



ATUL BUDUKH

Cervical Cancer Control in Rural India



ACADEMIC DISSERTATION

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the Faculty of Medicine of the University of Tampere,
for public discussion in the auditorium of Tampere School of
Public Health, Medisiinarinkatu 3, Tampere,
on October 26th, 2007, at 12 o'clock.

UNIVERSITY OF TAMPERE

ACADEMIC DISSERTATION

University of Tampere, Tampere School of Public Health
Finland

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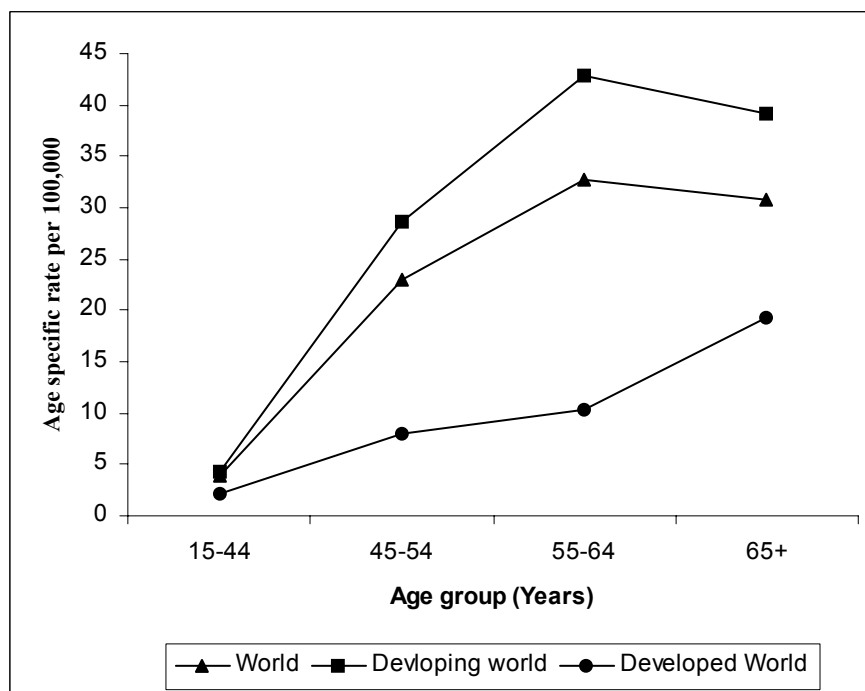


Figure 3. Estimated age specific mortality rate per 100,000 PYRS of cervical cancer in the world in 2002 (Ferlay et al. 2004)

2) Page no. 109 – line no. 3

infrastructure and human resources then 60 million (17 %) women from rural areas of the country will obtain the services for cervical cancer prevention.

3) Page no. 110 – line no. 7

only 17 % of the rural Indian female population.

4) Page no. 114 – line no. 16

This in only 17 % of the Indian rural female population of 360 millions.

Dedicated to my beloved parents

Contents

1. Introduction	6
2. Review of the literature	9
2.1 Cancer registration in India	9
2.2 Cervical cancer burden	11
2.3 Risk factors of cervical cancer	14
2.4 Health education for cervical cancer control	18
2.5 Cervical cancer screening	19
2.6 Treatment, survival and mortality	25
2.7 Cancer control programme in India	29
3. Objective of the study	34
4. Burden of cervical cancer	35
4.1 Background	35
4.2 Objective	36
4.3 Setting up the rural cancer registry	36
4.3.1 Population covered	39
4.3.2 Case finding	40
4.4 Statistical methods	45
4.5 Results	45
4.5.1 Cancer cases	45
4.5.2 Cervical cancer incidence	46
4.5.3 Cervical cancer mortality	47
4.5.4 Cervical cancer prevalence	48
4.5.5 Incidence, mortality and prevalence relationship	49
4.6 Discussion	50
5. Health education programme and its effect on cervical cancer	53
5.1 Background	53
5.2 Objective	53
5.3 Area and population covered	54
5.4 Method	56
5.5 Statistical methods	60
5.6 Results	61
5.6.1 Baseline awareness survey	61
5.6.2 Intervention	62
5.6.3 Increase of the awareness due to intervention	63
5.6.4 Impact of programme on stage of disease and completion of treatment	64
5.6.5 Effect of the programme on survival	70
5.6.6 Effect of the programme on cervical cancer incidence and mortality	72
5.7 Discussion	74

6. Screening, attendance and impact on process indicators	78
6.1 Background.....	78
6.2 Objective.....	78
6.3 Method.....	79
6.4 Statistical methods	84
6.5 Results	84
6.5.1 Determinants of participation	85
6.5.2 Self reported reasons for non participation.....	88
6.5.3 Impact of screening on stage of disease and treatment	89
6.5.4 Determinants of acceptance of treatment in screen positive women	93
6.6 Discussion.....	95
7. A cervical cancer control plan for rural India	99
7.1 Objective.....	99
7.2 Infrastructure.....	99
7.3 Method.....	100
7.4 Programme cost	102
7.5 Discussion.....	109
8. Summary	111
9. Abbreviations	115
10. Acknowledgements.....	116
11. References	119

1. Introduction

India has exceeded a population of 1 billion, which corresponds to 16.5% of the world population. In India 72% of the population lives in more than half a million villages (Census of India 2001, 2005). The health services in these villages are provided either by the State government or by the private sector. Not every district has a comprehensive cancer centre, the district hospital and the private hospitals take care of whatever primary diagnosis and treatment is possible and they refer the cases to the regional cancer centres or to the modern hospitals in the cities for further management and treatment. India accounts for a quarter of the world cervical cancer burden having 132,000 new cases and 74,000 deaths occurred in 2002 (Ferlay et al. 2004). India is a high-risk zone for cervical cancer. The reported age standardized incidence rate of cervical cancer during the period 1993–1997 was 11–30 per 100,000 person years at risk (PYRS) in different regions of India (Parkin et al. 2002). More than 70% of the cases present in the late stages of the disease (Nandakumar et al. 1995, Sankaranarayanan et al. 1998a, Dinshaw et al. 2001). Very few studies on the prevention of cervical cancer in a rural population of India have been conducted (Nene et al. 1994, Jayant et al. 1995, Nene et al. 1996, Gajalakshmi et al. 1996, Sankaranarayanan et al. 2004c, 2005, 2007b).

The Tata Memorial Centre (TMC), Mumbai, India is one of the premier institutes in the country for cancer care and the regional cancer centre for the Maharashtra State of India. The TMC has encouraged the initiative of a non-governmental organization (NGO) called Ashwini Rural Cancer Research and Relief Society, Barshi (ARCRRS), Maharashtra State for providing cancer care. Barshi is a small town in the Solapur district of Maharashtra State, it is 450 km away from Mumbai (Bombay). The ARCRRS planned to start a rural comprehensive cancer centre at Barshi to provide services like cancer education, early detection, treatment and pain relief to the rural areas of Solapur and Osmanabad district in Maharashtra State and set up the Nargis Dutt Memorial Cancer Hospital (NDMCH) in 1982 equipped with an out-patient department and a surgical facility. The TMC under the aegis of its rural cancer extension project provided continuing technical assistance to organize and develop the clinical and community extension services for the hospital.

Based on the experience at NDMCH Barshi, an attempt has been made in this dissertation to show how a community centre can be developed for cervical cancer

control activity in a rural area with support from the regional cancer centre. The rural cancer registry was started and after that a health education project to control cervical cancer in a selected area apart from the existing infrastructure. Subsequently, the screening programme employing a randomized controlled trial was undertaken. Based on the experience of the studies conducted at NDMCH Barshi this dissertation focuses on the prevention of cervical cancer and describes the infrastructure, resources and manpower needed in a rural area. When the resources are available, cervical cancer screening can be implemented in the rural area. In this dissertation a plan for cervical cancer control for rural India is proposed, if it is implemented properly, cervical cancer can be controlled to a great extent in rural areas of India.

In the year 1982, the TMC provided NDMCH with a mobile van to conduct the cancer detection clinics in the rural areas of Solapur and Osmanabad district. The NDMCH social workers were trained in cancer education and in identifying suspected cancer cases in the community. The social workers conducted a cancer education programme in the village and motivated symptomatic cases to attend the detection clinic. The suspected cases from the clinics were referred to the hospital. In the initial period surgeons from the TMC visited the hospital monthly for the operation. The basic diagnostic and surgical facilities were provided along with a community cancer awareness programme. The TMC has also trained the staff in surgery, radiotherapy, pathology, cytology and in other component services of the hospital. Then the first Rural Cancer Registry (RCR) (1987) in the country, radiotherapy centre (1992) and medical oncology services (1997) were started. The ARCRRS over the years has developed the services with technical support from TMC as per the resources available.

RCR Barshi has provided the cancer patterns from this region. This is the first rural cancer registry in the country established by the TMC at NDMCH, Barshi under National Cancer Registry Programme (NCRP) of the Indian Council of Medical Research (ICMR). The registry has shown that due to case finding methodology, the cancer awareness in the population has increased and the percentage of early cases of cervical cancer two years after the inception of the registry increased compared to earlier years (Jayant et al. 1995). The survival of these cases has also improved (Jayant et al. 1998). This was found to be possible due to continuous health education and motivation of symptomatic women to undergo diagnosis and treatment. To confirm these findings a health education project in a selected area close to Barshi was undertaken in 1995 to see the effect of health education on stage, incidence and mortality of cervical cancer. Due to experience of the NDMCH in cervical cancer control, the International Agency for Research on Cancer, Lyon, France (IARC/WHO) in collaboration with NDMCH and TMC conducted a randomized controlled intervention trial to evaluate the comparative efficacy and cost-effectiveness of three

cervical cancer screening approaches viz, visual inspection with 3–5% acetic acid (VIA), low intensity cytology and human papilloma virus (HPV) testing in cervical cancer prevention. This was the world's largest randomized controlled trial for cervical cancer; more than 125,000 women participated in this trial (Sankaranarayanan et al. 2005).

2. Review of the literature

2.1 Cancer registration in India

The Indian Council of Medical Research initiated a network of cancer registries across the country under the National Cancer Registry Programme in December 1981 (NCRP Annual Report 1982). The objective of the programme was to generate reliable data on the magnitude and patterns of cancer, to undertake epidemiological studies and to develop the human resources in cancer registration and epidemiology. The NCRP began with three population based cancer registries the existing Mumbai (Bombay) registry and new registries at Bangalore, Chennai (Madras) and three hospital based cancer registries at Chandigarh, Dibrugarh, and Thiruvananthapuram (Trivandrum). Further expansion of the NCRP saw the initiation of urban population cancer registries at Bhopal and New Delhi in 1987 and a rural population based cancer registry at Barshi in 1987 and hospital based cancer registries at the main hospitals of PBCRs at Bangalore, Mumbai (Bombay) and Chennai (Madras) in 1986. A hospital based cancer registry functioned at Chandigarh from 1982 until 1992. Since 2003 new population based cancer registries have been established at Guwahati, Dibrugarh and Silchar in Assam, Aizwal in Mizoram, Imphal in Manipur and Gantok in Sikkim with a monitoring unit at the Regional Medical Research Centre, Dibrugarh in the northeast region of India (Nandakumar et al. 2004). Apart from the NCRP network there are some more population-based cancer registries functioning in Pune, Nagpur and Aurangabad in Maharashtra State, Kolkata (Calcutta) in West Bengal State, Thiruvananthapuram (Trivandrum) and Karunagapally(rural) in Kerala State, Ambillikai (rural) in Tamil Nadu State, Ahmedabad (urban) in Gujarat State (Rajkumar et al. 2000, Parkin et al. 2002, Sen et al. 2002). One more rural PBCR was set up from January 2003 to cover rural Ahmedabad district under NCRP and from 1, February 2005 the urban PBCR of Kolkata (Calcutta) was included in the NCRP network (NCRP 2005). The location of these cancer registries in India is shown in Figure 1.



Figure 1. Map of India with the location of cancer registries

During 2000 the NCRP started a programme for the development of a cancer atlas for India. The overall aim of the study was to get to know the similarities and differences in patterns of cancer across the country in a relatively cost-effective way using recent advances in computer and information technology transmission. Knowing the patterns of cancer across the country would provide important leads in undertaking etiological research, in targeting cancer control measures and in examining clinical outcomes. In this programme in the period 2001–2002, 105 centres from all over India have contributed 200,000 new cases from different districts of the country, the minimum age adjusted incidence rates based on microscopically diagnosed cases have been calculated for the districts (Nandakumar et al. 2004). The area, the population covered by the population based cancer registries (PBCR) and the age-standardized rate (ASR) of cervical cancer are presented in Table 1. Data from 1990s are presented, while some registries were started in 2003, for which their data is expected soon.

Table 1. Area, population covered and age standardized cervical cancer incidence rate per 100,000 PYRS in Indian registries

Registry	Area in Sq Km ²	Population in million	Year	ASR
<i>Rural</i>				
Barshi ^a	3713.4	0.47	1993–1997	23.0
Karunagappally ^b	192.32	0.41	1993–1997	15.0
Ambillikai ^c	2058	0.36	1996–1998	65.4
<i>Urban</i>				
Mumbai (Bombay) ^b	437.7	10.7	1993–1997	17.1
Pune ^b	344.2	2.64	1993–1997	22.5
Nagpur ^b	236.9	1.04	1993–1997	23.2
Ahmedabad ^b	255.0	3.75	1993–1997	13.4
Chennai ^b	170.0	3.99	1993–1997	30.1
Bangalore ^b	365.7	4.79	1993–1997	23.5
New Delhi ^b	685.3	9.81	1993–1996	25.8
Trivandrum ^b	336.0	1.11	1993–1997	10.9
Bhopal ^d	284.9	1.20	1990–1996	21.7
Kolkata ^e	300.0	6.4	1998–1999	19.9

ASR: Age standardized rate per 100,000 PYRS

^a Barshi registry database

^b Parkin et al. (2002)

^c Rajkumar et al. (2000)

^d National Cancer Registry programme (2001 a)

^e Sen et al. (2002)

2.2 Cervical cancer burden

Cervical cancer is the second most common cancer among women worldwide. The estimated number of cases in 2002 in the developed world was 83,437 (17%) and in the developing world was 409,404 (83%). The estimated number of cervical cancer deaths in 2002 was 39,512 (14%) and 233,776 (86%) respectively in the developed world and developing world. The annual age standardized incidence rate was 10.3 per 100,000 PYRS in the developed world while in the developing world it was 19.1 per 100,000 PYRS. The age standardized mortality rate was 4.0 per 100,000 PYRS and 11.2 per 100,000 PYRS respectively in the developed world and developing world. The estimated number of incident cases, number of deaths, crude and age standardized incidence and mortality rate by age in the developed world and in the developing world in 2002 are presented in Table 2 and 3. The graphical presentation of the age specific incidence rate and mortality rate in the world are presented in Figures 2 and 3. The estimated number of five year prevalent cervical cancer cases in the developed world was 0.3 million (21%) and in the developing world was 1.1 million (79%). For India it was estimated as 0.37 million. These estimates were extracted from sources systematically compiled by the International Agency for Research on Cancer, Lyon, France (IARC) in 2002 (Ferlay et al. 2004).

Table 2. Estimated number of cases, age specific incidence rate, crude incidence rate and age standardized rate of cervical cancer per 100,000 PYRS in the world in 2002 (Ferlay et al. 2004)

World	Estimated number of cases around 2002	Age specific incidence rate per 100,000 PYRS				Crude incidence rate per 100,000 PYRS	Age standardized rate per 100,000 PYRS
		15–44	45–54	55–64	65+		
Developed	83437	10.97	21.85	21.06	21.85	13.6	10.3
Developing	409404	10.04	54.94	63.80	51.37	16.6	19.1
Overall	493243	10.21	46.01	50.46	38.84	16.0	16.2

Table 3. Estimated number of deaths, age specific mortality rate, crude mortality rate and age standardized rate of cervical cancer per 100,000 PYRS in the world in 2002 (Ferlay et al. 2004)

World	Estimated number of cases	Age specific mortality rate per 100,000 PYRS				Crude mortality rate per 100,000 PYRS	Age standardized rate per 100,000 PYRS
		15–44	45–54	55–64	65+		
Developed	39512	2.14	8.06	10.36	19.29	6.4	4.0
Developing	233776	4.27	28.59	42.80	39.19	9.5	11.2
Overall	273505	3.89	23.04	32.67	30.75	8.9	9.0

The highest incidence of cervical cancer from NCRP registries was reported from Chennai PBCR 30.1 per 100,000 PYRS, while Ambilikai registry reported the highest rate of cervical cancer, 65.4 per 100,000 PYRS (Rajkumar et al. 2000) in India. The Trivandrum population based cancer registry has reported the lowest rate 10.9 per 100,000 PYRS compared to other Indian registries. In the programme for the development of a cancer atlas of India, cervical cancer was reported as either first leading site or second leading site. The minimal age adjusted incidence rate higher than the Chennai registry was reported in the North Eastern districts of Tamil Nadu State including Pondichery, 39.2 per 100,000 (Nandakumar et al. 2004).

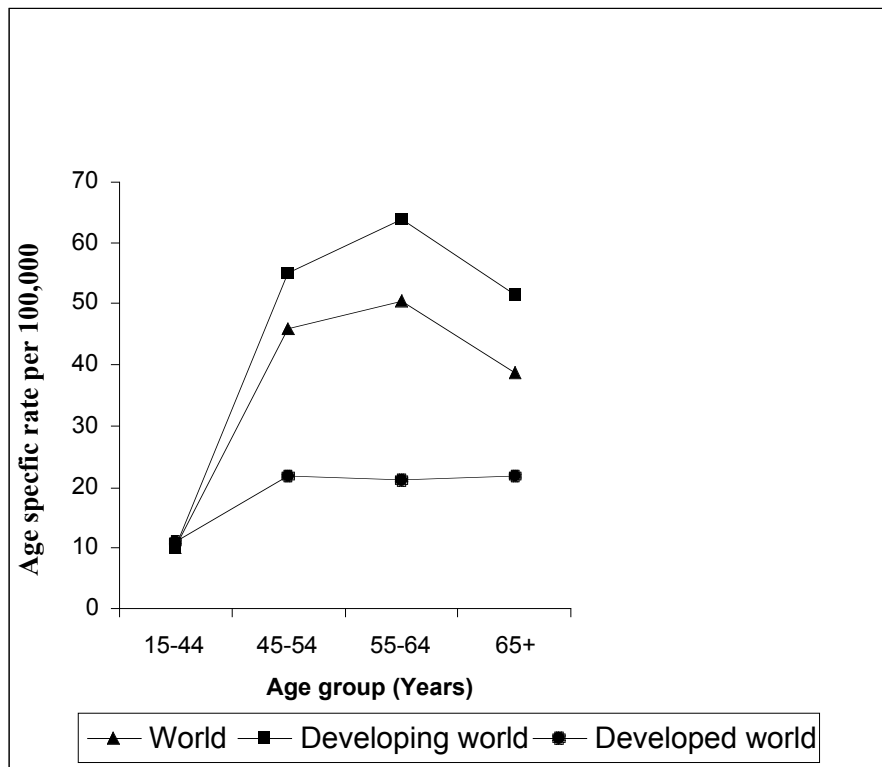


Figure 2. Estimated age specific incidence rate per 100,000 PYRS of cervical cancer in the world in 2002 (Ferlay et al. 2004)

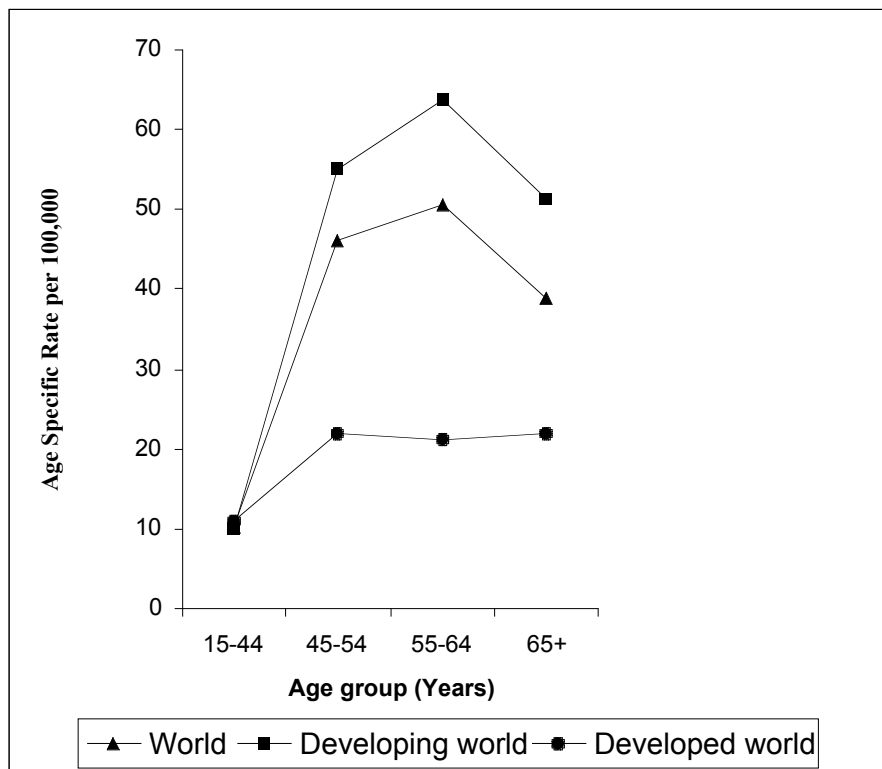


Figure 3. Estimated age specific mortality rate per 100,000 PYRS of cervical cancer in the world in 2002 (Ferlay et al. 2004)

2.3 Risk factors of cervical cancer

Low socioeconomic status was observed as an important risk factor for cervical cancer (Hakama 1983, Jussawalla and Yeole 1984, Segnan 1997, Bhattacharyya et al. 2000). In the meta-analysis of social inequality and risk of cervical cancer based on 57 studies, social class disparity in cervical cancer rates was found consistently and it was more pronounced in North America and in low/middle income countries than in Europe (Parikh et al. 2003).

A WHO report (1986) suggested that genital hygiene of both men and women might be an important factor for cervical cancer control in India. In a study conducted in Kerala, India it was reported that genital hygiene has a role in the development of dysplasia and cervical cancer (Varghese et al. 1999). It was reported that many women could not afford sanitary pads while adequate facilities for washing after coitus were not available. The study conducted at Mali (Bayo et al. 2002) reported that poor genital hygiene conditions were the main cofactor for cervical cancer. In this study it was reported that the cases that did not take care of washing the genital organs had OR = 5.64 (95% CI 2.5–12.8) after adjustment for HPV infection and other cofactors. The cases that reused sanitary napkins had an OR = 45.93 (95% CI 8.84–238.68) after adjustment for HPV infection and other confounding factors. In a study conducted in rural area of China (Zhang et al. 1989) it was reported that risk was associated with poor personal hygiene with regard to genital washing and use of sanitary napkins. The study conducted in Sichuan, China (Peng et al. 1991) demonstrated strong protection in women who used commercial sanitary pads, washed the genital area and abstained from sexual intercourse during the menses. But some studies have not shown any association of hygienic practice and risk of cervical cancer (Brinton et al. 1987, Herrero et al. 1990).

