioral and biological factors, duration between onset of symptom and diagnosis, stage of cancer at the time of diagnosis and symptoms that led to seeking care were collected through direct interviews and review of medical records. Our study considered primary health center (PHC), AYUSH practitioners, private clinics and nursing homes as a primary care facility. Government or private hospitals with obstetrics and gynaecology specialists were considered as a secondary care facility. Government or private medical colleges and private multi-specialty hospitals were considered as a tertiary care facility. Considering the world health organisation (WHO) criteria exclusively for cancer diagnosis, a duration exceeding one month (30 days), from identification of the first symptom to histopathological confirmation of cervical cancer was considered as diagnostic delay.[7]

Data entry was done in Epi data entry client v4.4.3.1 and analysed using IBM SPSS software version 19.0. Socio-demographic characteristics, risk factors and stages of cancer were summerized as percentages. Continuous variables like age and time gap were summarized as mean with standard deviation (SD) or median with interquartile range (IQR).

Ethical approval

The study protocol was reviewed and approved by the institutional ethics committee with the number JIP/IEC/2018/0267. Informed written consent was obtained from all the participants after explaining the purpose of the study.

RESULTS

The mean (SD) age was 54 (10.92) years, 63.3% belonged to the middle age group (40-60) years, 55% had no formal education, 88% were unemployed or homemakers and majority (88%) were from rural areas among the 101 participants (Table 1).

Table 1: Distribution of the study participants by socio-demographic characteristics (n=101).

Variable	Category	N (%)
Age (in years)	<40	11 (10.9)
	40-60	64 (63.4)
	>60	26 (25.7)
Residence	Rural	89 (88.1)
	Urban	12 (11.9)
Educational status	No formal education	56 (55.4)
	Primary education	33 (32.7)
	High school and above	12 (11.9)
Occupation	Home maker	37 (36.6)
	Daily laborer	30 (29.7)
	Formally employed	2 (2.0)
	Agriculture	32 (31.7)
Marital Status	Ever married	100 (99.0)
	Never married	1 (1.0)

The median (IQR) age of marriage was 17 (15-20) years and 32 (31.7%) of them were married before the age of 15 years. Two-fifths of the participants had four or more children. Thirty percent of patients were tobacco chewers (Table 2). The commonest initial symptom reported was abnormal vaginal discharge (62%), followed by abnormal vaginal bleeding (61%). Squamous cell carcinoma was the commonest type of cancer (91%) reported after biopsy confirmation and more than half (53.5%) of the patients were diagnosed at an advanced stage (IIB - IV) of cancer (Table 3).

The median (IQR) number of providers visited was 2 (1-5) and three fourth had a diagnostic delay. None were aware of the screening of cervical cancer or had undergone any screening tests before diagnosis.
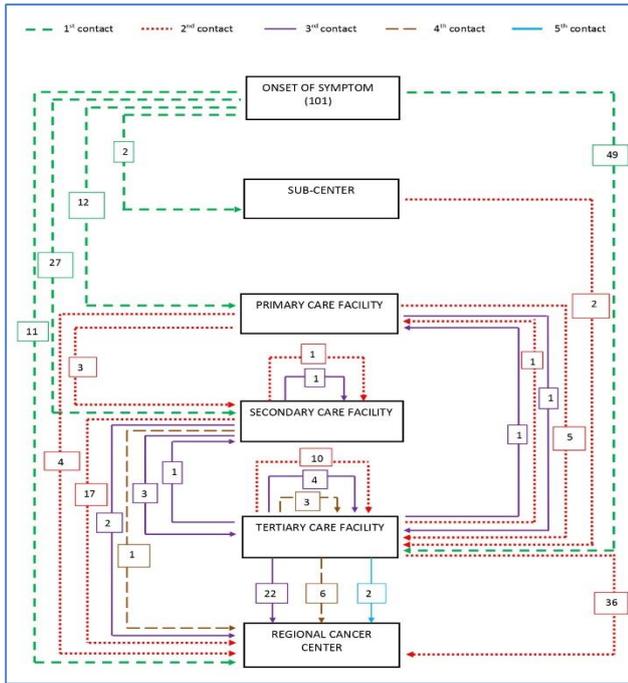
Figure 1: Pathways undertaken by 101 cervical cancer patients to seek care, 2018.