Tobacco smoking is an important risk factor responsible for cervical carcinogenesis. Winkelstein (1977) reported that smoking could be one of the important factors in the progress of cervical carcinogenesis. In the review of the literature (Winkelstein 1990) it was found that out of 15 studies, 11 studies confirmed that smoking was an important factor in the progress of cervical carcinogenesis. In the meta-analysis (Berrington et al. 2004) it was reported that current smoking was associated with a significantly increased risk of squamous cell carcinoma OR = 1.47 (95% CI 1.15–1.88) but not of adenocarcinoma OR = 0.82 (95% CI 0.60–1.11). Smoking was reported to be an independent significant factor after adjustment for other confounding factors (Slattery et al. 1989, Zivaljevic et al. 2001). Smoking as a risk factor for

intraepithelial neoplasm has been reported (La Vecchia et al. 1986, Brock et al. 1989, Kalogeraki et al. 1996).

In 1844 it was reported that (Stern 1844) uterine cervical cancer occurred more frequently among married women than among unmarried women. It was reported by Martin (1967) that the epidemiology of cervical cancer was based on a) near absence of neoplasm in nuns b) near absence of neoplasm among other species other than humans c) extremely low incidence of disease among virgins. It was reported that early age at marriage, marital dissolution and remarriage were causal factors of cervical cancer. A study (Biswas et al. 1997) conducted in Kolkata (Calcutta), India reported a maximum risk for women who reported their first intercourse at age <12 (OR = 3.5, 95% CI 1.1–10.9) compared to that of women who reported their first intercourse at age \geq 18 years. Early age at marriage was identified as a predictor for the disease status (Mukherjee et al. 1994). In Tunisia the cervical cancer incidence was low and attributed to late age of first sexual contact (Maalej et al. 2004).

Multiparity was found to significantly increase the risk for cervical cancer (Brinton et al. 1987, 1989, Gawande et al. 1998). The women who reported more births had a higher risk for cervical cancer than those with 1 or 2 births, OR=2.6 (95% CI 1.6–4.3) for 3–4 births, OR= 5.7 (95% CI 3.0–11.1) for 5–6 births and for more than \geq 7 births OR= 5.7 (95% CI 2.4–13.3) (Franceschi et al. 2003). The most common practice adopted for family planning was the use of oral contraceptives. Most of the studies have shown some evidence of an increased risk for users of contraceptive pills for five or more years. The higher risk was observed in adenocarcinoma cases (Brinton and Fraumeni 1986, Beral et al. 1988). In the meta-analysis (Delgado-Rodriguez et al. 1992) it was observed that the use of oral contraceptives may be a risk factor for all stages in the development of cervical cancer and the reported RR was 1.52 (95% CI 1.3–1.8) for dysplasia, 1.52 (95% CI 1.3–1.8) for carcinoma in situ and 1.21 (95% CI 1.1–1.4) for invasive cancer. According to Hellberg (Hellberg et al. 1985) oral contraceptive use for 5 years or more was significantly associated with CIN, but there was no effect when it was adjusted for confounding factors. Hildesheim (Hildesheim et al. 1990) proposed that the effect of oral contraceptives on cervical cancer and precancerous condition might operate through enhanced viral carcinogenicity.

Women with cervical cancer reported multiple sexual partners more often than the control women. The risk increased as per the number of partners (Brinton et al. 1987). This study has special significance as it included five geographical areas and different racial groups. The number of sexual partners reported by the husbands of women with dysplasia or carcinoma of the cervix uteri was found to be a significant relative risk of 7.8 for fifteen or more partners (Buckley et al. 1981). Women having \geq 2 lifetime sexual partners were at significantly associated risk for cervical cancer OR=4.0 (95% CI

1.1–14.8) (Franceschi et al. 2003). The number of sexual partners as a risk factor of cervical cancer was also reported by others (Skegg et al. 1982, Das et al. 1989, Zhang et al. 1989, Bosch et al. 1992, Agarwal et al. 1993, Eluf-Neto et al. 1994)

Boyd and Doll (1964) reported that cervical cancer risk was related to the sexual activity. Beral (1974) suggested that exposure to sexually transmitted infection is an important determinant of cervical cancer. zur Hausen (1976) and Purola and Savia (1977) suggested the hypothesis that human papilloma virus HPV could be a cause of cervical cancer. It is now well established that cervical neoplasia is caused by persistent infection with certain oncogenic types of human papillomaviruses (IARC 1995, Bosch et al. 2002).

HPV is a sexually transmitted disease and the risk is associated with sexual activity. The prevalence of HPV decreases with age and increases with the sexual activity (Hildesheim et al. 1993). In the international prevalence survey a study conducted by IARC in 22 countries (Munoz 2000) it was reported that HPV was a necessary cause of cervical cancer. The most prevalent types were HPV 16, HPV 18, HPV 45, HPV 31 and HPV 33. HPV 16 was the most common type in all geographical areas and HPV 18 was common in South East Asia. In a case control study carried out in thirteen countries (Munoz 2000) it was reported that pooled odds ratio for positivity of any HPV DNA was 70 (95% CI 57–88). The association was equally strong for both squamous cell carcinomas (OR= 74)* and adenocarcinoma (OR= 50)* for HPV 16 and 18 as well as for the less common HPV type. In addition to HPV 16 and 18 HPV types 31, 33, 45, 51, 52, 58 and 59 can now be considered carcinogenic. In study conducted in Andhra Pradesh, India (Sowjanya et al. 2005) regarding high-risk HPV type in invasive squamous cell carcinoma cases it was reported that the most frequently detected HPV types were HPV 16, HPV 18, HPV 33 and HPV 35. The study conducted in New Delhi,

*95% CI was not reported in the article

India (Murthy et al. 1990) regarding biological factors in the progression of dysplasia to carcinoma in situ reported that the results of investigation for HPV revealed that out of 63 progressive cases, 43 (68.3%) were found to be positive for HPV 16 and 18 while out of 44 non-progressive cases 12 (27.3%) were positive for HPV 16 and 18. The difference between these was statistically significant with a relative risk of 5.9 (95% CI 2.5–14.1). In the study conducted in Mumbai, India (Saranath et al. 2002) it was reported that a high prevalence of HPV 16/18 was observed in cervical cancer, the prevalence in LSIL confirmed HPV16/18 as an early event and further indicated a role in the progression of lesions. Various case control studies have shown a consistent association with HPV infection for preinvasive lesion, squamous cell carcinoma and adenocarcinoma (Herrero et al. 2000, Josefsson et al. 2000, Munoz et al. 2000, Ylitalo et al. 2000).

The continuous presence of high risk HPV was necessary for the development, maintenance and progression of CIN (Koutsky et al. 1992, Remmink et al. 1995, Ho et al. 1998, Nobbenhuis et al. 2001). In the review of the literature of risk factors for the precancerous lesion of the cervix (Murthy and Mathew 2000) it was reported that HPV was the major infectious aetiological agent associated with the development of precancerous lesions of the cervix. The association between HPV DNA in cervical specimens and cervical cancer was consistent in a large number of investigations in different countries and populations.

Women who are co-infected with HPV and another sexually transmitted agent, such as HSV-2 or *Chlamydia trachomatis* are more likely to develop cervical cancer than are women who are not infected. Herpes simplex virus (HSV-2) was first considered as a possible causal agent for cervical cancer in the 1960s and 1970s (Rawls et al. 1968, Munoz et al. 1975). After HPV DNA was detected in cervical cancer tissue it was hypothesized that HSV-2 infection might initiate mutations and carcinogenesis in HPV-infected cervical cancer cells (zur Hausen 1982). In a study conducted in the Nordic countries (Lehtinen et al. 2002) it was reported that the adjusted relative risk for HSV-2 was 1.0 (95% CI 0.6–1.7) and 0.7 (95% CI 0.3–1.6) for HPV seropositive after adjustment for smoking, HPV16, HPV18 and HPV33.

Hakama et al. (1993) reported a strong association of *Chlamydia trachomatis* with cervical cancer OR=5.0, (95% CI 1.6–15.7) after adjustment for smoking and other sexually transmitted diseases. Another study was conducted (Hakama et al. 2000) to estimate the joint effects of infections with human papillomavirus type 16 and *Chlamydia trachomatis* and smoking on the risk of cervical cancer, whether joint effects can be accounted by misclassification the HPV type serology. The study reported that HPV16, *Chlamydia trachomatis* and smoking are likely to be risk factors of

squamous cell carcinoma with strong antagonistic joint effect. The *Chlamydia trachomatis* seropositivity in the absence of HPV 16 antibodies showed increased risk OR = 3.4 (95% CI 1.5–7.7)

2.4 Health education for cervical cancer control

It was recommended (WHO 2006) that health education should be an integral part of comprehensive cervical cancer control. In an article on cancer control efforts in the Indian subcontinent (Desai 2002), it was reported that no cancer control effort could be mounted without education at all levels, public and professional. The importance of the health education programme to target the community in the screening programme has been reported (Miller et al. 2000). In the US government health agencies, volunteer health agencies, health care systems and providers have focused on improving cancer communication to enhance the prevention, detection and treatment of cancer (National Cancer Institute 1997, 1999).

Several studies have reported that lack of knowledge of the disease was the main barrier in cervical cancer screening (Ansell et al. 1994, Lantz et al. 1997, Pearlman et al. 1999). A number of studies from developing countries reported that women were not aware of the disease and that most of them had not attended for the Pap smear and they were not aware of the Pap test (Ajayi and Adewole 1998, Maaita and Barakat 2002, Gichangi et al. 2003, Stewart and Kleihues 2003, Ray and Mandal 2004). A study conducted on South Asian women in Canada (Gupta et al. 2002) reported that the awareness of the disease was very low among South Asian women. Even in a country like U.K. a review of the published literature on the cancer knowledge of the general public suggested that overall knowledge of cancer was poor and greater attempts should be made to raise the awareness (Adlard and Hume 2003). In Sweden (Ponten et al. 1995) much of the improvement in cervical carcinoma control observed in terms of early diagnosis and reduction in mortality before the introduction of cervical cytology screening has been attributed to improvements in population awareness. Poor health literacy was a better predictor for cervical cancer screening knowledge than ethnicity or education was reported (Lindau et al. 2002). The development of the low literacy intervention may improve the cervical cancer screening.

A study conducted in the USA (Dignan et al. 1998) reported that a health education programme provided one-on-one in women's homes by trained health educators has shown the effect on the knowledge of the women and on their attendance for the Pap test. A similar result has been reported by others, the health education

programme (including distribution of electronic and printed information, media messages and direct education of women) has shown an effect in improving the awareness level of cervical cancer and cervical screening (Michielutte et al. 1989). The health education provided by videotape, which was culturally sensitive, has shown an improvement in the knowledge of the cervical cancer (Stillwater et al. 1995). Another study (Yancey et al. 1995) reported that health education through culturally sensitive videos increased the Pap smear attendance in the study group women compared to the control women. A study conducted for Vietnamese-American women (Jenkins et al. 1999) to see the effect of a media led education programme for breast and cervical cancer screening showed that the media led education intervention succeeded in increasing the awareness and intention to take a screening test. It was reported that an educational campaign to motivate women for the Pap test was mandatory (Nene et al. 1994).

It was reported (Davis et al. 2002) that health education messages through pamphlets was not sufficient but required oral instructions, video and proper communication between providers and patient. In this article the author provided useful guidelines to fill the gap in cancer communication for cancer control. A successful community based cancer education programme requires several components –appropriate training, an outreach individual, a strong relationship with the public and a private medical provider and navigational services. A lay health worker trained in cancer education can be a highly effective component of a cancer educational programme in the role of trained community educator and medical providers (Hurd et al. 2003).

The study conducted at Ambillikai, South India (Sankaranarayanan et al. 2003b) recommended that health education about cervical cancer and person-to-person invitations and local clinics were essential elements to be included in a screening programme in a developing country. It has been recommended that in countries in which cytology screening was not feasible health education should be integrated into primary health care services to motivate high-risk individuals to adopt appropriate health behaviour (Sankaranarayanan 2002). Health communication has great potential to help to reduce cancer risks, incidence, morbidity and mortality. Effective health communication can encourage cancer prevention (Kreps 2003).

2.5 Cervical cancer screening

Screening represents an important component of cervical cancer control. It involves a relatively simple and inexpensive test on asymptomatic subjects in order to classify

them as being likely or unlikely to have the disease, which is the object of the screening. The positive cases can then be subjected to conventional diagnostic procedure and if necessary given appropriate treatment. The ultimate objective of screening for a particular cancer is to reduce mortality from the disease among the subjects screened (Santos Silva 1999). Population based screening programmes using Pap smear were introduced in many countries in the 1950's and 1960's. The programme was started in British Columbia in 1949, in the regions of Norway in 1959 and in Scotland in 1960 (Stewart and Kleihues 2003). The overall incidence and mortality has declined in the last 40 years in Western Europe, USA, Canada, Australia, New Zealand, and Japan. This decline has been associated with the screening programme by cytology and in the reduction in the risk among the older generation of women (Parkin et al. 2001). Comparison between the Nordic countries has shown that the extent to which screening programmes were organized had an effect on the magnitude of the reduction in mortality from the cervical cancer (Läärä et al. 1987). In a study on the trends in incidence and mortality on Icelandic and Nordic cervical screening programmes (Sigurdsson 1999) it was reported that in the period 1986–1995 reduction in both mortality and incidence was more in Iceland (mortality 76% and incidence 67%), followed by Finland (mortality 73% and incidence 75%), Sweden (mortality 60% and incidence 55%), Denmark (mortality 55% and incidence 54%) and Norway (mortality 43% and incidence 34%). The difference was due to the policy of the screening interval and the coverage of the population and the age group targeted. In a cervical cytology screening programme in British Columbia (Anderson et al. 1988), it was reported that incidence of clinically invasive squamous carcinoma of the cervix fell by 78% and mortality from squamous carcinoma of the cervix by 72% during the review. The decrease in the incidence and mortality was attributed to the screening programme.

In a case control study for organized vs. spontaneous Pap smear screening for cervical cancer conducted in Finland (Nieminen et al. 1999) it was reported that OR of invasive cervical cancer among those who participated in the organized screening was 0.38 (95% CI 0.26–0.56) whereas any lifetime spontaneous Pap smear had OR = 0.82 (95% CI 0.53–1.26). The decrease in the incidence and mortality from cervical cancer in Finland was mainly due to organized mass screening. Fifteen case control studies on the efficacy of cervical screening from the period 1979 to 1996 were reviewed (Parkin 1997). They all reported lower risk of cervical cancer in screened compared to unscreened subjects. The IARC Working Group carried out an evaluation of cervical cancer screening programmes to estimate the risk of invasive cervical cancer associated with different screening histories (IARC Working Group 1986). The estimates were based on the screening programme conducted in the 1960s and 1970s by eight countries in North America and Europe. The working group reported a potential reduction in the

cumulative incidence rate of cervical cancer with different screening frequencies. For the agegroup 35–64 years reductions in the cumulative incidence for screening intervals of one, two, three, five and ten years were observed to be 93.5%, 92.5%, 90.8%, 83.6% and 64.1% respectively. The reduction was assumed on 100% screening sensitivity, screening coverage over 80% and effective treatment of every women in whom high-grade dysplasia was detected. As per the recommendation by WHO (1986) the countries with limited resources should aim to screen every woman once in her lifetime. It was reported (Prabhakar 1992) that India should provide one life-time screening for women at the age of 45 years considering the number of cervical cancer cases saved and number of women years saved considering the cost aspects. Similar results were reported by Murthy et al. (1993) to determine at what age that screening could contribute to the greatest overall reduction in mortality from cervical cancer. The study used data from Mumbai (Bombay), Bangalore and Chennai (Madras) and compared the rates of cervical cancer incidence in unscreened women with the incidence in women screened once in their lifetime at various ages between 20–64. It was reported that screening at age 45 would be most effective, on the basis of the number of cervical cancer cases prevented and the number of productive years of life saved.

The success of a screening programme depends on the organizational aspects of the programme. The failure of a screening was attributed to organizational difficulties (Hakama et al. 1986). Some developing countries in Latin America and Asia have introduced screening during the past 30 years. Generally they have achieved very limited success in controlling the cervical cancer in this region (Sankaranarayanan et al. 2001). In a multicentre study for accuracy of the conventional cytology (Sankaranarayanan et al. 2004a), 22,663 women were tested for conventional cytology. In this study the pooled sensitivity, specificity, positive and negative predictive values at ASCUS threshold were 64.5%, 92.3%, 11.8% and 99.4% respectively. The corresponding values at LSIL threshold were 58%, 94.9%, 15.2%, and 99.3% while at HSIL threshold they were 45.4%, 99.2%, 46.3% and 99.1%. In the studies conducted sensitivity varies between 37.8–81.3% at ASCUS, 28.9–76.9% at LSIL and 24.4–72.3% at HSIL threshold. The finding of this study and other reviews indicate that to improve the sensitivity and specificity of the cytology sustained efforts in improving sampling preparation and reading of cytological specimens and improvements in clinical judgment were essential. Cytology based screening is beyond the capacity of the health services of the developing countries and hence alternative methods to cytology were investigated (Sankaranarayanan et al. 2003a). The lack of success of cytology based programmes in low resource settings (Sankaranaryanan et al. 2001) and the wide variation in the sensitivity of conventional cytology (Fahey et al. 1995, Nanda et al. 2000) has encouraged the search for the alternative methods like HPV testing, visual

inspection of the cervix after application of 3–5% acetic acid (VIA) and visual inspection after application of Lugol's iodine (VILI).

Human papilloma virus has been established as the primary cause of cervical cancer. Interest is growing in the potential of HPV testing in cervical cancer prevention programmes as an alternative to cytology and in primary screening. The accuracy of HPV testing by HC II in primary screening has been studied in various cross sectional studies. Studies conducted in the developing countries on HPV testing by HC II have reported that sensitivity varied between 62% to 97% and specificity varied between 41% to 92% (Kuhn et al. 2000, Schiffman et al. 2000, Womack et al. 2000, Wright et al. 2000, Belinson et al. 2001a, Blumenthal et al. 2001, Belinson et al. 2003, Salmeron et al. 2003). In a multicentre study for the accuracy of human papillomavirus testing in the primary screening of cervical neoplasia conducted in India (Sankaranarayanan et al. 2004 d) involving 18,085 women from the agegroup 25–65, the sensitivity for detecting the CIN 2–3 lesion varied from 45.7% to 80.9% and specificity varied from 91.7% to 94.6%. In this study it was reported that comparison of HPV testing with other screening tests VIA, VILI and cytology indicated that HPV testing had a similar sensitivity to detect CIN 2–3 lesions to the other tests and specificity was higher than that in the visual test but lower than in cytology. High cost and low specificity are likely to present large scale application of HPV-testing in a developing country.

VIA involves inserting the vaginal speculum and swabbing the cervix with 3–5% acetic acid. The normal squamous epithelium is light pink in colour and the columnar epithelium is red. CIN lesions will turn white for a few minutes after application of acetic acid. The effect of acetic acid is thought to depend on the amount of nuclear proteins and cytokeratins present in the cervical epithelium. These increase in CIN (Sellors and Sankaranarayanan 2003).

In a study conducted in Harare, Zimbabwe (University of Zimbabwe/JHPIEGO Cervical Cancer Project 1999) it was shown that VIA was more sensitive than cytology (VIA: sensitivity 76.7% cytology sensitivity 44.3%) but for VIA specificity was reported to be less than cytology (VIA specificity 64.1%, cytology specificity 90.6%). In a study conducted in China (Belinson et al. 2001b) it was reported that the sensitivity for low-grade intraepithelial lesions or worse for detecting biopsy proven CIN II or worse was 71% and specificity was 74%. The sensitivity was 65% for smaller lesions and 89% for larger lesions. The studies in China and Zimbabwe were conducted at a time when interest in VIA was evolving. The VIA technique has the potential to be reasonably accurate (Kitchener and Symmonds 1999). Studies conducted in India (Sankaranarayanan et al. 1998b, Basu et al. 2003), Iran (Ghaemmaghami et al. 2004), South Africa (Megevand et al. 1996, Denny et al. 2000, 2002), Italy (Cecchini et al. 1993), Pakistan (Tayyeb et al. 2003) reported higher sensitivity for VIA. The review of

the 15 studies conducted between 1982 to 2002 (Gaffikin et al. 2003b) reported that sensitivity ranged between 66% and 96% and specificity ranged between 64% and 98%. Comparing VIA with cytology that showed that the overall usefulness of VIA, compares favourably with that of the Pap test. The reported findings reviewed here suggest that VIA has the potential to be a cervical cancer-screening tool. It has quiet recently been reported in a randomized controlled trial conducted in Tamil Nadu, India (Sankaranarayanan et al. 2007b) that VIA screening in the presence of good training and sustained quality assurance is an effective method to prevent cervical cancer in developing countries. The study reported a 25% reduction in cervical cancer incidence (Hazard ratio 0.75, CI 0.55–0.95) and a 35% reduction in mortality (Hazard ratio 0.65, CI 0.47–0.89) compared with the control group.

The iodine is glycophilic and when it is applied on newly formed mature squamous metaplastic epithelium it becomes stained due to more glycogen, but areas of CIN and invasive cancer do not take up iodine as they lack glycogen and appear as a mustard yellow or saffron coloured area (Sellors and Sankaranarayanan 2003). In a study conducted in Kerala, India (Sankaranarayanan et al. 2003c) it was reported that VIA and VILI test were as good as cytology for detecting cervical neoplasia in low resource settings. In an IARC multicentre study in India and Africa (Sankaranarayanan et al 2004b) it was reported that the pooled sensitivity for VIA was 76.8% while the pooled sensitivity for VILI was 91.5%. The pooled specificity for VIA was 85.5% while pooled specificity for VILI was 85.4%. The range of sensitivity of VIA was 56.1–93.9% and specificity was 74.2–93.8%. The range of sensitivity for VILI was 74.2–93.8% and specificity was in the range 73–91.3%. VILI had a significantly higher sensitivity than VIA in detecting high-grade lesions but specificity was similar. Because of the low manpower cost of visual inspection it may be applicable in developing countries if the specificity can be improved. This seems to be achievable with proper training.

A high rate of participation in the screening programme is essential in reducing the incidence and mortality from the disease (Ponten et al. 1995, Lazcano-Ponec et al. 1999). A study conducted in Iceland and in Northern Ireland regarding non-attendance at screening has shown that women felt that they did not need the test (Bergmann et al. 1996, Murray and McMillan 1993). Non-participation in the screening programme by older age group, low income, less educated women and by women without partner was shown in a study conducted in South Africa (Bradley et al. 2004). Insufficient contact with General Practitioners and unpleasantness associated with the gynaecological examinations was one of the main reasons in non-participation in screening (Larsen and Olesen 1998). It was reported in a study conducted in Ambillikai, India (Sankaranarayanan et al. 2003b) that younger, educated, married, multiparous and those who had tubal sterilisation participated in the screening and the young women those

who practised contraception and with high grade lesions and invasive cancers were more likely to comply with treatment.

In a review of the studies (Fylan 1998) examining the factors influencing women's participation in a screening programme, their psychological reaction to the receipt of an abnormal cervical smear result and the experience of colposcopy, it was reported that administrative failure, unavailability of a female screener, inconvenient clinic times, lack of awareness of the test indications and benefits, considering oneself not to be at risk of developing cervical cancer and pain or the fear of detection of cervical cancer were the main reasons for non-participation. In a cervical cancer-screening programme in Mexico (Lazcano-Ponce et al. 1997) it was reported that women who were aware of the purpose of the Pap test participated in the screening programme. The study was conducted in the rural and in urban areas to determine the main factors for predicting participation in a cervical cancer-screening programme. Knowledge of the Pap test, high socioeconomic status, high educational level and access to social security level were strongly associated with the participation in the screening programme.

Fear of an abnormal test and referral for colposcopy cause high levels of distress owing to limited understanding of the meaning of the smear test. In a study conducted in Sweden (Idestrom et al. 2003) regarding women's experience of coping with news of a positive smear a questionnaire was sent to 329 women who were reported as having mild dysplasia in two consecutive smears, 74% replied to the questionnaires. 76% experienced follow-up in a positive way, 72% reported that they understood the meaning and consequence of having mild dysplasia, 59% reported feelings of worry and anxiety, 30% reported that it affected their day to day lives and 8% reported a negative effect on sexual activity. In a study conducted in Mexico (Lazcano-Ponce et al. 2002) regarding the positive experience of screening quality among the users of cervical cancer detection in 2094 women with a history of previous Pap smear it was reported that previous experience of good quality of screening was strongly associated (OR = 4.2, 95% CI 1.6–10.9) with the use of screening services. The women who knew why the Pap test was given (OR = 3.0, 95% CI 2.1–4.3) had a better history of Pap screening. The wives of the educated husbands had participated frequently in the Pap smear screening (OR = 1.8, 95% CI 1.1–2.9). The women who had used two or more family planning methods had better history of Pap smear screening (OR = 1.6, 95% CI 1.2–2.1).

The loss to follow-up of patients with abnormal smear was a common problem in screening programme. In a study conducted in Thailand (Thinkhamrop et al. 1998) it was reported that 41% of women with abnormal smear did not attend for further investigation and treatment. A common reason for not coming for the test was inadequate improper communication by the screening organization. The women

(13.6%) perceived that the test result was not serious. In a study conducted on racial difference in the rate of cervical abnormalities and incomplete follow-up (Carey and Gjerdingen 1993) it was reported that the rate of abnormality was greater in black women (16.4%) than Southeast Asian women (6.1%) and white women (11.6%). But the proportion of moderately severe or worse changes for the women was more in Southeast Asian women. It was concluded that the Southeast Asian women were less likely to comply with the recommended follow-up than the white and black women. It was reported that the low-income group lacked the timely follow-up of abnormal smear (Engelstad et al. 2001). This study reported that an aggressive follow-up strategy (telephone contact, making an appointment, follow-up in the special CARE clinic) had significantly improved the follow-up of women with abnormal smear. The finding suggested that lack of resources on the part of the health system performing the procedure was the likely reason for loss to follow-up.

2.6 Treatment, survival and mortality

In India the population-based cancer registry has reported that more than 70% of cervical cancer cases attend at a late stage of the disease (Sankaranarayanan et al. 1998 a). According to the reports of the hospital based cancer registries (HBCR), 27.4% of cervical cancer cases in Mumbai HBCR, 44.7% in Chennai HBCR, 41.5% in Bangalore HBCR, 18.8% in Trivandrum HBCR and 10.2% in Dibrugarh HBCR were not treated (NCRP 2001b). In the rural cancer registry at Ambillikai, (Rajkumar et al. 2000) it was reported that 60% of cases attend the hospital at a late stage and 29.6% of cases did not complete the treatment. In a study conducted in Kerala, India (Sankaranarayanan et al. 1995) it was reported that 54% cases were from stage IIIb–IVb and treatment completion rate was 80%. In a study conducted at Kolkata, India regarding distribution of cancer patients according to time taken from starting day of symptoms to reporting at the cancer centre (Mandal et al. 2001) it was reported that 97% of patients attended the hospital after several months from starting day of their symptoms and the late presentation by the patient resulted in poor treatment compliance as well as poor treatment response.

In India most cancer patients take alternative medicine before coming for treatment at the cancer hospital (Chaturvedi et al. 2002). In another study in India (Pal 2002) it was reported that 16% of patients go for alternative medicine due to financial problems. In a study using qualitative interviews with cancer patients and their careers in Scotland and Kenya (Murray et al. 2003) it was reported that patients from Kenya hide their symptoms from their families because they were worried about finding the

money to attend outpatient consultations and to pay for the medicine. In the developing countries women attend the hospital at the advanced stages of the disease and treatment completion is a great problem. In a study conducted at Dar es Salaam, Tanzania (Kidanto et al. 2002) it was reported that more than 90% of the cases attended the hospital at a late stage. In Harare, Zimbabwe (Chokunonga et al. 2004) it was reported that more than 50% cases attend the hospital at an advanced stage of the disease. In this study it was reported that out of 284 cases, 145 (51%) did not complete the treatment. In a study conducted at Harare, Zimbabwe regarding the factors associated with tumour stage (Ndlovu and Kambarami 2003) it was reported that poorly differentiated tumour histology and no history of prior cervical screening were found to be significantly associated with late tumour stage at presentation.

More than one fifth of women over 65 years who had Stage III or IV cervical cancer did not receive any treatment for their cancer according to the result of a study presented at the 32nd Annual Meeting of Gynecological Oncologists (CancerConsultants.com). The researcher used the National Cancer Institute Surveillance, Epidemiology and End Results (SEER) programme data to identify 10,281 women diagnosed with cervical cancer between 1992 and 1997. The researcher found that 22% women with Stage III or IV over 65 years of age did not have any treatment, compared with 15% of women aged 50–64 and 12% of women under 50. In comparison with the women with Stage I or II cervical cancer only 7% of women over 65, 4% of women aged 50–64 and 3% of women were untreated. Due to poor documentation of medical records the percentage of unknown stage of the disease was high in the developing countries (Sankaranarayanan et al. 1998a). The American College of Surgeons conducted a national study in care patterns for the years 1984 and 1990 (Jones et al. 1995). The data were obtained from 684 hospitals on 5904 patients diagnosed in 1984 and from 700 hospitals on 5817 patients diagnosed in 1990. The overall stage distribution was Ia 15.9%, Ib 36.8%, IIa 8.2%, IIb 15.5%, IIIa 2.5%, IIIb 13.3%, IVa 2.6% and IVb 5.2%. The overall early case percentage (Ia–IIb) was 76% and late stage cases (IIIa–IVb) were 24%. 92% cases had completed the treatment, 8% cases had not completed the treatment at the reporting institute. Stage unknown cases were reported as 20%.

In developing countries very few patients are treated when the disease is localized and most of the patients present at an advanced stage. Surgery can be an effective treatment for early stages of the disease. However, for advanced stage of the disease, radiotherapy treatment was used. According to the International Atomic Energy Association (IAEA 2003), 80% of cancer patients in developing countries would benefit from radiation therapy. However in many developing countries the radiotherapy facilities do not meet the demand, as many countries lack the technology and expertise

to provide such treatment. Some countries in Africa and Asia have no radiotherapy facility available for cancer patients (IAEA). Even when cancer treatment exists in poor countries, access to services may be extremely difficult for the majority of the population. The Alliance for Cervical Cancer Prevention (ACCP) is running a programme in various developing countries like Burkina Faso, Congo, El Salvador, Ghana, India, Kenya, Mali, Niger, Peru, South Africa and Thailand. In all these programmes women with cancer and their families face different barriers to obtaining treatment such as lack of transport and limited funds to cover the service fees. In a cervical cancer prevention programme in Peru, a local NGO group was formed with the help of the Ministry of Health to educate women in cervical cancer prevention and to raise the funds for women who were not completing the treatment due to financial barriers (Alliance for Cervical Cancer Prevention 2004).

Cancer survival and mortality are useful indicators in monitoring the effectiveness of the cancer services in a specified population. The cancer registry plays an important role in monitoring survival and mortality in a registry population. The population based cancer registry survival results include the treated cases and 'no treatment' cases. The survival data summarises the duration of life of the cancer patient in a population. The survival from cervical cancer was available from the United States, Canada, Western Europe, Japan and Australia. Recently an attempt has been made by the IARC to publish the survival results from the developing countries (Sankaranarayanan et al. 1998a). The survival results from India, Cuba, the Philippines, Thailand and China were available. The population based survival results from the African region (56 countries), Central and South America (21 countries) were not available. Out of 8 countries from the Caribbean region only 1 country had survival results, while out of 44 countries in Asia, only for 5 countries, were population survival results available (Stewart and Kleihues 2003). The three-year survival 49% (Wabinga et al. 2003) and five-year survival 18% from the Kampala registry, Uganda (Gondos et al. 2005) was reported. A four-year survival of 33.7% was reported for the Zimbabwe National Cancer Registry (Chokunonga et al. 2004). In India the five-year survival results of cervical cancer were available from the population based cancer registries of Barshi, Mumbai (Bombay), Bangalore and Chennai (Jayant et al. 1998, Nandakumar et al. 1998, Shanta et al. 1998, Yeole et al. 1998a, Gajalakshmi et al. 2000). The long-term survival from cervical cancer from the Mumbai registry was available (Yeole et al. 1998b). The age standardized relative survival in developing countries and developed countries is presented in Table 4.

Table 4. Age standardized five-year relative survival rate (%) in developing countries and developed countries (Sankaranarayanan et al. 1998a)

Population/ Country	Year	Age standardized five-year relative survival (%) (0–74 years)
Barshi, India	1988–1992	32.0
Bangalore, India	1982–1989	39.9
Bombay, India	1982–1986	49.5
Chennai, India	1984–1989	56.7
Khon Kaen, Thailand	1985–1992	55.4
Chaing Mai Thailand	1983–1992	64.9
Cuba	1988–1989	54.3
Rizal, Philippines	1987	28.0
Qidong, China	1982–1991	42.0
Shanghai, China	1982–1991	61.9
Europe	1978–1985	61.5
US White	1967–1973	58.7
US White	1974–1986	68.2
US White	1986–1991	70.1

Population based survival represents the average prognosis in the population and is an indicator of the effectiveness of cancer care in general. In a population where screening for cervical cancer is implemented there will be cases diagnosed at the preinvasive stage. These cases would have surfaced clinically more often at the localized stage than with distant metastases, due to length biased sampling. Therefore the remaining invasive disease in a well-screened population is more aggressive and faster growing with poorer survival than disease in a population not covered with screening. Hence survival is a poor indicator of cancer control and mortality reduction should be considered as an indicator for the cancer control.

In the world the highest mortality rate from cervical cancer in the year 2002 was estimated in East Africa 34.6 per 100,000 PYRS while it was in the range of 15–16 per 100,000 PYRS in South Central Asia, the mortality of less than 5 per 100,000 PYRS was estimated in Northern America, East Asia, West Asia, Northern Europe and in Western Europe (Ferlay et al. 2004), in India in 2002 it was estimated as 17.8 per 100,000 PYRS. The cervical cancer mortality rate in Chennai PBCR was reported for the period 1999–2000 ASR 6.46 per 100,000 PYRS and truncated mortality rate was 15.61 per 100,000 PYRS while in Mumbai (Bombay) PBCR ASR was 5.88 per 100,000 PYRS and truncated rate was 11.53 per 100,000 PYRS (NCRP 2005). Mortality data

occasionally used as substitutes for incidence data in countries with little screening or treatment activity since cervical cancer is nearly always fatal if not detected and treated (Herdman and Sherries 2000).

Mortality from cervical cancer was higher in the developing countries due to the lack of preventive measures and access to health care and poor infrastructure for treatment. According to the world cancer report (Stewart and Kleihues 2003) very limited facilities for cancer control services were available in developing countries, while in the developed world due to preventive measures the incidence and mortality has declined (Läärä et al. 1987, Parkin et al. 2001). There would be at least a 30% reduction in cervical cancer mortality rates in Africa and Asia if women's access to early detection and appropriate treatment were equivalent to that in developed countries (Pisani et al. 1999).

2.7 Cancer control programme in India

The National Cancer Control Programme (NCCP) was initiated in 1975. The objectives of the programmes are mentioned below (Rao et al. 2002).

1. Primary prevention of cancers by health education regarding hazards of tobacco consumption and necessity of genital hygiene for prevention of cervical cancer.
2. Secondary prevention by early detection and diagnosis of cancers for example, cancer of cervix, breast cancer and the oro-pharyngeal cancer by screening methods and patients education on self examination methods.
3. Strengthening of existing cancer treatment facilities, which were inadequate.
4. Palliative care in terminal stage cancer.

Under the NCCP following schemes exist, the details of the scheme were explained (Rao et al. 2002, Gupta et al. 2006).

- a. **Oncology wing scheme:** This scheme has been initiated to bridge the geographical gaps in the availability of cancer treatment facilities in the country. Central assistance was provided for the purchase of equipment, which includes radiotherapy equipment and also other equipment of related specialty. The civil work and manpower are to be provided by the State government/ institutions concerned. In view of the recommendation of the evaluation report of the NCCP as well as the working group for the 10th plan strategies, the financial assistance under this scheme has now been raised from Rs. 20.00 million (US\$ 416,667) to Rs. 30.00 million (US\$ 625,000). There are several district hospitals, which are comparable to Medical College in terms of facilities and need enhanced financial assistance, which is now taken care of by this scheme.
- b. **Regional Cancer Center Scheme:** There are 25 Regional Cancer Centre (RCCs) recognized by the Government of India. Assistance to RCCs is provided not exceeding Rs. 30 million (US\$ 625,000) for existing RCCs and Rs. 50 million (US\$ 1,041,667) for new RCCs based on the action plan for developing the infrastructure of the institution including equipment for cancer treatment to bring them to the desired level. The grant, which was provided annually, was now been increased and is made as a one-time grant.
- c. **District Cancer Control Programme:** According to the scheme cancer prevention, health education, early detection and pain relief measures were started in 1990-1991. Under this scheme a provision of Rs. 2.2 million (US\$ 45,830) is provided to the State government concerned for each district project selected under the scheme with a provision of Rs. 1.7 million (US\$ 35,417) every year for the remaining four years of the project period. The project is linked to a Regional Cancer Centre or an institution having good facilities for the treatment of cancer patients. The patients are provided with treatment at the Regional Cancer Centre or the nodal institution concerned. The financial assistance is now proposed to be released to the nodal agency (RCC/well developed Oncology wings in medical college) instead, to the State government as an earlier scheme.
- d. **NGO Scheme –** Earlier an NGO scheme for cancer awareness prevention was operated centrally. Now this scheme has been decentralized and entrusted to the RCC/Government medical college as nodal agencies. Under the scheme financial assistance of Rs. 8000 (US\$ 167) per camp is to provided to the

registered voluntary organization recommended by the nodal agency and the State government for undertaking health education and early detection activities.

- e. Modified District Cancer Control Programme: The objective of this programme is to conduct a baseline health information and health education drive for 1.2 million women in the age group 20–65. This programme has been initiated in four States namely Uttar Pradesh, Bihar, Tamil Nadu and West Bengal. Health education about general ailments, cancer prevention and early detection besides ‘Breast Self Examination’ was imparted. This project will provide much needed information on the prevalence of the risk factors and will help to identify a high risk group, who can provided with services for early detection.

There were some other activities carried out under the National Cancer Control Programme such as training of cytopathologists and cytotechnicians in the quality assurance in Pap smear technology, training of personnel in early detection and awareness of cancer, telemedicine and supply of hardware and software, Information, Education and Communication activities (IEC activities).

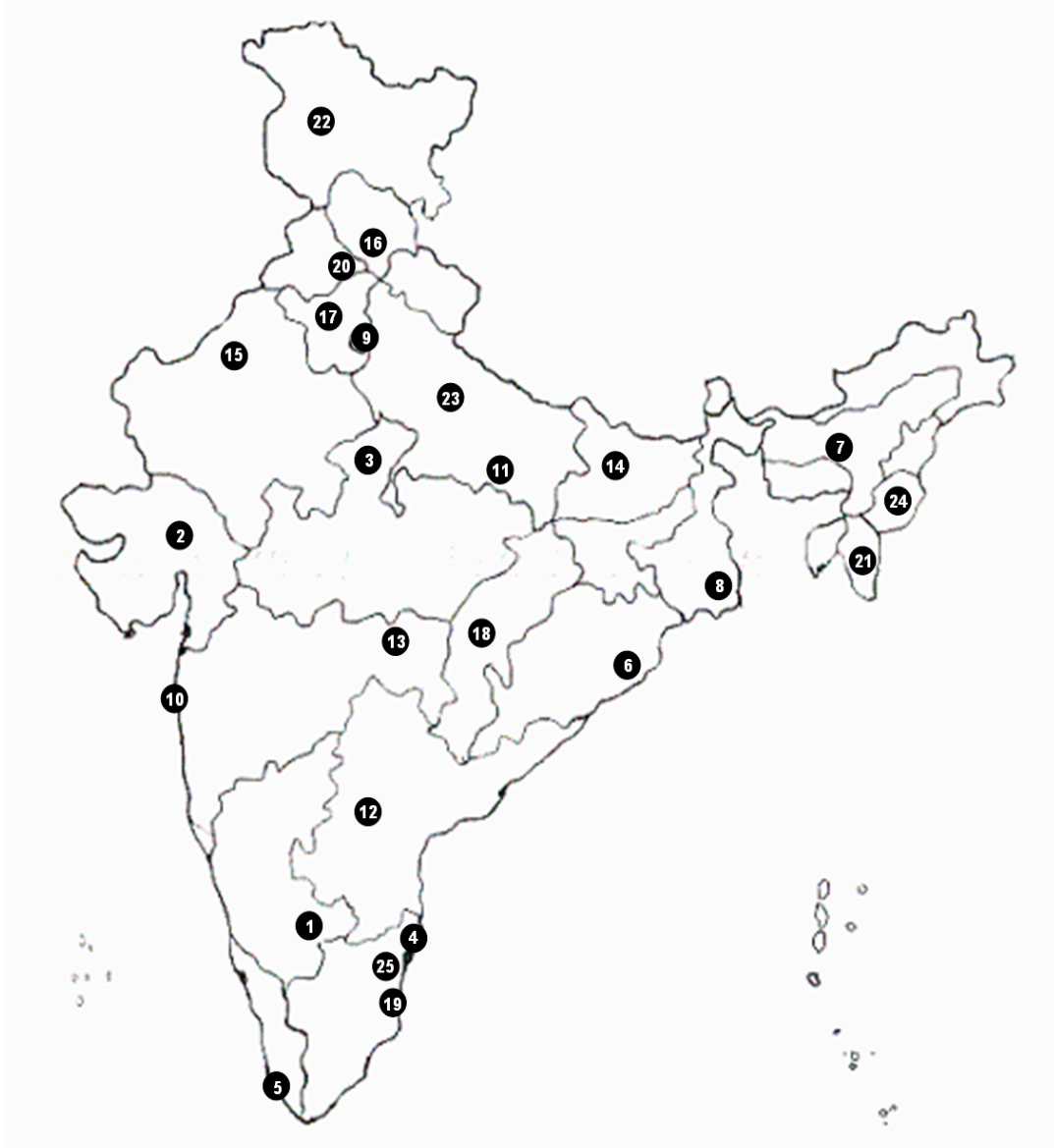


Figure 4. Location of Regional Cancer Centres in India, numbers refer to the list on page 33.

The list of regional cancer centre is given below. These centres, providing the cancer treatment services and working for cancer control in their respective regions. The map (Figure 4) shows the geographical locations of RCC in India with corresponding numbers.

1. Kidwai Memorial Institute of Oncology, Bangalore (Karnataka)
2. Gujarat Cancer and Research Institute, Ahmedabad, (Gujarat)
3. Cancer Hospital Research Institute, Gwalior (Madhya Pradesh)
4. Cancer Institute, Chennai (Tamil Nadu)
5. Regional Cancer Centre, Thiruvananthapuram (Kerala)
6. Regional Centre for Cancer Research and Treatment Society, Cuttack (Orissa)
7. Dr. B.B. Cancer Institute, Guwahati (Assam)
8. Chittaranjan National Cancer Institute, Kolkata (West Bengal)
9. Dr. B.R.A. Institute Rotary Cancer Hospital, AIIMS, (New Delhi)
10. Tata Memorial Hospital, Mumbai (Maharashtra)
11. Kamala Nehru Memorial Hospital, Allahabad (Uttar Pradesh)
12. M.N.J. Institute of Oncology, Hyderabad (Andhra Pradesh)
13. R.S.T. Cancer Hospital, Nagpur (Maharashtra)
14. Indira Gandhi Institute of Medical Science, Patna (Bihar)
15. Acharya Harihar Tulsi Das Regional Cancer Centre, Bikaner (Rajasthan)
16. Indira Gandhi Medical College, Shimla (Himachal Pradesh)
17. Post Graduate Institute of Medical Sciences, Rohtak (Haryana)
18. Pt. J.N.M. Medical College and RCC, Raipur (Chattisgarh)
19. Pondicherry Regional Cancer Society, JIPMER, (Pondichery)
20. Post Graduate Institute of Medical Education and Research (PGIMER), (Chandigarh).
21. Civil Hospital, Aizawal (Mizoram)
22. Sher-I –Kashmir Institute of Medical Science, Srinagar (Jammu and Kashmir)
23. Sanjay Gandhi Post-graduate Institute of Medical Sciences, Lucknow (Uttar Pradesh)
24. Regional Institute of Medical Sciences, Imphal (Manipur)
25. Government Arignar Anna Memorial Cancer Research Institute and Hospital, Kancheepuram (Tamil Nadu)

Cancer has become one of the ten leading causes of death in India. As per the 10th plan the emphasis is on the generation of comprehensive data, primary and secondary prevention of cancers and strengthening of existing treatment facilities along with palliative care.