Figure 1 describes the care pathways taken to seek care by cervical cancer patients. The number of care providers visited by patients varied from one to five. As the first contact, 14 went to a primary care provider, 27 to a secondary care provider, 49 to a tertiary care provider and 11 went directly to RCC. A backflow of patients was observed from a tertiary care level to primary care and secondary care level (3%) in the pathway. Among those who visited secondary and tertiary care providers, 19 patients had consulted another health provider of the same level of care.

**Table 2: Distribution of the study participants by risk factors that may cause cervical cancer (n=101).**

Variable	Category	n (%)
Age at marriage (in years)	<15	32 (31.7)
	15-18	34 (33.7)
	19-25	31 (30.7)
	>25	4 (4.0)
Parity	0	2 (2.0)
	1-2	30 (29.7)
	>2	69 (68.3)
Menopausal status	Attained	79 (78.2)
	Not attained	22 (21.8)
Use of OCP*	Yes	1 (1.0)
	No	100 (99.0)
HIV status	Yes	1 (1.0)
	No	100 (99.0)
Tobacco use (ever in lifetime)	Smoking	0 (0)
	Chewable	30 (29.7)

*Oral contraceptive pills.

Table 3: Distribution of the study participants by symptoms, type, stage of cervical cancer (n=101).

Variable	Category	N (%)
Symptoms*	Abnormal vaginal discharge	63 (62.3)
	Abnormal vaginal bleeding	62 (61.3)
	Abdominal pain	51 (50.4)
	Lower backache	59 (58.4)
	Others†	30 (29.7)
Type of carcinoma	Squamous cell carcinoma	92 (91.0)
	Adenocarcinoma	5 (4.9)
	Squamous and adenocarcinoma	4 (3.9)
Stage of carcinoma‡	Early (stage I to IIA)	23 (22.8)
	Late (stage IIB to IV)	54 (53.5)
	Missing	24 (23.8)

*Multiple responses are possible, †Loss of appetite, urinary incontinence, nausea/vomiting, abdominal distension, dysuria, pain/bleeding during sexual intercourse, uterine prolapse, sudden weight loss, ‡FIGO staging.
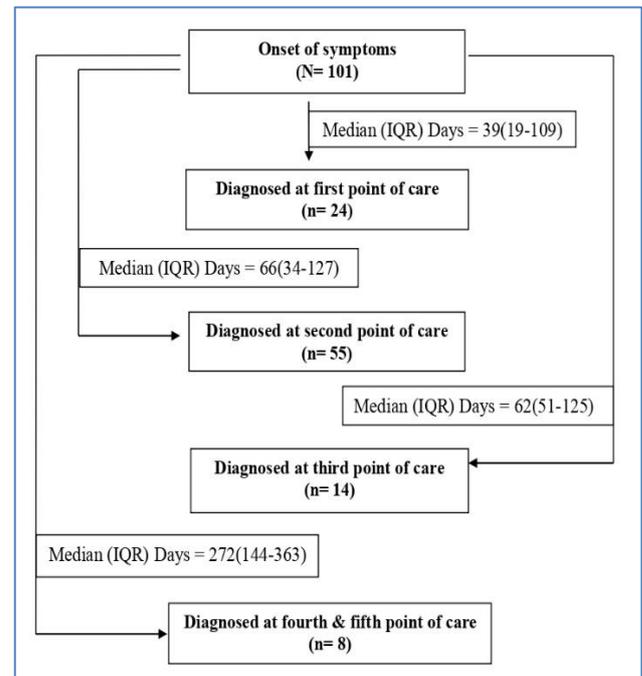
Figure 2: Duration (in days) from the onset of symptoms to diagnosis at the various point of care.

Among the 101 patients, 54% were diagnosed at a second point of care. The median (IQR) diagnostic interval was 66 (30-130) days. The diagnostic interval was found to increase with the number of providers i.e. participants who were diagnosed at the first provider took 39 (19-109) days, while those diagnosed at fourth or fifth provider took 272 (144-363) days (Figure 2). At first provider, referral to a higher center was not done in 42%, gynaecological examination was not done in 19% and investigations were not recommended for 48% participants (Table 4).