3. Objective of the study

The objective of this study is to show the prerequisites of a cervical cancer control programme in a rural area of a developing country and to describe the programme and evaluate its feasibility, process and outcome. Specifically in rural India representing a developing country setting with limited resources and infrastructure.

- 1) To assess the burden of cervical cancer in terms of number of patients as well as incidence, prevalence and mortality from the disease.
- 2) To study the effect of health education on cervical cancer control in terms of stage, treatment, incidence, survival and mortality from cervical cancer.
- 3) To study the compliance of women with screening and the impact of screening on the process indicators.
- 4) On the basis of the empirical results to make a plan for cervical cancer control.

4. Burden of cervical cancer

4.1 Background

To assess the magnitude of the problem of cancer, the cancer registry provides information on the burden of the cancer in a defined area. Cancer registration is the process of continuous, systematic collection of data on the occurrence and characteristics of reportable neoplasm. A population based cancer registry attempts to record information on reportable neoplasms occurring in a given geographically defined population. The registry shows the nature of the cancer burden in the population and assists in planning cancer control activities for public health. Cancer registration is an important and fundamental tool of cancer control. In India more than 70% of the population lives in rural areas. A realistic estimate of the national cancer burden is therefore possible only if rural cancer incidence is documented. The cancer incidence in the rural areas of the country was estimated by undertaking ad hoc surveys in selected areas at considerable cost in both money and time (Wahi 1968, Jayant et al. 1975, 1976, Gupta et al. 1980). To ascertain the patterns of cancer from the rural area the ICMR decided to extend the scope of the NCRP to include rural areas. It was proposed to set up the registry for the rural population in the vicinity of Barshi, where the Nargis Dutt Memorial Cancer Hospital Barshi is located and fulfilled the diagnostic and treatment needs of the population in the area. The hospital also had a good rapport with the community. NDMCH is run by an NGO Ashwini Rural Cancer Research and Relief Society Barshi and is technically supported by the Tata Memorial Centre under its Rural Extension Programme. The medical centres and the general practitioners in the area of Barshi also supported the activity of the NDMCH. ICMR asked TMC to set up the rural cancer registry. The Barshi hospital is a rural extension project of TMC, so the choice for the rural cancer registry was the area in the vicinity of this rural cancer hospital. The ICMR provided financial support, TMC provided technical support in setting up the registry. Initially funding was provided by ICMR and later TMC took over the funding in a phased manner. TMC also provided the necessary technological support. Due to continued support of TMC and ICMR the registry has adequate trained staff and the necessary data processing facilities.

4.2 Objective

To assess the burden of cervical cancer in the rural area of Barshi in terms of incidence, mortality and prevalence as per the data of the Rural Cancer Registry Barshi.

The first objective of the dissertation is described in this chapter.

4.3 Setting up the rural cancer registry

Setting up a rural cancer registry was a difficult task. The system and the situations were very different from those in the urban centre of the country. The limitations for setting up the registry in the rural area of the Barshi are as follows.

- a) Poor medical record system.
- b) Low literacy rate.
- c) Lack of cancer awareness.
- d) Lack of modern medical facilities in the rural area. The patients have to reach one of the urban centres to have a proven diagnosis. However, the cases generally reach these centres in an advanced stage of the disease if they reach them at all.
- e) No death certificate is required for cremation/burial. The contents of the death certificates are deficient both quantitatively and qualitatively.
- f) The administrative records are not helpful instead they create considerable difficulties in verification. Medical records from private and governmental health care systems are very poorly maintained and the demographic as well as the medical information is hardly available. Special effort has to be made to obtain the correct information.

To overcome these deficiencies an innovative method was developed and found to be successful. The detailed methodology has been reported elsewhere (Jayant et al. 1991, 1994). The registry methodology in brief is described here. The location of the Barshi registry in India is shown in Figure 5 and area covered is shown in Figure 6.

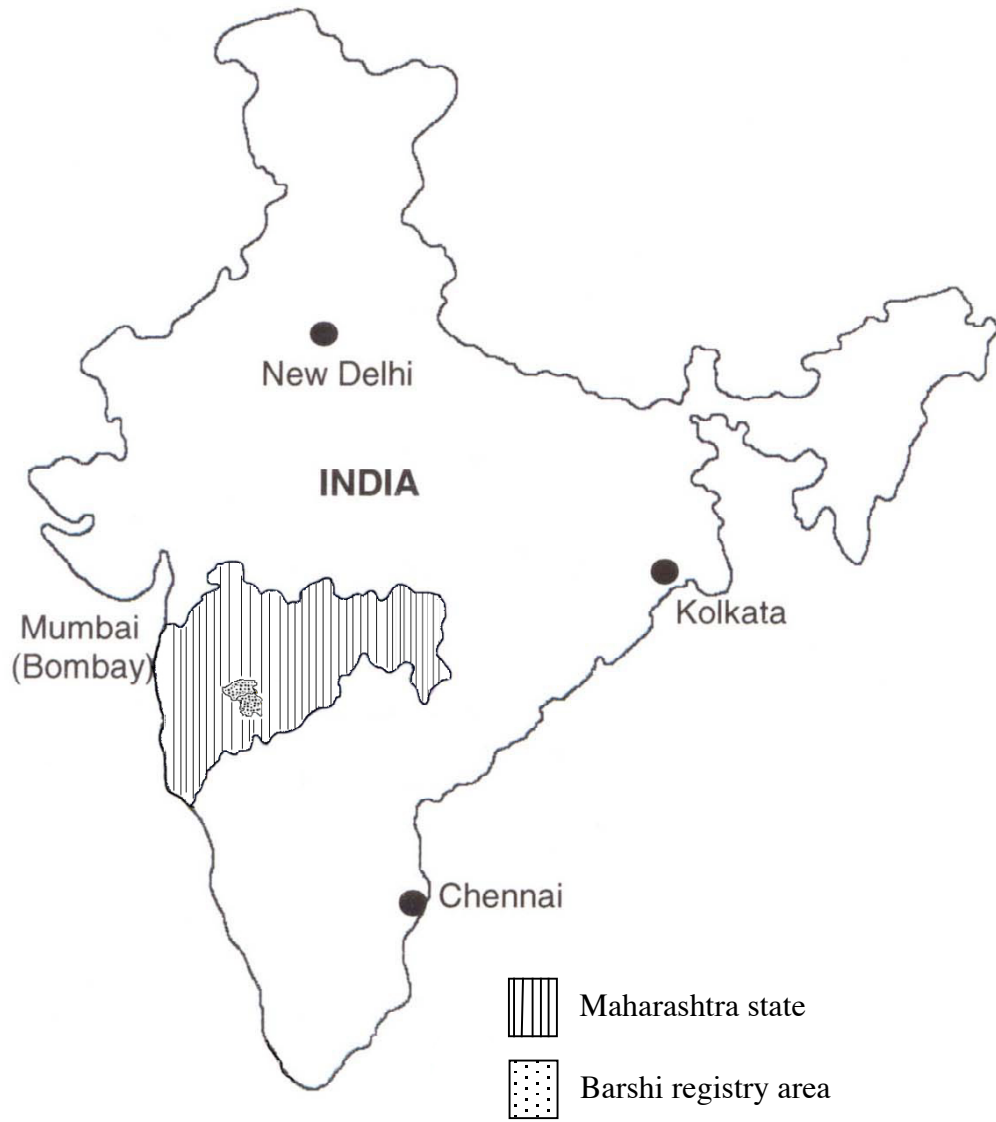
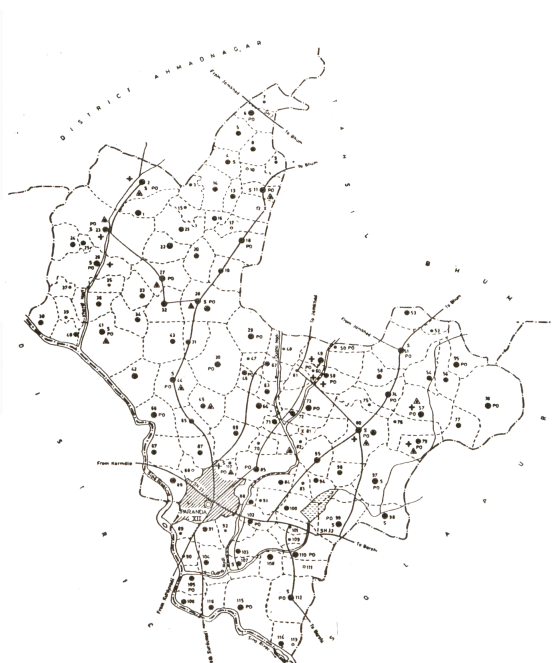


Figure 5 Map of India with Barshi registry area

Barshi Rural Subdistrict (134 villages)

Paranda Rural Subdistrict (117 Villages)



Bhum Rural Subdistrict (95 villages)



Figure 6. Area covered by Rural Cancer Registry, Barshi

4.3.1 Population covered

The registry covers the rural areas of Barshi, Paranda and Bhum subdistricts comprising 346 villages spread over 3713.4 km² according to the village directory in the district census handbooks of the census of India (1991a, 1991b) and includes about 0.46 million people. The registry area and number of villages covered are shown in Table 5.

Barshi is in Solapur district, Paranda and Bhum are in Osmanabad district. Barshi subdistrict is situated in northeastern part of Solapur district, which is located between 17° 10' and 18° 32' north latitude and 74° 42' and 76° 15' east longitude. Paranda and Bhum are northwestern subdistricts of Osmanabad district, which is between 17° 35' and 18° 40' north latitude and 75° 16' and 76° 40' east longitude. Osmanabad district is 600 meters above sea level, Solapur is about 550 meters above sea level.

The population of each village by gender was available in the decennial census reports of Maharashtra. However, age distribution of each gender was not available for each subdistrict. To obtain the age sex distribution for the rural area of the registry it is assumed that the age distribution of the district (rural) will be similar to the registry sub districts. The population for the period 1988 to 1991 was interpolated on the basis of the growth rates of the census 1981 and 1991 while for the period 1991 to 2000 the census population for the period 1991 and 2001 was used and yearly population estimated. The 2001 census report was available on compact disk but the age distribution of the district for the 2001 was not available. The 2001 population was estimated by age group by applying the age distribution in the extrapolated 2001 population with 1981–1991 growth rates to the total census population of 2001. The mid year population (1988–2000) for 1994 is mentioned in Table 6.

The Barshi subdistrict is more developed than Paranda and Bhum subdistricts. The literacy level is high in Barshi (70.8%) compared to Paranda (62.6%) and Bhum (64.5%). Paranda and Bhum are in the Marathwada region, which is considered to be a backward area of Maharashtra State. The health care delivery is administered through the primary health centre and rural hospitals. There is one primary health centre (PHC) with a medical officer and support staff for about 30,000 populations. Under each PHC, there are several subcentres in charge of Auxiliary Nurse Midwife (ANM) and multipurpose workers (MPW). Besides these employees, there are community health workers (one for every 1,000 population) who are paid an honorarium. The educational and medical facilities in the registry area in 2001 are presented in Table 7.

Table 5. Rural cancer registry area and number of villages covered

Subdistrict	Rural area in sq kms	Number of villages
Barshi	1668.5	134
Paranda	1146.0	117
Bhum	898.9	95
Total	3713.4	346

Table 6. Distribution of the registry population as on 1st July 1994 by age and sex

Agegroup (years)	Male	%	Female	%	Total	%
0-4	31811	13.4	29490	13.2	61301	13.3
5-9	31662	13.3	29293	13.1	60955	13.2
10-14	24883	10.5	22657	10.2	47540	10.3
15-19	21226	8.9	15735	7.1	36961	8.0
20-24	19308	8.1	19344	8.7	38652	8.4
25-29	17337	7.3	18367	8.2	35704	7.8
30-34	15603	6.6	15717	7.1	31320	6.8
35-39	14612	6.2	13890	6.2	28502	6.2
40-44	12104	5.1	12010	5.4	24114	5.2
45-49	10981	4.6	10534	4.7	21515	4.7
50-54	9635	4.1	9213	4.1	18848	4.1
55-59	7620	3.2	6795	3.1	14415	3.1
60-64	7775	3.3	7459	3.4	15234	3.3
65-69	4950	2.1	4629	2.1	9579	2.1
70-74	4016	1.7	3833	1.7	7849	1.7
75+	4084	1.7	3852	1.7	7936	1.7
Total	237607	100	222818	100	460425	100

Table 7. Educational and medical facilities in the registry area in 2001

	Barshi	Paranda	Bhum
Primary school	134	117	95
Primary health centres	7	6	4
Subcentre	26	25	21
Health workers	111	76	71
Medical practitioners	63	42	46
Pathologists (rural area)	Nil	Nil	Nil

4.3.2 Case finding

The trained field staff identified likely or proven cases in the rural population. The field staff visited the allotted village at least once in six months. The field staff collected the

information of chronically ill people by contacting all the medical practitioners in the area and by interacting with health workers of the PHC during their monthly meetings. In the village they held group meetings with the village administrator, school teacher and with community leaders to raise cancer awareness, they visited every 10th house during the house visits, they announced the purpose of their visit and they made the household members aware of the warning signals of cancer and the facilities available for cancer diagnosis and treatment at NDMCH, Barshi. They enquired about the health of the household members and their close neighbours. Generally in the villages household members were aware of the illness of a neighbour. Furthermore, they visited all those persons identified as likely cancer cases and chronically ill patients to ascertain whether they had cancer symptoms. If they found any they gave them a referral card to attend at the cancer hospital at Barshi or at a cancer detection clinic conducted periodically by the registry in the village or in the nearby village for further diagnosis. If the field staff found a proven cancer case in the village diagnosed in a different hospital they collected the necessary information from the medical papers if available. If the papers were not available the patient was asked about the hospital attended and the date of the visit to assist in tracing the medical records. During the village visit all the previously diagnosed cancer case were seen to ascertain their health status. The health status of cancer cases diagnosed previously was updated during each visit. Due to the active follow up method the follow-up status of all cancer cases were available. The likely cancer cases identified by field staff who had not attended the cancer hospital at Barshi or the cancer detection clinic for a medical check up were revisited during their subsequent village visits to ascertain whether the symptoms persisted and if necessary, they were motivated for diagnosis and for further treatment.

Cancer detection clinics were organized to screen the symptomatic cases identified by the field staff. The registry area was divided into 12 zones, each comprising roughly 30 villages. All villages under a specific primary health centre were included in the same zone. Two cancer detection clinics per year were held in each zone to identify likely cases. These clinics were arranged after completion of the village visits in the zone. The date of the clinic was noted on the referral card given to the suspected cases. To facilitate referrals, a complete list of the clinic programme for a period of six months was given to all medical practitioners, the PHC and others in the area. The field staff usually arranged the clinic at one of the PHCs or at a subcentre of the PHC by rotation. One or two days before the clinic, suspected cases in the nearby villages were again reminded to attend the village clinic.

The cases identified as suspected were called to the detection clinic held in the village or in the near by village. The mobile van of the NDMCH headed by an oncologist, with nursing staff examined the symptomatic cases in the mobile van. The

likely cancer cases diagnosed in the detection clinic in the village were referred for further investigation to the NDMCH, Barshi.

The referred cases from the village clinics, those referred by the field staff and the medical practitioners were investigated at the NDMCH, Barshi. Due to the interaction with the community a few cases attend NDMCH, Barshi on their own. These cases were also investigated. The registry clerk conducted the interview of all the patients who attended from the registry area to confirm that patient was a permanent resident of the registry area. The NDMCH provided the diagnostic and treatment facility free of cost. Only proven resident cases with invasive cancer were registered. Benign and in situ cases were not registered.

The method of collecting the cancer case information from other hospitals and pathology laboratories was similar to the method of urban registries (NCRP Annual Report 1982). Patients from the registry area seek medical attention in urban centres at a district place or nearby town. They visit the district hospitals of Solapur, Osmanabad, Beed, Aurangabad, charitable hospitals and hospitals run by the co-operative societies and radiotherapy centre in the district headquarters as well as in other towns. The registry staff visited approximately 50 hospitals, 20 pathology laboratories and 17 primary health centres as well as the Tata Memorial Hospital, Mumbai and the population based cancer registries of Mumbai, Pune and Aurangabad. Records of all these centres scrutinized and particulars of relevant cancer cases were recorded. Additionally, diagnosis of cases reported as 'cancer' to the investigators during village visits was verified in relevant data sources. Additionally information is collected from private nursing homes. The hospitals covered are situated far and wide and it is not feasible to visit them on a daily or even weekly basis for the purpose of interviewing patients. To collect the necessary demographic information on proven cancer cases attending such hospitals, patients were generally interviewed in their residence in the registry area after it had confirmed that they were permanent residents of the village. The new hospitals and pathology laboratories that were set up in these places were also included as data sources, as and when they were established.

The village administrative office maintains the death records of the village. The death record was based on the oral information provided by the health worker or by the relatives of the deceased. These records were submitted monthly to the Block Development Office (BDO) of the town and the BDO submits the records to the zonal office and from the zonal office they go to the central office of the State. In the first week of every month the field staff collected the death records from the BDO office. Additionally they collected similar information on deaths directly from the villagers during village visits. During their house visits they met the relatives of the deceased to ascertain the cause of death. Medical papers if available were scrutinized, and if not

details regarding hospital attended, dates of illness etc were recorded to facilitate a 'follow back' to the medical records in the treating hospital. Furthermore the death records of Barshi town at the municipal office and the death registers of all the major hospitals were perused for cancer deaths in the registry population.

All the deaths reported/ recorded as 'cancer death' by the relatives or by the village death records were checked against the registry files and the database maintained by the registry of all patients (including non-cancer cases). Those found to be registered cancer cases were entered as 'matched deaths' and those matched with cases that were diagnosed before the commencement of the registry (1 July 1987) as deaths of 'prior cancer case'. Additionally, all the cancer cases which had died during the follow up visits of the field staff were registered as 'matched cancer deaths' irrespective of whether they were recorded in the death records or not. All the cases reported or recorded as a cancer death that were unmatched were excluded from the registry. These cases were followed back and if a patient's relative had some evidence (for example that the patient was taking radiotherapy, was admitted under a cancer surgeon in the hospital, had been prescribed a chemotherapy drug) then the case was included in the registry.

Due to the inadequate death record system to assessing the completeness of cancer registration in a rural area is a difficult task. To assess the completeness of the registry a house-to-house survey was conducted. In 2003, a 10% random sample of villages survey was conducted. The house-to-house survey was conducted during the first week of January every year, six field staff members were assigned to this work. The field staff members were asked to note all the cancer cases alive and all the cancer deaths in previous year. The cases reported by the staff were crosschecked with the registry database.

The information received from field staff during the village visit, the house-to-house survey, from the death records, from the detection clinic and the NDMCH as well as from different hospitals medical records were included in the registry database. After excluding the duplicate cases and after confirmation of residence, the case registration and coding as per ICD9 and ICD-01 were done in the designed proforma of the ICMR. After completion of the proforma all the cases were entered in the software and the consistency of the cases was checked by the CHECK programme of the IARC (Parkin et al. 1994). The data was sent to NCRP/ICMR. In the initial year ICMR was doing the consistency check. The flow chart of the rural cancer registry method is shown in Figure 7.

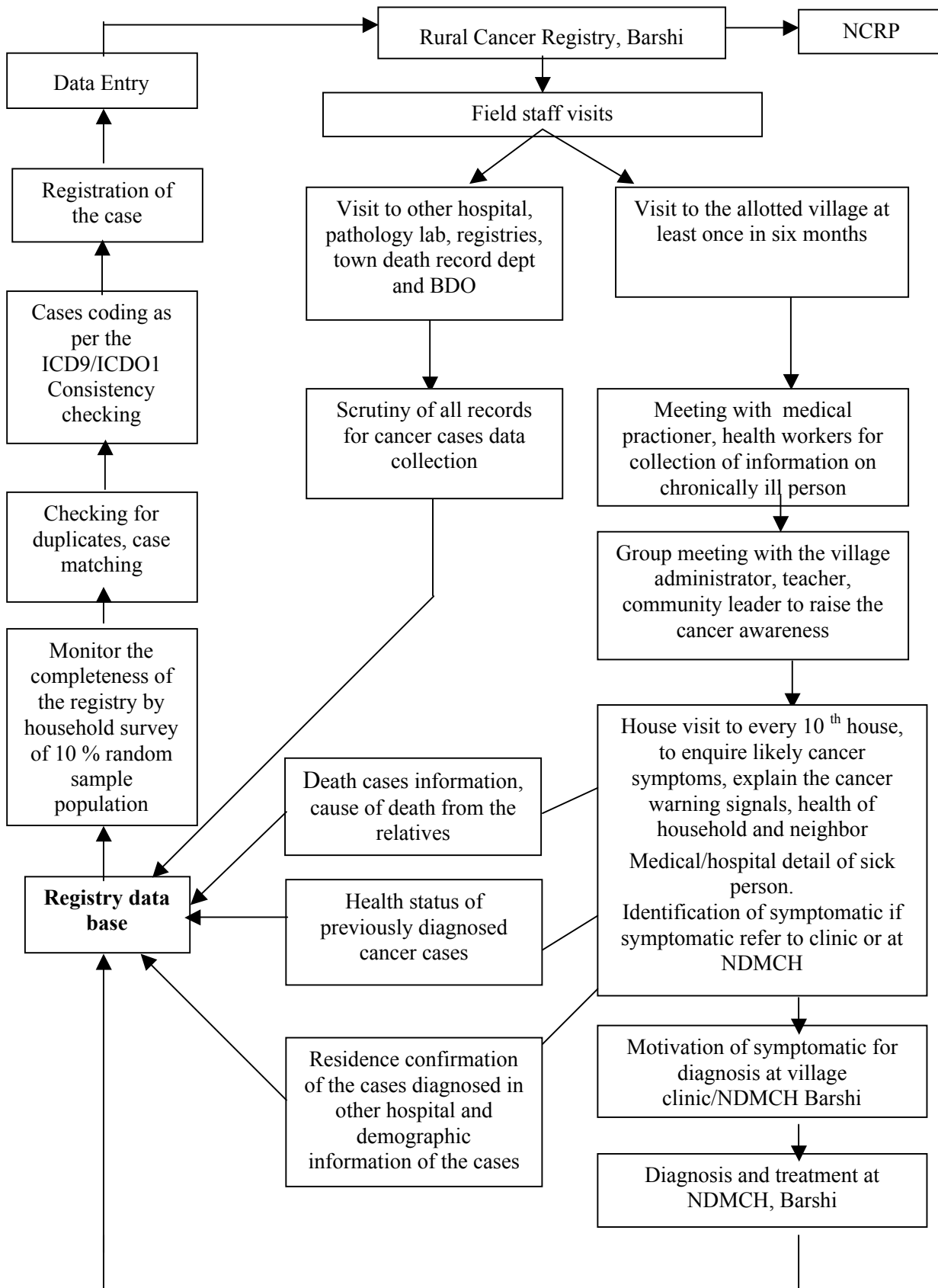


Figure 7. Registry Methodology

4.4 Statistical methods

The data were entered in the software provided by NCRP and was analysed using the Epi-Info-6 and SPSS package. The various rates such as crude cancer incidence rate, age specific incidence rate, age standardized incidence rate, crude death rate, age specific death rate and age-standardized death rates were calculated. Prevalence was estimated as per household survey. The number of cancer cases alive at the survey point was taken and divided by the number of total persons as per the household survey. For the comparison of prevalence it was standardized as per the world standard population.

4.5 Results

The results of the Barshi registry from 1988 have been published in the registry reports, in the reports of the ICMR and in Cancer Incidence in Five Continents Volume VII. The results for the period 1988–2000 are reported here.

4.5.1 Cancer cases

The number of cancer cases registered according to the source of registration is mentioned in Table 8.

The major source of registration was NDMCH (62%) where the registry is set up and (4%) cases were registered due to the field clinics. The cases registered from death certificates were minimal. The percentage of cases with microscopic confirmation in males was 84.9% and in females it was 88.7%. The clinical cases percentage in males was 8.8% and in females it was 7.4%.

Table 8. Number of cancer cases registered by source of registration in the period 1988–2000

Source of registration	Males	%	Females	%	Total	%
Village Clinic	17	1.4	92	6.7	109	4.2
NDMCH	753	61.8	866	62.9	1619	62.4
Other hospital	423	34.7	399	29.0	822	31.7
Death certificate only	26	2.1	19	1.4	45	1.7
Total	1219	100.0	1376	100.0	2595	100

4.5.2 Cervical cancer incidence

During the period 1988–2000, 659 cases of cervical cancer were registered. After excluding DCO and incomplete information cases there are 645 cases. Out of these cases 71 (11.0%) cases were registered due to a detection clinic, 419 (65%) cases from NDMCH and 155 (24%) cases from other hospitals and 327 (51%) cases had completed the treatment. At the closing date of the follow up, i.e. 31st December 2003, 157 (24.3%) were alive, 483 (74.9%) were dead and 5 (0.8%) had migrated. The data quality indices of cases registered are presented in Table 9.

Most of the cases were in the age group 40–69 (77%), 555 (86%) cases had no education and 95% cases belonged to the Hindu religion. The percentage of widowed women was 15.7%.

Cervix uteri takes the burden of 48% of cancer in females. The average annual age standardized incidence rate for cervical cancer was 27 per 100,000 PYRS. The average annual age-standardized incidence rate of all cancer sites in males was 47.9 per 100,000 PYRS and in females it was 56.1 per 100,000 PYRS, the cancer incidence is mentioned in Table 10.

Table 9. Data quality indices of cervical cancer cases registered period 1988–2000

Data item	Number of cases	Percentage
Cases registered	659	100.0
Cases excluded		
DCO	2	0.3
Incomplete information	12	1.8
Cases available for analysis	645	97.9
<i>Diagnosis</i>		
Clinical	37	5.7
Cytology	40	6.2
Histology	568	88.1
<i>Follow-up status on 31st December 2003</i>		
Alive	157	24.3
Dead	483	74.9
Migrated	5	0.8

Table 10. Cancer incidence per 100,000 PYRS from Rural Cancer Registry, Barshi 1988–2000

Site	Number	CR	ASR
<i>Males</i>			
Hypopharynx	127	4.1	5.2
Oesophagus	107	3.5	4.3
Penis	79	2.6	3.1
Oral Cavity	69	2.2	2.7
Rectum	61	2.0	2.4
Liver	60	1.9	2.4
Tongue	52	1.7	2.1
Lung	42	1.4	1.7
Leuk Myeloid	38	1.2	1.4
Skin Other	37	1.2	1.5
All sites, males	1219	39.5	47.9
<i>Females</i>			
Cervix Uteri	659	22.8	27.0
Breast	198	6.8	8.3
Oesophagus	57	2.0	2.5
Ovary	37	1.3	1.5
Rectum	28	1.0	1.1
Oral Cavity	27	0.9	1.1
Skin Other	27	0.9	1.1
Vagina	23	0.8	1.0
Lung	17	0.6	0.7
Leuk Myeloid	17	0.6	0.6
All sites, females	1376	47.5	56.1

CR – Crude incidence rate ASR – Age standardized incidence rate per 100,000 PYRS

4.5.3 Cervical cancer mortality

The observed annual crude death rate and age standardized rate per 100,000 PYRS for cervical cancer and for the all sites of males and females are presented in Table 11.

Table 11. Cancer mortality per 100,000 PYRS from Rural Cancer Registry, Barshi 1988–2000

Site	Number	CR	ASR
Cervical Cancer	437	15.1	18.6
All sites – Males	1004	32.5	39.1
All sites – Females	985	34.0	40.8

CR – Crude mortality rate ASR – Age standardized mortality rate per 100,000 PYRS

4.5.4 Cervical cancer prevalence

House-to-house survey data was used to estimate the prevalence in the registry area as on 1st January 2003. The survey was started in the first week of January 2003, it was complete in the last week of February 2003. The field staff zones were changed during the survey. More than 10,000 households were visited. From the house-to-house survey record it was found that the registry had not missed any diagnosed case. The results of the survey are presented in Table 12 and in Table 13.

Table 12. Number of households and population covered

Subdistricts	Number of households	Males	Females	Total
Barshi	5141	13507	12330	25837
Paranda	2533	6937	6346	13283
Bhum	2460	6544	6067	12611
Total	10134	26988	24743	51731

Tables 13. Results of the household survey

Cancer cases reported	Males	Females	Total
Number of cases reported as cancer by the field staff from house- to- house survey	28	74	102
Record as per the registry database			
<i>True positive</i>			
Cases matched as cancer cases	18	49	67
Deaths matched as cancer deaths	5	7	12
<i>False Positive</i>			
Non-cancer as per registry record	4	8	12
Non-registry area case migrated to registry area	–	1	1
Cases diagnosed prior to registry	1	6	7
Cancer deaths prior to registry	–	2	2
Carcinoma in situ cases	–	1	1

From the household survey 102 cancer cases were noted by the field staff, as per the registry database 79 (77.5%) cases were true positive and 23 cases (22.5%) were false positive. There were 19 cancer cases in males and 55 cases in females that were alive on 1st Jan 2003. Out of 55 cases in females 22 (40%) cases were from cervical cancer. The estimated crude prevalence for cervical cancer was 88.9 per 100,000 PYRS and age adjusted prevalence was 96 per 100,000 PYRS. The crude prevalence for males all sites were 70.4 per 100,000 PYRS while for females all sites it was 222.3 per 100,000 PYRS. The age-adjusted prevalence was 74.7 for all sites males and 245.1 for females all sites per 100,000 PYRS

4.5.5 Incidence, mortality and prevalence relationship

The cancer incidence mortality and prevalence relationship are presented in Table 14.

For cervical cancer the prevalence was 3.6 times the incidence while the mortality to incidence ratio was 0.69. The cancer prevalence was 1.6 times the incidence in males while in females it was 4.4 times the incidence. The mortality to incidence ratio was 0.82 in males and 0.73 in females. The age specific incidence, mortality and prevalence of cervical cancer are shown in Figure 8.

Table 14. Cancer incidence, mortality and prevalence relationship

Site	Incidence Per 100,000 PYRS (ASR)	Mortality Per 100,000 PYRS (ASR)	Prevalence (Age adjusted)	Mortality to Incidence	Prevalence to Incidence
Cervical Cancer	27.0	18.6	96.0	0.69	3.6
All sites-Males	47.9	39.1	74.7	0.82	1.6
All sites- Females	56.1	40.8	245.1	0.73	4.4

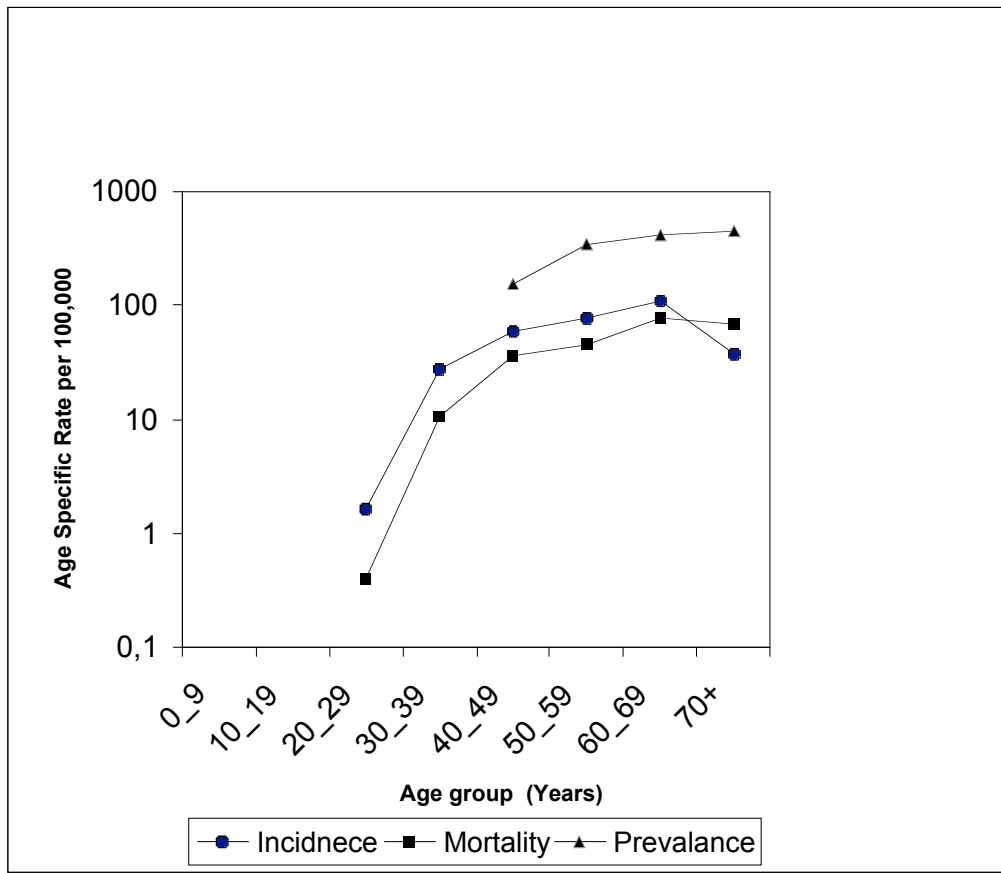


Figure 8. Age specific incidence, mortality and prevalence per 100,000 PYRS of cervical cancer from Barshi registry: 1988–2000

4.6 Discussion

The Barshi registry is the first population based rural cancer registry in India. The registry has provided data of the cancer pattern from the rural areas of India (Jayant et al. 1991, NCRP 1992, Jayant et al. 1994, Parkin et al. 1997, NCRP 2001a). The registry has used a simple approach of case finding with the help of field workers by raising the cancer awareness and identifying the symptomatic cases in the community and motivating them to attend for diagnosis at the village clinic or at NDMCH, Barshi. This methodology has worked as the registry was set up at the cancer hospital, where a facility for diagnosis already existed. The result showed that the methodology used for registering the cancer case is a feasible way of cancer registration for the rural areas of India.

As far as the completeness of the registry is concerned the house-to-house survey has shown that the registry did not miss any diagnosed case. The registry methodology

has lot of internal checks. If the staff missed the diagnosed case during the data collection at different hospitals, it can be ascertained during house visits in the routine village round. During a house visit the patient provides the information about the date of admission and procedures carried out in the hospital. Such information was useful in tracing back the record. A few centres were reluctant to give the recorded information of cases attending their centres. During such instances it is possible to collect the information from house visits. The patients who were diagnosed elsewhere generally attend our clinics. There were very few chances of missing a diagnosed case. The microscopic confirmation of the cases was high compared to other urban registries in India. It was due to under diagnosis of the cases in the older age group. The age specific mortality was reported higher in the older age group than the incidence. This shows that under registration /under diagnosis of incident cases was more in the older age groups.

To overcome the deficiencies of the death registration system, which is very poorly maintained, the method used was to follow back all the deaths occurring in the registry area. If the routine method of cancer registration has been followed then the number of cases registered would have been far below the true rates. Most of the cases (66%) were registered due to easy accessibility of the diagnosis centres viz the village clinic and NDMCH, Barshi.

The reported cancer incidence and mortality rates were lower compared to other Indian registries (Parkin et al. 2002). The life-style of people in this rural area is different from that of urban population, especially regarding tobacco use. Smoking related cancer in men was uncommon in this population. In the results of the tobacco survey conducted by the registry it was reported that only 6% of the men were smoker (Nene and Dinshaw 2000).

In females cervical cancer is the leading cancer site, the age standardized incidence rate of 27 per 100,000 PYRS was higher than in other Indian registries (10.9–23.2 per 100,000 PYRS) except those in Chennai registry (30.1 per 100,000 PYRS) and in Ambillikai registry (65.4 per 100,000 PYRS) (Parkin et al. 2002, Rajkumar et al. 2000). The age standardized mortality rate was 18.6 per 100,000 PYRS, which was slightly higher than estimated for India and much higher than in the developed world (Ferlay et al. 2004). The prevalence of cervical cancer was 3.6 times the incidence. While comparing the relationship of incidence and prevalence with that observed in the Finnish Cancer Registry the prevalence to incidence ratio reported at Barshi registry was very low, in Finland for cervical cancer it was 6.3 times the incidence for the year 1997–2001 (Cancer Incidence in Finland 2000 and 2001, 2003). The age-standardized prevalence for males was 1.6 times the incidence while in females the age-standardized prevalence was 245.1, which is 4 times the incidence

The registry has generated useful data on cancer incidence, mortality and prevalence. The regional cancer centre TMC has played an important role in setting up the rural cancer registry at Barshi. The other regional cancer centres should take an initiative in setting up rural cancer registries in India. This study would like to recommend locating the rural cancer registries in the same state as the urban registries to obtain the urban-rural ratios for cancer incidence. The registry methodology developed by Barshi Registry (Jayant et al. 1991, 1994) is a model for starting rural cancer registries in other parts of India, which will play an important role in assessing the burden of cancer mainly cervical cancer, which is the leading cancer in the rural areas and will assist in planning cancer control activity for public health.

5. Health education programme and its effect on cervical cancer

5.1 Background

A stage shift in cervical cancer cases attending Nargis Dutt Memorial Cancer Hospital, Barshi was observed three years after the inception of the Barshi Registry (Jayant et al. 1995). It was felt that this stage shift was due to creation of cancer awareness in women due to the registry methodology, which involved education, motivation and close contact with the community. It was necessary to test this hypothesis of the effect of health education on cervical cancer in a study. A study was conducted in the period 1995–2002 in the two subdistricts in the vicinity of Barshi. Unfortunately the necessary facility to undertake a randomized intervention study was not available. It was felt that with the available infrastructure and limited budget we could run this programme in a selected area to control cervical cancer. The programme was started in 1995 with an annual budget of US\$ 2000, as a partial grant provided by the International Agency for Research on Cancer, Lyon, France.

5.2 Objective

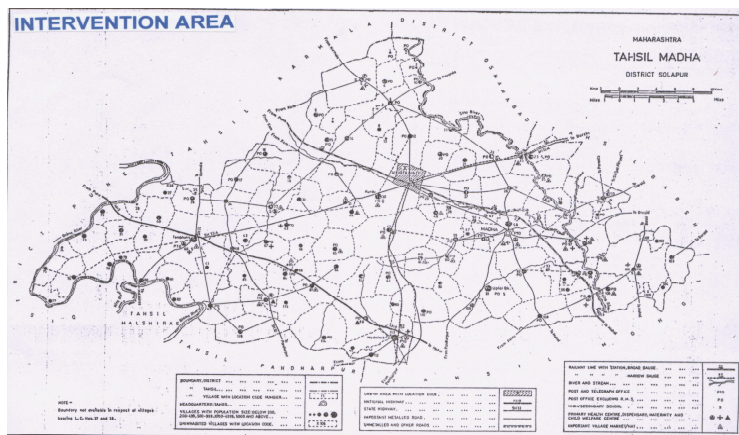
- a. To study the determinants of cancer awareness.
- b. To study the effect of health education on stage at presentation and completion of treatment of cervical cancer.
- c. To study the effect of health education on survival from cervical cancer.
- d. To study the effect of health education on incidence and mortality of cervical cancer.

Objective number two of the dissertation is described in this chapter.

5.3 Area and population covered

The intervention area was a rural area of Madha subdistrict covering 116 villages with a female population of 100,000 and an area of 1542.65 sq kms. The control area was a rural area of Karmala subdistrict covering 118 villages with a female population of 84,000 with an area of 1588.61 sq.kms (Census of India 1991a). Both Madha and Karmala subdistricts are under Solapur district of Maharashtra State, India. The map of the intervention area and the control area of the project is shown in Figure 9. The female population for the year 1995 was estimated as per 1991 and 2001 census growth rate and is mentioned in Table 15. For the estimation of the population same method as mentioned in 4.3.1 was used.

Intervention: Madha subdistricts (rural): 116 villages



Control: Karmala subdistricts (rural): 118 villages

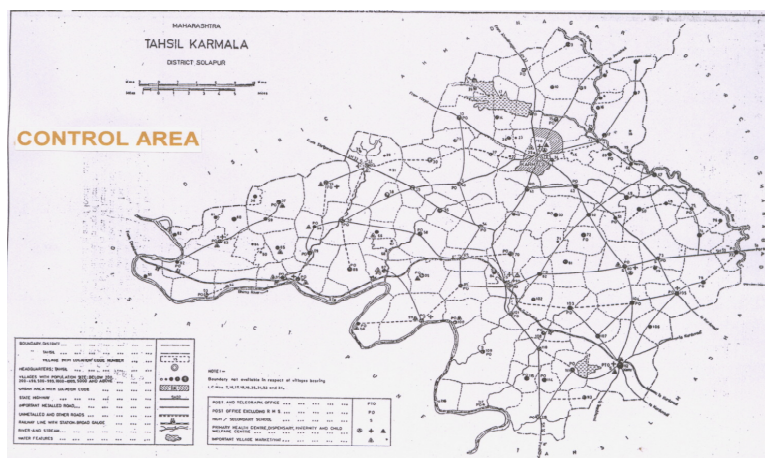


Figure 9. Area covered by the health education project

Table 15. Female age distribution in the intervention and control areas as on 1st July 1995

Age group (years)	Madha Sub district (Intervention area)		Karmala Sub district (Control area)	
		%		%
0-4	12724	10.8	9865	10.8
5-9	13729	11.7	10644	11.7
10-14	13272	11.3	10290	11.3
15-19	8971	7.6	6956	7.6
20-24	9522	8.1	7383	8.1
25-29	9648	8.2	7480	8.2
30-34	8804	8.2	6826	8.2
35-39	8236	7.5	6385	7.5
40-44	6810	7.0	5280	7.0
45-49	5722	5.8	4436	5.8
50-54	4793	4.9	3716	4.9
55-59	3724	4.1	2887	4.1
60-64	4118	3.2	3193	3.2
65-69	3081	3.5	2389	3.5
70-74	2256	1.9	1748	1.9
75+	2284	1.9	1771	1.9
	117693	100	91249	100

ANS – Age not specified

Educational and medical facilities available in the area

Madha and Karmala subdistricts are geographically similar. The literacy level in females according to 2001 census was 57.7% in Madha and 55.4% in Karmala. Most of the population was dependent on agricultural work. The health care delivery is administered through the primary health centre. Educational and medical facilities in the rural areas of Madha and Karmala subdistricts as per 2001 census are presented in Table 16.

There is no pathologist's position in the PHC/subcentre. People from this area consult the primary health centre/town hospital/district hospital for routine health problems. Nargis Dutt Memorial Cancer Hospital Barshi is the nearest cancer centre for both sub districts.

Table 16. Educational and medical facilities in the rural areas of Madha and Karmala subdistricts as per 2001 census

Facilities	Madha Subdistrict (Intervention area)	Karmala Subdistrict (Control area)
Primary schools	116	118
Rural hospitals	2	1
Primary health centres	6	5
Subcentres	39	33
Health workers	77	69
Medical practitioners	13	7

5.4 Method

Before starting any intervention a baseline awareness survey was conducted to assess the awareness level of cervical cancer in females in the intervention area. The survey was conducted in a 10% sample of female population from randomly selected villages. The woman in each household who is the key person in a family (the lady who takes care of preparation of food, who maintains the housework as well as shares other family responsibilities with the head of the family) was interviewed to ascertain whether she was aware of the symptoms and preventive measures in cervical cancer.

The intervention area comprised villages under six primary health centres, Modnimb, Kurduwadi, Manegaon, Madha, Pimplner and Tembhorni in Madha sub district. Each primary health centre covered at least 20 villages with a population of 30,000. The intervention consisted of health education on cervical cancer and arranging a field clinic for the diagnosis of cervical cancer in the primary health centre (easy access for diagnosis). The study population included only those who had been living in the village for at least one year and would likely to continue living there. Population was enumerated by household survey. The head of the family and all females in the house were enumerated. At the enumeration the field workers discussed cervical cancer symptoms and precautions to be taken to prevent the disease (person-to-person education on cervical cancer). They also informed that the diagnosis facilities available at the planned detection clinic and the treatment facilities available at Nargis Dutt Memorial Cancer Hospital Barshi. During the enumeration if any symptoms related to cervical cancer were found a referral card for further diagnosis at NDMCH/field clinic was provided. The method used by the Rural Cancer Registry Barshi was followed; instead of every 10th house the field staff visited each house in the village. The field staff completed the enumeration of all villages under the primary health centre in a similar manner. After the enumeration cervical cancer detection clinic at primary health

centre was organized. As a preparation for setting up the clinic the field staff has organized a video show (film show) in each school for adolescent girls and requested the girls to motivate their mothers to attend the detection clinic if anyone's mother was having any symptoms. To increase the awareness in the women and their families a video show on cervical cancer was arranged in the evening. One senior staff member and four field staff members had conducted the health education programme followed by a video film on cervical cancer in the local language (Marathi). The health education message was given in simple language so that participants and their husbands could understand. In the health education programme the senior staff explained about.

How does cervical cancer develop?

How to prevent cervical cancer?

The importance of hygiene

Symptoms and risk factors of cervical cancer

Why should one have a Pap smear examination?