Table 4: Referral, gynecological examination, and investigations performed at various providers.

Provider	Referral N (%)	Gynecological examination* N (%)	Investi-gations† N (%)
1st provider (n=101)	59 (58.4)	82 (81.1)	53 (52.4)
2nd provider (n=90)	21 (23.3)	87 (96.6)	77 (85.5)
3rd provider (n=35)	8 (22.8)	34 (97.1)	27 (77.1)
4th provider (n=10)	2 (20.0)	10 (100)	9 (90.0)
5th provider (n=2)	-	2 (100)	2 (100)

*Speculum examination, per vaginal examination, †PAP smear, cervical biopsy, USG scan, MRI, CT, X-ray.

DISCUSSION

The NPCDCS program launched in 2010 was aimed to detect all NCD's including cancer at the early stages and to improve the prognosis and survival of the patients. Multiple strategies were proposed to achieve this. In the present study, we explored the care pathway of 101 cervical cancer patients and quantified their delay in getting diagnosed. The median number of providers visited was 2 (1-5) and the median diagnostic interval (IQR) of 66 (30-130) days was observed.

The younger age at marriage i.e. earlier initiation of sexual activity and higher parity observed among majority of our participants has been identified as major risk-factors of cervical cancer through numerous studies.[8,9] Abnormal vaginal discharge was the first symptom noticed by majority. Studies have found that discharge per vaginum is taken very casually and neglected and leads to long delays when compared to symptoms like bleeding.[9,10]

The study found that the median(range) number of providers visited by the patients until the diagnosis was 2 (1-5). A study from Africa too found that a major proportion of patients consulted two providers before diagnosis.[11] It has been observed through studies that the knowledge about cancer symptoms is associated with paying more attention to symptoms and unless a cancer symptom is grossly suspicious or obvious, patients neglect their symptoms and reports late to the provider.[12,13] The awareness about pre-cancer symptoms among our participants was low (6%). None of the patients were aware of screening and was not detected via screening. This is similar to the low rate of screening (0.2%) reported for common cancers, in the NPCDCS program report.[6] Lack of awareness of cancer symptoms and screening, lead to neglect and worsening of symptoms and ultimately most patients made multiple provider visits and were diagnosed only at an advanced stage (53.5%).

Among our participants, 22% had approached multiple providers (three or more) until diagnosis. Merely 14% of participants approached a nearby primary care provider when they identified their first symptom. Majority (60%) approached a tertiary care provider directly as their symptoms were serious by the time, they decided to approach a health provider. Undue delays occurred when multiple providers were approached and nearby primary care facilities were not utilized.

It was observed that gynecological examination was not performed in 19% of patients at the first provider even after reporting gynecological complaints. Failure to examine cervix has been identified as a major contributor to diagnostic delay. Studies have shown a reduction in delays when gynecological examination was performed at the first provider.[8,12,14]

A backflow of patients from tertiary to primary level and tertiary to secondary level was observed. One out of three participants reported that, at the first point of care, they were not referred to a higher center or communicated about the nature of their symptoms. An inadequate referral was a reason for the backflow of patients from tertiary and secondary level to primary level and lead to multiple provider visits of the same level and different levels of care. Lack of a proper referral system has been identified as a major cause of delays in cancer care.[8]

Our study identified that three out of every four participants (75%) had a diagnostic delay. A study from Nepal reports a similar finding (77%).[15] Another study from Morocco, considering 180 days as a diagnostic delay, found 36% of their participants to have a diagnostic delay.[10] Studies have found a significant association between higher diagnostic delay with factors like age (greater than 50 years), rural residence, low socio-economic level and lower literacy level.[9,15] Our participants too shared similar attributes of older age, rural residence, lower-income, and low literacy. All these factors lead to poor awareness of symptoms and risk factors, negative beliefs and attitudes among the women causing delays in seeking care.