In health education meetings senior staff announced the date and venue of the detection clinic and enquired if any one had been hiding symptoms during the staff visit, they should not do so and come forward to take a referral card. The programme was organized in a similar manner for all villages under the primary health centre. A day before the clinic field staff again visited the villages to remind the symptomatic women about the detection clinic. It was practically impossible to visit all the villages before the clinic. Village leaders were requested to remind the women about the detection clinic. Clinics were organized on market day, as the villagers do not go to their daily work on that day.

A mobile van of NDMCH headed by a lady medical officer, a cytotechnician, a nurse, a registration clerk and field staff conducted the clinic for the symptomatic women in the primary health centre. The nursing staff and cytotechnician collected the Pap smear, the medical officer provided free medicine for the complaints of the participant. After three weeks field staff distributed the reports to the participants. Those who were cytology positive were referred to the NDMCH for further diagnosis and treatment. The cancer cases were treated either by surgery /radiotherapy at NDMCH Barshi. Transport was provided for a few patients who were unable to spend the money for transport from the village to NDMCH. Programme was organized in a similar manner in other primary health centres too. The Barshi registry collected the information on cervical cancer cases from this region though this area was not under the registry. The cervical cancer cases from the project area received from the Barshi registry were confirmed during the village visit. The registry confirmed the cases reported as hysterectomy to the field staff during their visit to the hospital concerned.

Four staff members were assigned to the intervention area. Depending upon the date of enumeration a follow up of intervention population by house visit was done and the same procedure of intervention by person-to-person education on cervical cancer and identifying cases and referring them to the NDMCH was followed. The second round was organized after nearly four years. The video show and clinic was arranged in each PHC.

The control area consists of villages under five primary health centres Kem, Jeur, Sade, Warkute and Korti. From the intervention area the nearest village of the control area is 40 kms away and the farthest village is 140 kms away. In the control area no education on cervical cancer was provided. However the people received routine message from the government health services. The enumeration of all the villages with the information of the head of family and all the females in the houses was done. The field staff enquired if anybody had undergone surgery of the uterus or had radiotherapy. They noted all the cases reported as removal of the uterus as well as those who underwent radiotherapy. The Barshi Registry confirmed these cases. The periodical follow-up of the control area was done. Two staff members were assigned to the control area. A schematic diagram showing the method adopted in the intervention and control area for testing the effect of health education is shown in Figure 10.

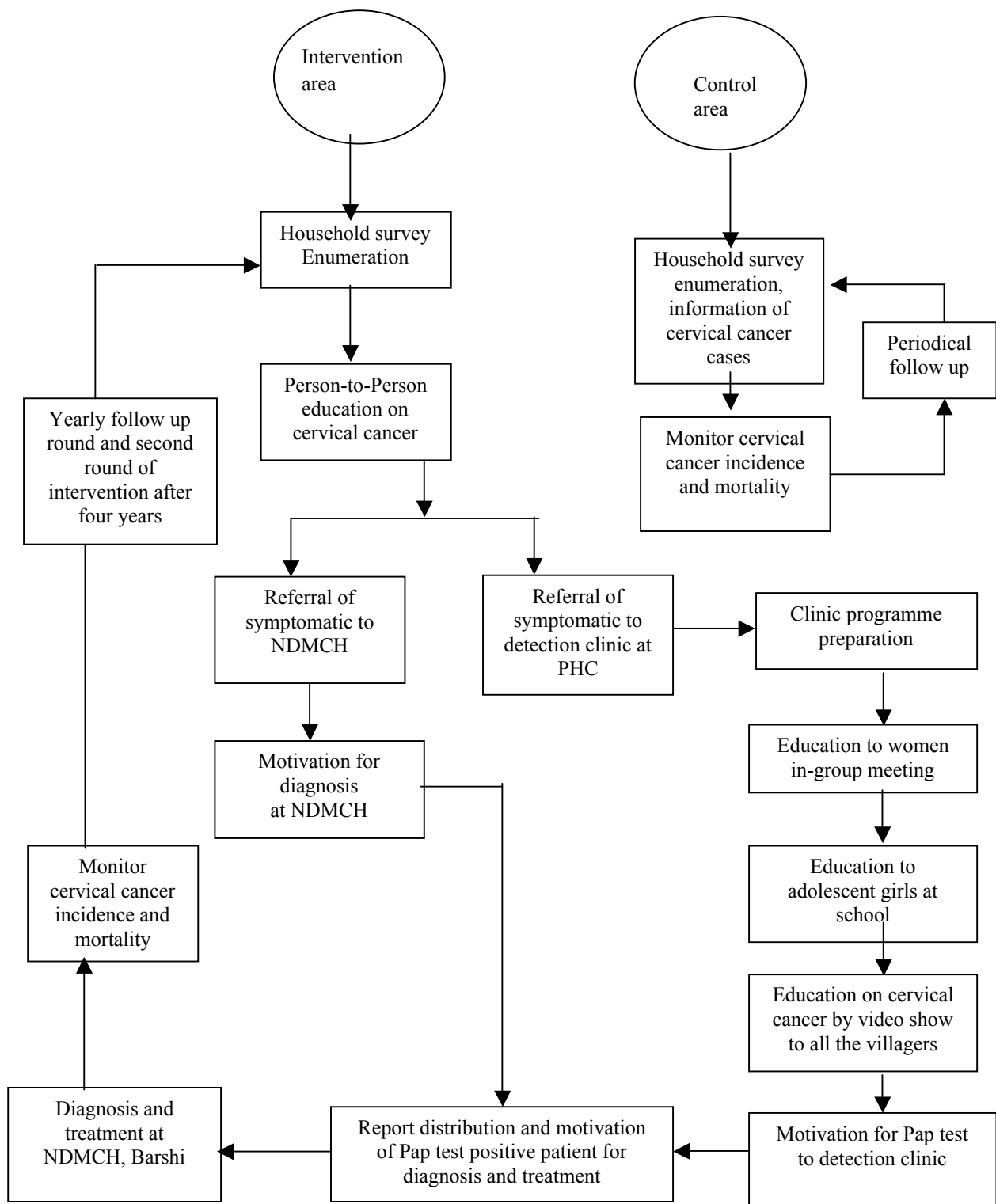


Figure 10. Schematic diagram showing the method adopted in the intervention and control areas for testing the effect of the health education programme

5.5 Statistical methods

The study data was entered into Epi-Info software. The data analysis was carried out using Epi-Info-6, SPSS and STATA software.

The test of significance for the comparison of the disease awareness levels, for the comparison of the staging of cervical cancer cases and for the comparison of the completion of treatment between the intervention group and the control group was calculated by comparing the proportion between two samples using Chi square test /Fisher's exact test.

The person years were calculated using STATA software. For the 'before intervention' group the person years were calculated from the 1st Jan 1995 and the last date was the day before the start of intervention. For the 'after intervention' group the starting date of the intervention was the first date and the last date was 31st December 2002. For the control area 1st January 1995 was the first date and 31st December 2002 was the last date of the follow-up. The crude incidence rate, age standardized incidence rate per 100,000 and crude mortality rate and age standardized mortality rate per 100,000 were calculated.

The standardized rate ratio (RR) is the ratio between the standardized incidence rate in the exposed group and to the standardized incidence rate in the unexposed group and represents the relative risk of disease in population 1 compared that in to population 2. The confidence interval of the standardized rate ratio was calculated as proposed by Boyle and Parkin (1991).

The observed survival in all the groups was calculated using the Life Table Method. The date of diagnosis was the starting date and 31st December 2002 was the final date for the follow-up. The index date for the calculation of survival time was the incidence date. The survival time for each case was the time between the index date and the date of death or date of loss to follow up or 31st December 2002. The analysis was carried out with SPSS software. The Log Rank Test was used for the comparison between the two survival rates.

5.6 Results

5.6.1 Baseline awareness survey

A baseline awareness survey was conducted in the intervention area, the results of this are presented in Table 17.

Most of the women interviewed were in the agegroup 30–49 (59%), 71% of the interviewed women were illiterate and only 12% women were aware of the disease. A woman who was aware of the warning signals of the excessive discharge or about vaginal bleeding or bleeding after intercourse or intermenstrual bleeding or who knew about the importance of the Pap test was considered to be aware of the disease.

Table 17. Distribution of the interviewed females by age, education and awareness about cervical cancer: Baseline awareness survey

Variable	Number	Percentage
<i>Age (years)</i>		
< 20	139	1.9
20-29	935	12.9
30-39	2504	34.6
40-49	1757	24.3
50-59	1194	16.5
60-69	420	5.8
70 +	188	2.6
ANS	94	1.3
<i>Education</i>		
No education	5100	70.7 *
Primary education	1644	22.8 *
Secondary education	472	6.5 *
No information	15	0.2
<i>Awareness</i>		
Aware of the symptoms and preventive measures of cervical cancer	886	12.3 *
Not aware of the symptoms and preventive measures of cervical cancer	6330	87.7 *
No information	15	0.2
<i>Total</i>	7231	100

ANS: Age not specified

* Percentage based on those with information available

5.6.2 Intervention

Intervention rounds and follow-up rounds conducted in the intervention area and in the control area are presented in Table 18 and Table 19.

In the intervention area health education on cervical cancer by video was organised before the detection clinic. In three villages no video show was organized due to heavy rain and electricity failure. During the period 1995 to 2001 health education programme for adolescent girls in the school was organised. The details of the school education programme is mentioned in Table 20.

Table 18. Intervention rounds conducted in the intervention area

Primary Health Centre	Number of villages	Number of rounds	First round (Education + Detection clinic at PHC)	Yearly follow up round (Education + Referral at NDMCH)	Second round (Education + Detection clinic at PHC)
Modnimb	19	5	1	3	1
Kudurwadi	20	5	1	3	1
Manegaon	22	5	1	3	1
Madha	19	5	1	3	1
Pimpalner	22	4	1	3	--
Tembhurni	14	4	1	3	--

Table 19. Initial and follow up round conducted in the control area

Primary Health Centre	Number of village	Initial round	Follow up round
Kem	18	1	1
Jeur	16	1	1
Korti	30*	1	1
Sade	27	1	1
Warkute	26	1	1

*One non-cooperative village in the control area was excluded.

Table 20. Health education on cervical cancer conducted in school for adolescent girls during 1995–2001

Primary Health Centre	Number of schools where education was conducted	Number of schoolgirls who participated in the programme
Modnimb	13	1245
Kurduwadi	6	320
Manegaon	7	320
Madha	7	592
Pimplner	4	194
Tembhurni	5	529
Total	42	3200

5.6.3 Increase of the awareness due to intervention

To evaluate the intervention awareness resurvey 2% of the population from the randomly selected villages of the intervention area was conducted. The method and criteria of the survey was similar to those of baseline awareness survey. The survey was conducted after the first round was over. The results of the awareness survey are presented in Table 21.

After the first round of the intervention awareness had improved from 12% to 52%. The result of the baseline awareness survey was compared with an awareness resurvey after one round of the intervention. The comparison was done on the basis of education level of the women interviewed. The results of the comparison between the two surveys are presented in Table 22 and also graphical in Figure 11.

The awareness level in the women having primary education was improved from 27% to 66%, in those with secondary education from 24% to 81% and in the women having no education it was improved from 7% to 45%, the increase in the awareness level was highly significant ($p < 0.001$).

Table 21. Distribution of the interviewed females by age, education and awareness about cervical cancer– Awareness Resurvey

Variable	Number	Percentage
<i>Age (years)</i>		
< 20	20	0.5
20–29	449	12.2
30–39	1717	46.7
40–49	676	18.4
50–59	462	12.6
60–69	147	4.0
70 +	38	1.0
ANS	171	4.6
<i>Education</i>		
No education	2484	70.7 *
Primary education	939	26.7 *
Secondary education	93	2.6 *
No information	164	4.5
<i>Awareness</i>		
Aware of the symptoms and preventive measures of cervical cancer	1810	51.5 *
Not aware of the symptoms and preventive measures of cervical cancer	1706	48.5 *
No information	164	4.5
<i>Total</i>	3680	

ANS: Age not specified * Percentage based on those with information available

Table 22. Awareness level by education before and after the intervention

Education	Awareness before the intervention			Awareness after the intervention			p
	Total women	Aware	%	Total women	Aware	%	
No education	5100	331	6.5	2484	1117	45.0	<0.001
Primary education	1644	441	26.8	939	618	65.8	<0.001
Secondary education	472	114	24.2	93	75	80.6	<0.001

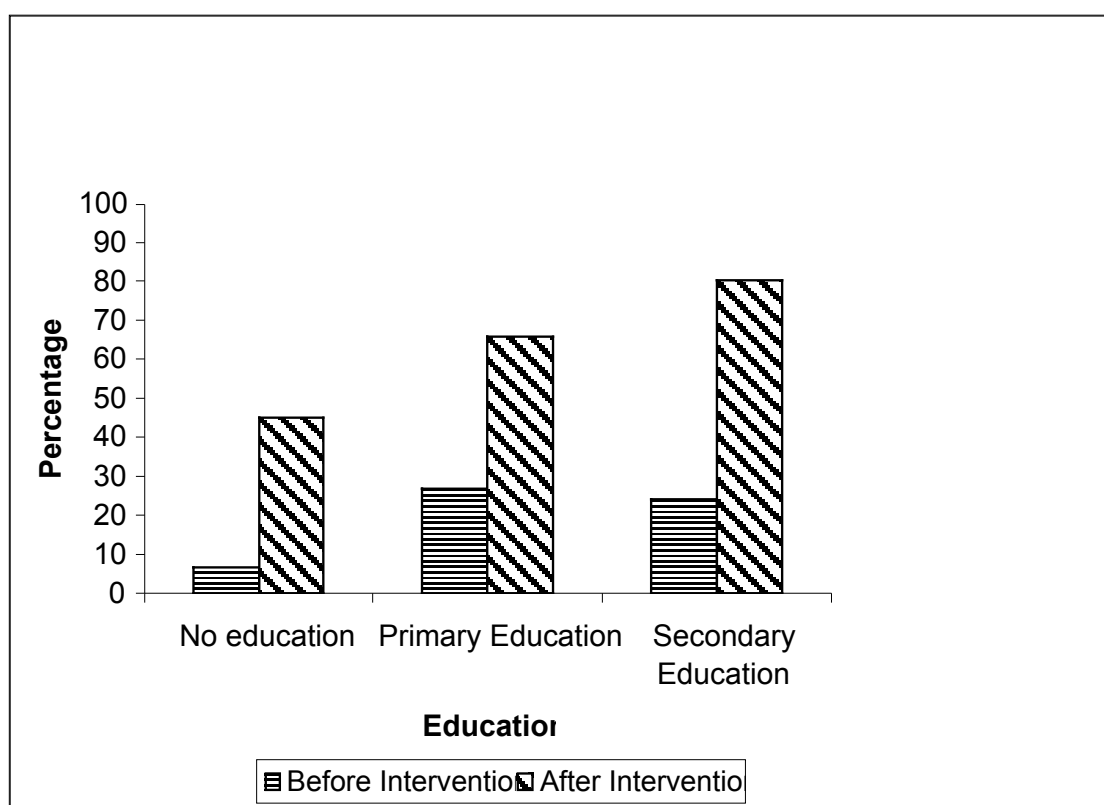


Figure 11. Awareness levels by education before and after the initial round of the intervention

5.6.4 Impact of programme on stage of disease and completion of treatment

A total of thirteen detection clinics were organized for easy access to diagnosis for the symptomatic women. The number of women who attended the detection clinic for Pap smear examination and the result of the Pap smear are mentioned in Table 23.

Table 23. Number of women who attended the detection clinic and result of the Pap smear

Item	Number
Number of clinics	13
Number attending	2839
Number examined	2667
<i>Result of cytology diagnosis</i>	
Atypia	111
Mild dysplasia	45
Moderate dysplasia	22
Severe dysplasia	18
Carcinoma in situ	2
Invasive cancer	34

The 196 cases where cytology was reported as atypia /dysplasia were called for the further diagnosis and treatment at NDMCH. Out of 111 cases of atypia, 62 (56%) cases attended the follow-up and out of 85 cases of dysplasia 56 (66%) attended the follow up. The Pap smear positive cases were further investigated, the carcinoma in situ and invasive cancer cases were investigated and treated, out of 36 cases, 17 (47%) cases did not complete the treatment. In addition to this 539 cases were referred by the field staff for the diagnosis at NDMCH in the period 1995–2002. Out of 539 cases, 24 cases were diagnosed as atypia, 77 dysplasia and 15 invasive cancer cases were detected. Out of which 11 (46%) atypia cases and 39 (51%) dysplasia cases attended further follow up and 8 (53%) invasive cervical cancer cases completed treatment.

Information on the cervical cancer cases was collected by house visit, by examining the death records and from the Rural Cancer Registry Barshi. The cases in the control area were also collected in the same manner. The intervention was started at different times in each area so two groups were made 1) Cases detected before intervention 2) Cases detected after intervention. The basic characteristics of the cases are presented in Table 24 while the clinical details of the cases are presented in Table 25.

Table 24. Basic characteristics of the cases from the intervention area and control area

Characteristics of the cases	Cases before intervention		Cases after Intervention		Control area	
	n	(%)	n	(%)	n	(%)
<i>Age group (years)</i>						
< 29	2	7.4	2	1.6	2	1.9
30–39	9	33.3	23	18.7	15	14.0
40–49	7	25.9	40	32.5	22	20.6
50–59	2	7.4	24	19.5	31	29.0
60 +	7	25.9	34	27.6	37	34.6
<i>Education</i>						
No Education	19	79.2*	83	74.1*	68	77.3*
Educated	5	20.8*	29	25.9*	20	22.7*
NI	3	11.1	11	8.9	19	17.8
<i>Type of House</i>						
Thatched	6	25.0*	33	30.6*	27	31.0*
Tiled	17	70.8*	59	54.6*	47	54.0*
Concrete	1	4.2*	16	14.8*	13	14.9*
NI	3	11.1	15	12.2	20	18.7
<i>Income.</i>						
< INR 2000 (US\$ ≤ 41)	19	79.2*	65	60.2*	57	66.3*
INR 2000-5000 (US\$ > 41 and < 104)	4	16.7*	30	27.8*	25	29.1*
INR ≥ 5000 (US\$ ≥ 104)	1	4.2*	13	12.0*	4	4.7*
NI	3	11.1	15	12.2	21	19.6
Total	27	100	123	100	107	100

NI : No Information, n: Number of cases, INR – Indian Rupees

* Percentage of those with information available

Table 25. Clinical information on the cases from the intervention area and control area

Clinical Information	Cases Before Intervention		Cases after Intervention		Control area	
	n	(%)	n	(%)	n	(%)
<i>Source of Registration</i>						
Detection clinic	–	--	35	28.5	--	--
NDMCH	18	66.7	68	55.3	84	78.5
Other Hospital	9	33.3	20	16.3	23	21.5
<i>Method of diagnosis</i>						
Clinical	2	7.4	5	4.1	4	3.7
Cytology	4	14.8	24	19.5	1	0.9
Histology	21	77.8	94	76.4	95	88.8
Missing					7	6.5
<i>Histological diagnosis</i>						
Squamous cell carcinoma	25	92.6	112	91.1	95	88.8
Adenocarcinoma	–	--	6	5.0	1	0.9
<i>Type of Treatment</i>						
Surgery only	3	11.1	15	12.2	14	13.1
Radiotherapy (RT) only	13	48.1	44	35.8	44	41.1
Other	3	11.1	17	13.8	18	16.8
<i>Completion of treatment</i>						
Treatment completed	19	70.4	70	56.9	69	64.5
Partial Treatment	–	--	6	4.9	7	6.5
No treatment	8	29.6	47	38.2	31	29.0

n: Number of cases

In the intervention area most of the cases were in the age group 30–49; 51% compared to 35% in the control group, there was not much difference between education status and income status among the cases in both the areas. Due to easy access to diagnosis 29% cases were detected in the detection clinic in the intervention area.

The proportion of early cases after intervention was greater in the intervention area than in control area (Table 26 and Figure 12). In the intervention area cases with unknown stage were fewer than in the control area.

Table 26. Stage distribution of the cervical cancer cases from the intervention and control area

Stage	After Intervention		Control area		p
	n	(%)	n	(%)	
Ia, Ib	44	35.8	19	17.8	0.0002* 0.0008**
IIa, IIb	23	18.7	13	12.1	
IIIa, IIIb	39	31.7	52	48.6	
IVa, IVb	02	1.6	01	0.9	
No Information	15	12.2	22	20.6	
Total	123		107		
% of early cases	54.5*	62.0**	29.9*	37.7**	

n: Number of cases

* % including no information on stage

** % excluding no information on stage

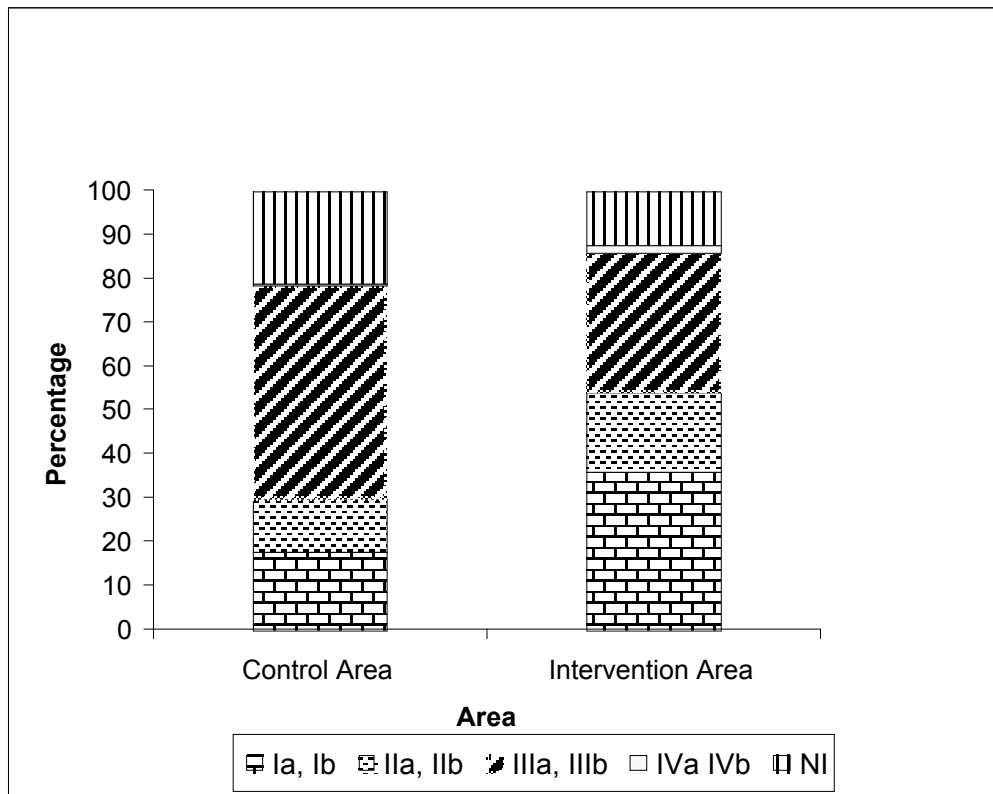


Figure 12. Stage distribution of the cervical cancer cases from the intervention area and control area

There was not much difference between the proportions of cases that completed the treatment from the intervention area compared to the control area. The results of the variable tested for the completion of the treatment are presented in Table 27.

Table 27. Variables tested for the completion of the treatment

Variable	Treatment	After intervention		Control area		p-value
		n	(%)	n	(%)	
Overall	Completed	70	56.9	69	64.5	0.24
	Not completed	53	43.1	38	35.5	
	Total	123		107		
Age < 49 (Years)	Completed	40	61.5	28	71.8	0.29
	Not completed	25	38.5	11	28.2	
	Total	65		39		
Age >= 49 (Years)	Completed	30	51.7	41	60.3	0.33
	Not completed	28	48.3	27	39.7	
	Total	58		68		
Monthly income < 2000 (INR) (US\$ <41)	Completed	37	56.9	35	61.4	0.62
	Not completed	28	43.1	22	38.6	
	Total	65		57		
Monthly income >=2000 (INR)(US\$ >=41)	Completed	28	65.1	23	79.3	0.19
	Not completed	15	34.9	6	20.7	
	Total	43		29		
Educated	Completed	19	65.5	16	80.0	0.27
	Not completed	10	34.5	4	20.0	
	Total	29		20		
Illiterate	Completed	48	57.8	43	63.2	0.50
	Not completed	35	42.2	25	36.8	
	Total	83		68		
Stage Ia, Ib	Completed	23	52.3	18	94.7	0.001
	Not completed	21	47.7	1	5.3	
	Total	44		19		
Stage IIa, IIb	Completed	17	73.9	10	76.9	0.84
	Not completed	6	26.1	3	23.1	
	Total	23		13		
Stage IIIa, IIIb, IVa, IVb	Completed	23	56.1	29	54.7	0.89
	Not completed	18	43.9	24	45.3	
	Total	41		53		

INR – Indian Rupees.

In the intervention area 57% cases completed the treatment compared to 65% cases in the control area, the difference between the two areas was not significant ($p > 0.05$). In the intervention area 61.5% cases in the age group < 49 completed the treatment compared to 71.8% women in the control area, the difference in the two areas was not significant ($p > 0.05$). When the completion of the treatment in the cases in the age group ≥ 49 was compared, 51.7% cases from the intervention area had completed the treatment compared to 60.2% cases from the control area, the difference between the two areas was not significant ($p > 0.05$). In the intervention area 56.9% women whose monthly family income was less than INR < 2000 (US\$ < 41) had completed the treatment compared to 61.4% women from the control arm, the difference between the two areas was not significant ($p > 0.05$). In the cases whose monthly income was \geq INR 2000 (US\$ ≥ 41), 65.1% cases from the intervention area had completed the treatment compared to 79.3% cases in the control area, the difference between the two areas was not significant ($p > 0.05$). In the educated group in the intervention area 65.5% cases completed the treatment as compared to 80.0% cases in the control area, the difference between the two areas was not significant ($p > 0.05$). In the illiterate group 57.8% cases completed the treatment in the intervention area compared to 63.2% cases in the control area, the difference between the two groups was not significant ($p > 0.05$). Of the cases diagnosed as Ia and Ib stage in the intervention area 52.3% completed the treatment compared to 94.7% cases from the control area, the difference between the two areas was highly significant ($p < 0.01$). There was not much difference in the completion of the treatment in the cases diagnosed at stage IIa, IIb and IIIa onwards.

5.6.5 Effect of the programme on survival

There were 257 cases from all groups. For the survival analysis 11 (4.3%) cases were excluded due to incomplete information on the date of follow-up, 4 (14.8%) cases from the before intervention group, 1 (0.8%) case from after intervention group and 6 (5.6%) cases from the control group. The observed survival is presented in Table 28 and in Figure 13.

Table 28. Observed survival rate (%) of cervical cancer cases by area

Group	Number of cases	Observed survival rate (%)				
		1 year	2 year	3 year	4 year	5 year
Before intervention	23	82.6	64.6	50.9	37.0	32.4
After intervention	122	83.4	65.6	57.0	50.8	49.2
Control	101	71.8	50.8	45.2	39.7	39.7

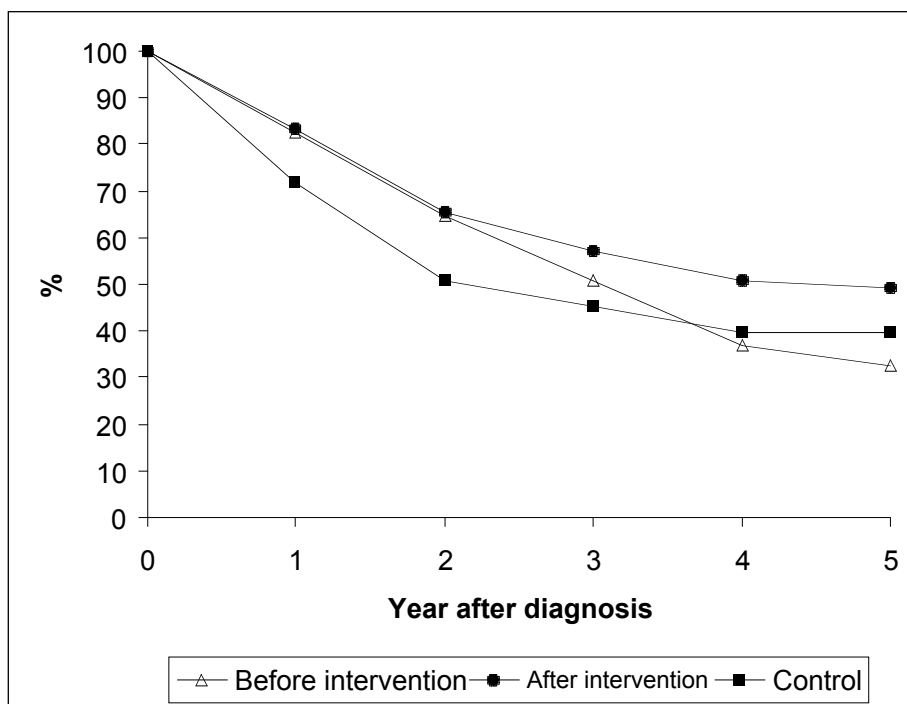


Figure 13. Observed survival (%) of cervical cancer patients by intervention and control area

The difference between the survivals was tested by the Log Rank test; none of the differences between the groups were statistically significant. However, they were consistent with the hypothesis that the health education was effective. The five-year survival of the cases diagnosed after intervention was higher compared to the cases diagnosed before intervention. When the difference between the two survivals was tested it was not statistically significant ($p = 0.34$). The 5-year survival of the cases diagnosed in the control area was lower than the cases diagnosed in the after intervention group, when the difference between the two survivals was tested it was not statistically significant ($p=0.08$).

5.6.6 Effect of the programme on cervical cancer incidence and mortality

In the period 1995–2002 there were 150 cases registered from the intervention area, of which 27 cases were found before the intervention was started. In the control area there were 107 cases registered. In the intervention area 69 cases died by the end of 2002, out of which 16 cases were from the before the intervention was started. In the control area 54 cases had died at the end of 2002. The incidence rate and mortality rate are presented in Table 29 and standardized rate ratio is presented in Table 30.

Table 29. Incidence and mortality rate for cervical cancer per 100,000 PYRS from the intervention and control area

Area	Incidence cases	Death cases	Person years	Incidence rate per 100,000 PYRS	ASR incidence rate per 100,000 PYRS	Mortality rate per 100,000 PYRS	ASR mortality rate per 100,000 PYRS
Before intervention	27	16	163684	16.5	16.8	9.8	10.4
After intervention	123	53	613673	20.0	23.1	8.6	10.3
Control	107	54	608096	17.6	18.5	8.9	10.1

ASR: Age standardized rate

Table 30. Standardized Rate Ratio (RR) of cervical cancer in the intervention area compared to the control area

Indicator	RR	95% CI
<i>Incidence</i>		
Before intervention /control	0.91	(0.89–0.99)
After intervention/control	1.25	(1.18–1.32)
After intervention/before intervention	1.38	(1.27–1.51)
<i>Mortality</i>		
Before intervention /control	1.03	(0.91–1.16)
After intervention /control	1.02	(0.94–1.10)
After intervention/before intervention	0.99	(0.88–1.12)

The age standardized incidence rate 23.1 per 100,000 PYRS in the intervention group was higher compared to the control group at 18.5 per 100,000 PYRS. The relative risk of 1.25 was statistically significant (95% CI 1.18–1.32). The incidence rate in the intervention group was higher than the incidence rate in the before intervention group. The relative risk 1.38 was statistically significant (95% CI 1.27–1.51). The area before the intervention was equivalent to the control area, when comparing the incidence rate of cervical cancer between the control area and the before intervention area a marginal difference was present between the two incidence rates which was borderline significant (95% CI 0.89–0.99). The mortality of 10 per 100,000 PYRS in all the arms was similar, there was no effect of the intervention on mortality. The graphical presentation of age standardized incidence and mortality rate from cervical cancer per 100,000 PYRS in the intervention area and control area is shown in Figure 14.

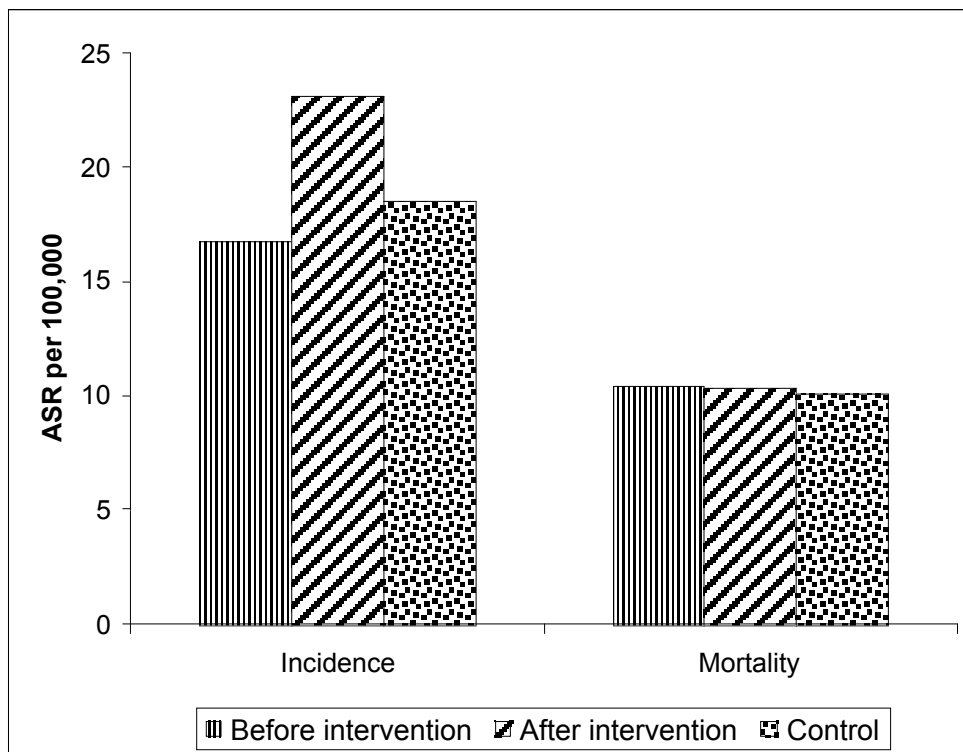


Figure 14. Age standardized incidence of and mortality from cervical cancer per 100,000 PYRS in the intervention area and control area

5.7 Discussion

The study was conducted within a limited budget with the available infrastructure. Six staff members were appointed for this programme on a minimum salary. The NDMCH provided available infrastructure like video, educational material, mobile van, a jeep (Vehicle), services for the cytology examination, a free diagnosis and treatment facility, the services of the senior staff for conducting the education programme and the services of the registry for monitoring the incidence and mortality in the region. The TMC provided quality control services for the cytology.

Before starting the intervention the awareness level of the disease was very low. The awareness level reported in the control area in the study undertaken by Barshi registry was low (Jayant et al. 1994). The awareness about cervical cancer has been reported to be very low in the studies conducted from developing countries, Kenya (Gichangi et al. 2003), Nigeria (Ajayi and Adewole 1998), Jordan (Maaita and Barakat 2002). It was reported in several studies that lack of knowledge of the disease was the major barrier in cervical cancer screening (Ansell et al. 1994, Kelly et al. 1996, Lantz et al. 1997, Pearlman et al. 1999). In this study the awareness level went from 12% up to 52% after the first round of the intervention, it improved more in the educated women than in the uneducated group. The education on the disease provided person-to-person by group meetings and in school has improved the awareness. In India video shows have been shown to result in a considerable improvement in the awareness level.

A total of thirteen detection clinics were organized for the symptomatic women as a facility for easy access to diagnosis. The clinics were organized on market day, as the villagers do not go their daily work on market day. The quality of cytology was satisfactory in this study, among the total screened 9% cases were cytology positive. In the randomized control trial conducted at NDMCH, Barshi the cytology positive cases constituted 7% of the 25,000 (Sankaranarayanan et al. 2005). The follow of cytology positive cases was poor, women refused further follow up as they felt it was not necessary.

An improvement was observed in the stage of the diagnosis of the cases in the intervention area compared to the control area. The difference between the two groups was significant. This was similar to Barshi registry findings and confirmed the hypothesis put forth by the Barshi registry that due to raising cancer awareness and motivating women to attend for detection we could diagnose the cases at an early stage (Jayant et al. 1995).

The cervical cancer incidence in the intervention area was higher than that in the control area, the difference was statistically significant. The incidence rate of cervical

cancer reported by the Barshi registry 27 per 100,000 PYRS, which was higher than the intervention area. The incidence in the intervention area was higher than control area due to continuous education and motivation for the diagnosis in the detection clinic as well as at NDMCH. Incidence in the control cohort was somewhat higher than in the screened cohort before intervention.

The cases diagnosed at an early stage indicated an improvement in the survival. The observed survival of the cases from the intervention area, 'before intervention' was 32.4% compared to 49.2% after intervention and in the control area it was 39.7%. The difference in the survival was less than expected due to stage shift and it was not significant. The reported survival in the entire group was higher than Barshi registry (Jayant et al. 1998), but in the Barshi registry the survival had significantly improved with 3 years of registry activity.

Mortality rate of all the three areas was similar. There was no difference in mortality rate between the intervention area and the control area. In the first four years (1995–1998) of the study the mortality rate in the control area was 8.2 per 100,000 PYRS while the mortality in the intervention area was much lower at 5.1 per 100,000 PYRS. These provisional results have been discussed (Parkin and Sankaranarayanan 1999). In the control area there may be underregistration as there was long gap between the two round. In future there may be a decreasing trend in the mortality from the intervention area as 57% of cases are alive compared to 50% in the control area.

The completion of the treatment in the intervention area was less than in the control area. The difference between the completion of the treatment between the two groups was not significant ($p>0.05$). However, it was substantial in the screen detected early (stage 1 cancers), which accounts for the small difference in survival between the intervention and control populations. The effect of the variable income, education, age and stage was tested for treatment completion. Income, education and age had no effect on the completion of the treatment. In the intervention area the cases diagnosed at an early stage did not complete the treatment as compared to the control area. It was reported in Harare, Zimbabwe (Chokunonga et al. 2004) that 51% patients did not complete the treatment and among nontreatment cases, 31.7% were localized cases and 35.2% were regional cases. Among those who completed the treatment, 65.5% cases were regional cases. It was reported that no treatment cases were more in the age group 35–44 years (47%). No treatment or delay in treatment was reported in the Hmong women in California (Yang et al. 2004). The 51% cases of Hmong women did not complete the treatment as they took first course of treatment from traditional healers and due to a cultural barrier, they did not complete the treatment. In the study conducted by Tata Memorial Hospital, Mumbai, India (Shastri et al. 2005) it was reported that out of 28 women with invasive cervical cancer 17 cases (61%) complied with the treatment.

Late presentation for treatment was also reported in South Africa (Treadwell 1992) and in India (Nandakumar et al. 1995, Dinshaw et al. 2001).

In our study the localized cases were diagnosed at the field clinic or at NDMCH, when these women were invited for further treatment, their attitude was they were not ill and they did not want any treatment. The villager's attitude was that when the disease became severe and when they were unable to work and were compelled to lie down on the bed they would consult the doctor. It was reported that in a resources of poor environment individuals define themselves as a 'sick' at a more extreme point on a health illness continuum and the symptoms were often quite severe before women sought for help (Johansson 1991). The women were happy with the antibiotic and calcium tablets provided by the clinic. Some women prefer traditional home medicine. They informed us that they would not come for the treatment, as they were more in need of daily wages of Rs. 40/- (US\$ 0.8 per day) than the treatment. It was observed that it was difficult for the women to spend the money for transport from the village to NDMCH, Barshi. Considering this problem a transport facility was provided but it has created misunderstanding among the women. The patients thought that 'the organizer must be getting some money through my surgery and he was only spending money for the transport'. Transportation has been observed to be a common barrier in screening and follow up (Black et al. 1993). The financial barrier in the completion of the treatment was also reported (Hunter 2004, Alliance for Cervical Cancer Prevention 2004). In India most of the cancer patients take alternative medicines before coming for the treatment at the cancer hospital (Chaturvedi et al. 2002). In another study in India (Pal 2002) it was reported that 16% of patients go for alternative medicine due to financial problems. In a study using qualitative interviews with cancer patients and their caretakers in Scotland and Kenya (Murray et al. 2003) it was reported that patients from Kenya hide their symptoms from their families because they were worried about finding the money to attend outpatient consultations and for the medicine.

The women were uneducated and on their own they can not attend hospital. If they attend alone the treating doctor needs consent from a relative. The women feel comfortable in the hospital either with husband/ close relative/village leader. According to a World Bank report on improving the women's health in India (World Bank Publication, 1996), poverty underlines the poor health status of the Indian population and they are prevented from travel without a chaperon and this has profound implications for their access to health. A need for social support by targeting the community representatives in the screening programme was reported (Gotay and Wilson 1998). However for the relatives the daily wages work was more important and they cannot spend two weeks or four weeks in the hospital. This problem was related to poor socioeconomic status. The late stages cases insisted on surgical treatment as they

are afraid of radiotherapy treatment. It was reported that women from the rural areas have false ideas about radiotherapy treatment (Nene et al. 1994).

In the intervention area those who came for the treatment underwent the biopsy. They had to visit the hospital after fifteen days for further treatment. The staff has to re-visit these women to motivate them for further treatment. The number of hospital visits (for diagnosis, lab test, x-ray, ultrasonography test, physicians fitness) also delays the treatment of the patient. This study would like to recommend that unnecessary visits to the hospital should be avoided, all the procedures before the treatment should be planned in a way that frequent visits to the hospital are avoided. The number of visits to the hospital has been reported to be a barrier to the treatment (Black et al. 1993). These cases have not attended immediately for treatment and attended only when the disease had reached the advanced stage. Those who attended for treatment left the hospital, as they did not have money to buy the medicine. This process has diluted the intervention effect and we did not find any difference in the mortality after seven years. Treatment completion was the main barrier in the cervical cancer control programme. In the intervention group in spite of significant downstaging a large proportion of Ia and Ib cases did not complete the treatment. Treatment requiring a short hospital stay (a week or less than 10 days) such as intracavitary radiation alone or simple hysterectomy in stage Ia cases or radical hysterectomies should be advocated for such cases to improve compliance of treatment. Proper counseling and motivational efforts to the husbands of the women and the other relatives is essential for completion of treatment.

Apart from all the limitations, this study has shown a way for cervical cancer control in a rural area within the available infrastructure and on limited resources. It has shown the weakness in the cervical cancer control programme in the rural area. Cancer awareness level can be improved by health education and we can detect cases at an early stage by providing a diagnostic facility on the doorsteps of the villagers, but completion of the treatment is an important factor for the control of disease. It is not sufficient to provide the free treatment, we have also to provide transport, free food during the hospital days as well as free medicine. In the randomized controlled trial conducted at Barshi, India (Sankaranarayanan et al. 2005) excellent facility (transport, food and free medicine to all the screen positive cases) was provided, the compliance with treatment for precancerous lesion and cancer cases was high. The facilities the organizer provides need to be properly focused during the educational drive to avoid further misunderstanding among the women. This study recommends that the cervical cancer control programme should focus detecting and treating the precancerous lesions in single or two visit strategies rather than detecting and treating invasive disease given our experience showing poor compliance with treatment.

6. Screening, attendance and impact on process indicators

6.1 Background

Well-organized cervical cancer screening programmes have resulted in a marked decline in mortality from cervical cancer in the developed countries (Hakama et al. 1986). However the lack of success in low-resource settings and the wide variation in sensitivity to conventional cytology (Fahey et al. 1995, Nanda et al. 2000) have stimulated interest in evaluating the effectiveness of alternative methods of screening such as visual inspection with 3–5% acetic acid (VIA) and human papillomavirus (HPV) testing that may be more readily implemented in different settings. Evaluation of their effectiveness in reducing the incidence of and mortality from cervix cancer, in comparison with the established standard cytological screening as well as the relative cost involved is essential for informed choices with respect to public health policy. Most of the scientific evidence for the efficacy of a cancer-screening test comes from randomized controlled trials (RCT) with a reduction in incidence of or mortality from the disease of interest as the end point. An RCT was initiated in 1999 at NDMCH Barshi. The screening attendance and impact on the process indicators such as staging of the disease and completion of the treatment are discussed in this chapter.

6.2 Objective

- a. To study the compliance of the women in screening for cervical cancer.
- b. To assess the knowledge and attitudes of women who participated in the screening and those who did not participate in the screening.
- c. To study the impact of screening on the stage of the disease and completion of treatment.
- d. To study compliance with treatment among screen positive women.

Objective number three of the dissertation is described in this chapter.