A median (IQR) diagnostic interval of 66 (30-130) days was observed in the present study. This was contrary to that observed in Nepal (157 days) and Maharashtra (105 days).[15,9] The higher diagnostic interval found in the Nepal study was accounted for the reduced access to specialists and that in Maharashtra, to the incompetency of health workers to identify and refer at the earliest. Though the diagnostic interval was lower among our participants, considering the WHO guideline for cancer i.e. a duration greater than 30 days as a diagnostic delay, we had 75% of participants with a diagnostic delay. Attributes of patients and health care providers have jointly contributed to the diagnostic delay of our

participants. The interplay of demographic risk factors and lack of awareness lead to patient delay. Ineffective implementation of screening, lack of early identification and inadequate referral lead to health provider delay.

Our study was largely dependent on information from patients and to minimize information bias, cross-checking with medical records and accompanies the patient was done. But a larger sample size would have given precise estimates to find the association of diagnostic delay and advanced stages with various patient attributes. The study can be attempted in a private cancer care facility to attain more generalizability in terms of socio-economic determinants.

CONCLUSION

In our study, three out of four participants had a diagnostic delay. The proposed strategies of NPCDCS for cancer requires strict implementation and monitoring. Focus should be shifted to improve awareness about pre-cancer symptoms and importance of screening through health education. Capacity building at all levels of health care i.e. strengthening primary care facilities to screen and detect pre-cancer lesions, secondary care facilities to diagnose and refer suspected cases and tertiary care facilities to treat invasive cancer lesions at the earliest can help shorten the health care provider delay.

REFERENCES

1. New Global Cancer Data: GLOBOCAN 2018. Available at https://www.uicc.org/news/new-global-cancer-data-globocan-2018. Accessed 18 March 2020.
2. World Health Organisation: Human Papillomavirus and Related Diseases, Summary Report. World Health Organization; 2014.
3. Fitzmaurice C, Akinyemiju TF, Lami AFH, Alam T, Navaei AR, Allen C, et al. Global, Regional, and National Cancer Incidence, Mortality, Years of Life Lost, Years Lived with Disability, and Disability-Adjusted Life-Years for 29 Cancer Groups, 1990 to 2016. JAMA Oncol. 2019.
4. Cervical Cancer. World Health Organization 2015. Available at https://doi.org/10.1007/978-1-4939-2013-6. Accessed on 18 March 2020.
5. Nandakumar A, Anantha N, Venugopal TC. Incidence, mortality and survival in cancer of the cervix in Bangalore, India. British J Cancer. 1995;71:1348-52.
6. Directorate General of Health Services. National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS). Available at https://dghs.gov.in/content/1363_3_NationalProgrammePreventionControl.aspx. Accessed on 18 March 2020.
7. World Health Organization. Guide to cancer early diagnosis. World Health Organization; 2017.
8. Awolude O, Adewole I. Time of symptoms to Health-seeking among cervical cancer patients in Ibadan, Nigeria. Tropical J Obstetrics Gynaecology. 2016;33:10.
9. Deshmukh VL, Rathod AD. Delays in reporting of cancer cervix in rural India - sociodemographic and reproductive correlation. Int J Reproduction, Contraception, Obstetrics Gynecology. 2017;6:4516-21.
10. Mohamed B, Majdouline O, Ahmed Z. Sociodemographic factors and delay in the diagnosis of cervical cancer in Morocco. Pan African Med J. 2012;8688:1-8.
11. Gayle L, Mary N. Health Seeking Behaviours of Women with Cervical Cancer. J Community Med Health Education. 2012;2:4-9.
12. Macleod U, Mitchell ED, Burgess C, Macdonald S, Ramirez AJ. Risk factors for delayed presentation and referral of symptomatic cancer: evidence for common cancers. British J Cancer. 2009;101:92-101.
13. Ouasmani F, Hanchi Z, Rahou HB, Bekkali R, Ahid S, Mesfioui A. Determinants of Patient Delay in Seeking Diagnosis and Treatment among Moroccan Women with Cervical Cancer. Obstetrics Gynecology Int. 2016;2016:9.
14. Vandborg MP, Christensen RP, Kragstrup J, Edwards K, Vedsted P, Hansen DG, et al. Reasons for Diagnostic Delay in Gynecological Malignancies. Int J Gynecological Cancer. 2011;21:967-74.
15. Gyenwali D, Khanal G, Paudel R, Amatya A, Pariyar J, Onta SR. Estimates of delays in diagnosis of cervical cancer in Nepal. BMC Womens Health. 2014;14:1-9.