6.3 Method

An RCT was initiated in October 1999 to address the efficacy and cost effectiveness of different screening regimes, one time screening with VIA, cytology and HPV testing in reducing cervical cancer incidence and mortality. The project was conducted in Osmanabad district, Maharashtra State, India because of the relatively high risk of cervical cancer and the availability of diagnostic and treatment facilities at the Nargis Dutt Memorial Cancer Hospital, Barshi and technical support from Tata Memorial Centre, Mumbai to the NDMCH, Barshi. The study protocol was reviewed and approved by the institutional scientific and ethical review committees of the TMC/NDMCH and the International Agency for Research on Cancer (IARC), Lyon, France. The study was a cluster-randomized trial, 497 villages in rural Osmanabad district were grouped into 52 clusters based on the primary health centres. These clusters were randomized by restricted randomization into four groups, 13 each, women in group 1 (133 villages) received VIA, in group 2 (122 villages) received cytology, in group 3 (115 villages) received HPV testing, group 4 (127) villages formed the control group. The women in the control group were educated about cervical cancer and its prevention, during house visits, in-group meetings and free diagnosis treatment facility were provided at NDMCH, Barshi. The recruitment was done between May 2000 to November 2003.

Women and their family members were given health education on cervical cancer and its prevention as well as on the details of the project both by person-to-person messages during house visits and in group meetings. Group meetings involving civic leaders, village administrators, officers of women's organizations, primary health care workers of the government health services, schoolteachers, local volunteers, eligible women, their partners and relatives were conducted in each village to explain about cervical cancer prevention and to provide information on the project. Health workers and local resource persons personally invited eligible women to the intervention groups one to three days prior to the screening clinic. All the invited women were provided with a card indicating date and time of the clinic. The clinics were organized according to the local village situation and avoiding festival days. Screening examinations were conducted locally in each village using adapted clinics in local primary health centres, village administrative offices, school or in women's club buildings, the necessary instruments and consumables were brought from the project office. The treatment of the screen positive women was carried out at the central clinic at NDMCH. All the women

were advised to visit the central clinic for investigations and treatments. The programme called all the screen positive women of a particular village for treatment on the same day. The programme provided transport, food, medicine and village leaders were requested to accompany the screen positive cases for treatment in NDMCH, Barshi. The recruitment for the study was completed in November 2003. In this study 26,755 women were screened by VIA, 25,535 were screened by cytology and 27,159 women were screened for HPV and 33,696 women were provided with health education on cervical cancer. The detail methodology has been reported elsewhere (Sankaranarayanan et al. 2005). The villages screened by VIA, cytology and HPV during the period July 2000 and January 2002 were randomly selected to cover 10% of screened women from those screened up to January 2002. 25 villages were selected, 6 from the VIA arm, 9 from the cytology arm and 10 from the HPV arm. The questionnaires were designed for screened women, for those who refused the screening and those who were screen positive and refused the treatment and for screen negative women. The interview was conducted in the house/work place of the participant. Two female social investigators conducted the interviews from April 2002 to January 2003. The interview was conducted as per the listing of the participants provided by the screening database. The study design is shown in Figure 15.

The programme covers the rural area of the four sub districts, Osmanabad, Kalamb, Umarga and Tuljapur from the Osmanabad district of Maharashtra State in India. The Rural Cancer Registry, Barshi established the Osmanabad cervical cancer registry to monitor the cervical cancer incidence and mortality in the programme area. The workflow of the Osmanabad cervical cancer registry is shown in Figure 16. The area covered by Osmanabad registry is presented in Figure 17.

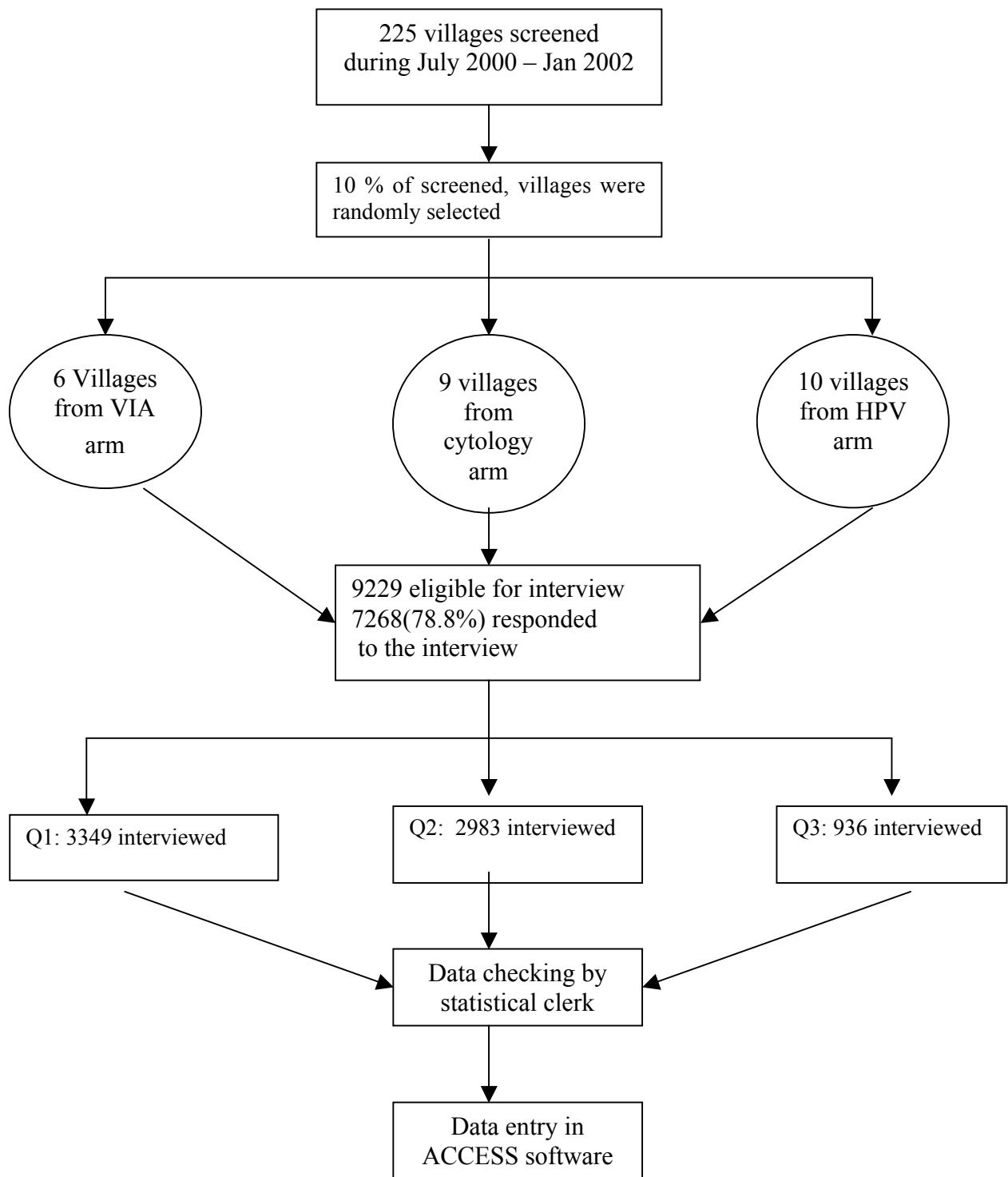


Figure 15. Study design

(Q1: Complied to screening Q2: Screen positive who refused treatment and screen negative women Q3: Screening refused)

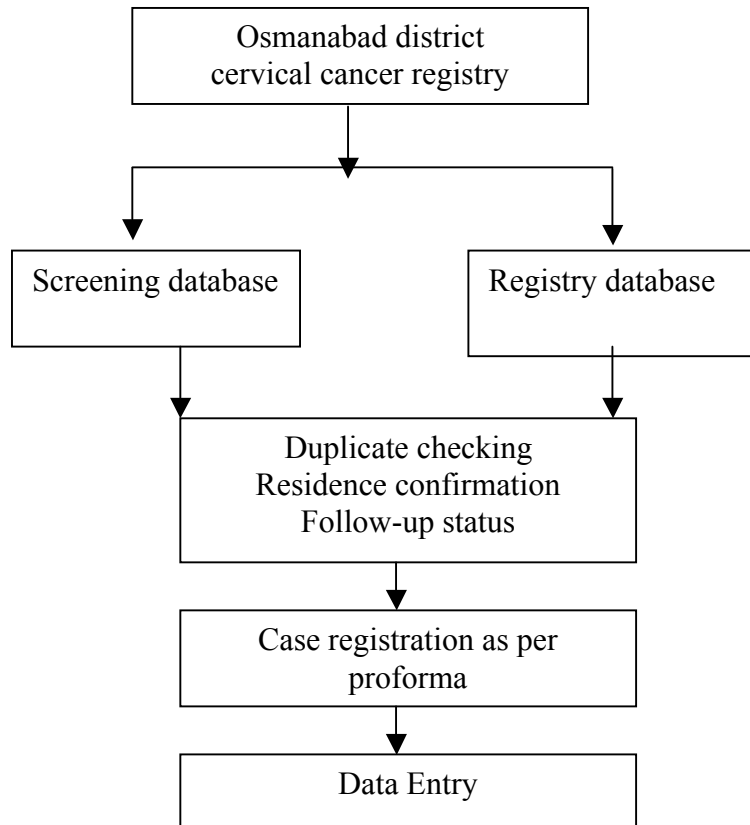
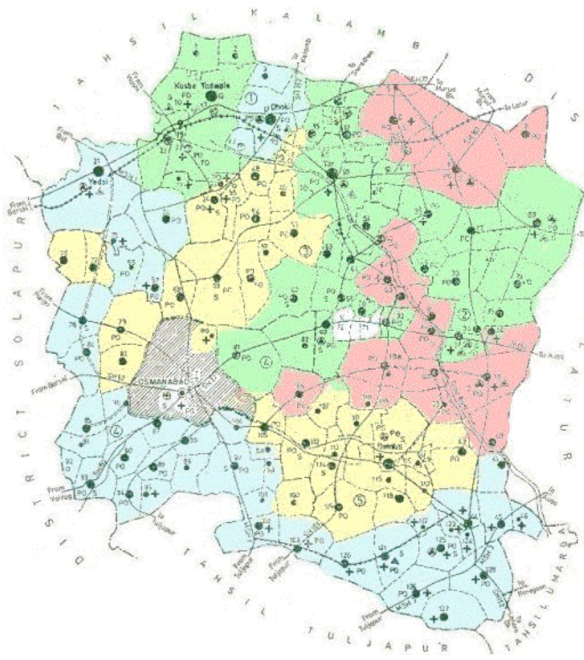
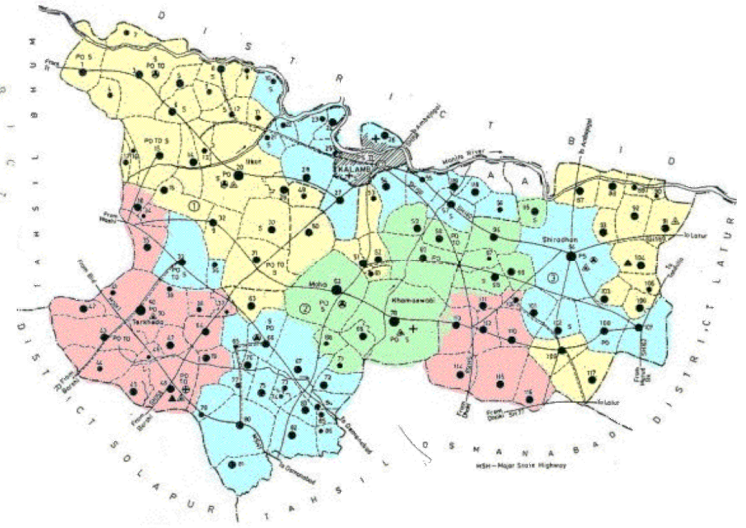


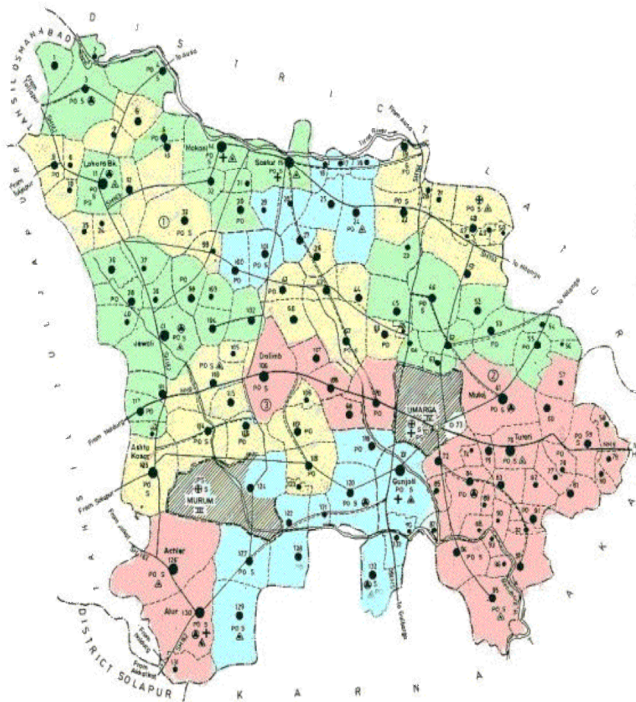
Figure 16. Workflow of Osmanabad cervical cancer registry



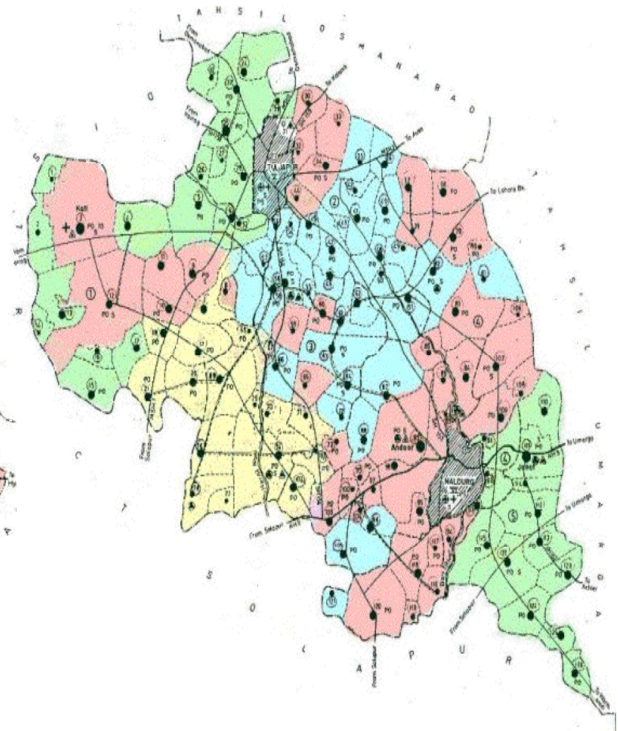
Osmanabad subdistrict (rural)



Kalamb subdistrict (rural)



Umarga subdistrict (rural)



Tuljapur subdistrict (rural)

Figure 17 Area covered by the Osmanabad cervical cancer registry

6.4 Statistical methods

The data entry was done in the ACCESS database and the data scrutiny was done by the statistical clerk in matching it with the screening database. The data analysis was carried out in SPSS and STATA. To determine the participation of women in the screening and for the compliance of the screen positive women with treatment the univariate and multivariate logistic regression analysis were used to evaluate the effects of socioeconomic and personal characteristics of the women estimating the odds ratio and their 95% confidence interval. The Chi square test was used for the comparison of the staging of cervical cancer.

6.5 Results

The number of women eligible for the interview as per the screening database and number interviewed is mentioned in Table 31.

Women complying with the interview for Q1-compliance to screening were 82.6%, 79.5% for Q2-screen positive who refused treatment and screen negative women and 65.9% for Q3-not screened women. In the analysis out of 936 women, 370 women who were out of station due to personal reasons or in menses during the screening day were not considered as unwilling. However, they were excluded from the analysis, 566 women who were not willing to participate were included in the analysis.

Table 31. Number of eligible women for the interview as per the screening database and number interviewed

Questionnaire	Total eligible women for the interview	Number interviewed	Response (%)
Q1. Compliant for screening	4054	3349	82.6
Q2. Screen positive who refused treatment and screen negative women	3754	2983	79.5
Q3. Not screened (not willing to participate, out of station/in menses)	1421	936	65.9
Total	9229	7268	78.8

6.5.1 Determinants of participation

The total number of women, proportion, univariate and multivariate odds ratio (OR) with 95% confidence interval (CI) of women not willing to participate in the screening compared to women who participated in screening are shown in Table 32.

Table 32. Total number, proportion, univariate and multivariate odds ratio (OR) with 95% confidence interval (CI) of women not willing to participate in screening compared to women who participated in screening

Variable	Not willing to participate		Univariate		Multivariate		
	Total	n	%	OR	CI	OR	CI
<i>Age group^a</i>							
30-39	2094	232	11.1	1		1	
40-49	1142	181	15.8	1.5	1.2-1.9	1.4	1.1-1.8
50-59	679	153	22.5	2.3	1.9-2.9	2.1	1.6-2.7
<i>Education of the women^a</i>							
No education	2737	466	17	1		1	
Educated	1178	100	8.5	0.5	0.4-0.6	0.6	0.4-0.8
<i>Occupation of the women^a</i>							
Housewife	1535	179	11.7	1		1	
Agriculture	2314	382	16.5	1.5	1.2-1.8	1.2	1.0-1.6
Other	66	5	7.6	0.6	0.3-1.6	0.8	0.3-2.3
<i>Marital status^b</i>							
Married	3500	459	13.1	1		1	
Widowed	327	87	26.6	2.4	1.8-3.1	1.7	1.3-2.2
Separated	88	20	22.7	1.9	1.2-3.2	1.6	1.0-2.7
<i>Education of the husband^{c *}</i>							
No education	1419	230	16.2	1		1	
Educated	2011	209	10.4	0.6	0.5-0.7	0.8	0.6-1.0
Not known	84	20	23.8				
<i>Occupation of the husband^{c *}</i>							
Agriculture	2963	390	13.2	1		1	
Other	540	68	12.6	0.95	0.7-1.3	1.2	0.9-1.7
Not known	10	--					
<i>Income^a</i>							
< INR. 2000 p.m. (US\$<41)	1890	339	17.9	1		1	
>=INR.2000 p.m. (US\$>=41)	2016	224	11.1	0.6	0.5-0.7	0.8	0.6-0.97
NI	9	3	33.3				
<i>Screening procedure^a</i>							
Understood	3006	442	14.7	1		1	
Not understood	909	124	13.6	0.9	0.7-1.1	0.8	0.6-0.98

a For multivariate analysis adjusted with all the variables in the table

b For multivariate analysis adjusted with all the variables after excluding husband's education and occupation

c For multivariate analysis adjusted with all the variables after excluding marital status

NI – No information, n – number of cases, INR – Indian Rupees.

* Widowed/separated women having partner their information was included

The results of the univariate analysis showed that the older, illiterate, low income, widowed, separated women, illiterate husband's wives and the women involved in agriculture were less likely to participate in the screening programme. The multivariate analysis was carried out for all the variables in the table but for the variable marital status, husband's education and occupation was excluded and conversely for the husband's education and occupation because there were no data for the previous husbands of widowed and separated women. The women in the age group 40–49 had 1.4 times risk (95% CI 1.1–1.8) of not participating in the screening programme while women in the age group 50–59 had 2.1 times risk (95% CI 1.6–2.7) of not participating in the screening programme compared to the women in the age group 30–39, which was significant. The educated women had 0.6 risk (95% CI 0.4–0.8) of not participating in the screening compared to the illiterate women, which was also significant. The women involved in the agriculture there risk of not participating were 1.2 (95% CI 1.0–1.6), but it was not significant. The risk of widowed women not participating in the screening programme was 1.7 (95% CI 1.3–2.2), which was significant. The risk of not participating among separated women was 1.6 compared to married women, but was not significant (95% CI 1.0–2.7). The risk of not participating among higher income group women was 0.8 (95% CI 0.6–0.97) compared to the lower income group women, which was significant. The women who did not understand the importance of the screening procedure were less likely to participate, 0.8 (95% CI 0.6–0.98), which was significant. Education and occupation of the husband has not shown any effect in the participation.

The knowledge, attitude towards the screening programme and the sexual intercourse practices in screened women and those who were not willing to participate is presented in Table 33.

Table 33. Knowledge, attitude towards the screening programme and sexual intercourse practices in screened women and those who were not willing to undergo screening

Factor	Screened Women		Not willing to participate	
	n	%	n	%
<i>Total women</i>	3349		566	
<i>Knowledge about the programme</i>				
From project staff	3293	98.3	532	94.0
Other ways	56	1.7	34	6.0
<i>Women's attitude</i>				
Will encourage others	3205	95.7	363	64.1
Will not encourage	144	4.3	203	35.9
<i>Attitude of husband/partner*</i>				
Encouraged	2461	80.6	NA	
Discouraged	47	1.5	NA	
Not interested	166	5.4	NA	
Husband not aware of screening	361	11.8	NA	
Husband does not matter	6	0.2	NA	
Not known	14	0.5	NA	
<i>Practice (sexual intercourse)</i>				
Regular intercourse	1234	40.4	136	29.1
Occasional intercourse	1573	51.5	249	53.2
No intercourse	248	8.1	83	17.7
<i>Washing of vagina after sexual intercourse**</i>				
Regular	575	20.5	48	12.5
Sometimes	94	3.3	7	1.8
No washing	2138	76.2	330	85.7

*Separated/widowed women having a partner, the information on their partner was included

**Percentage based on the intercourse practices (no intercourse was excluded)

NA – Not applicable, n – number of cases

More than 90% women were aware of the programme due to person-to-person contact by the project staff and more than 80% of the husbands of the screened women encouraged the participants while 96% of women who participated informed that they would encourage other women to participate in the programme. Among non-participants 64% said that they would encourage others to participate in the programme. Regular sexual intercourse with the husband/partner among the screened women was 40% compared to 29% among the non-willing to participate. The washing of the vagina after intercourse was poor in both groups, more than 75% of the women did not wash the internal organs after sexual intercourse.

6.5.2 Self reported reasons for non participation

The self-reported reasons for not participating in the programme are presented in Table 34.

The main reason of not participating in the screening programme was women having a feeling that the test was not necessary, while 66% and 24% women were afraid of the test. None of women reported reasons numbers 3 and 4. The effect on screening, effect after screening and perception about the programme in screened women and in those not willing to participate in screening is presented in Table 35.

More than half of the women felt shy during the screening and 10% women felt uneasy during the screening. Three quarters of the women were happy after the screening and 10% women felt uneasy and nervous after the screening. Of the husbands of the screened women, 82.5% were happy with the services provided by the programme.

About 10% of women felt sorry that they were not able to participate in the screening, 17% of husbands felt sorry that their wives did not participate in the screening. Women feeling that they would benefit from screening amounted to 78% while the non-participants only 2.3% felt that it would be beneficial. Screened women feeling that such types of programme were necessary amounted to 90% while 24% women who were not willing to be screened felt that such a programme was necessary. Those women happy with the services provided by the programme.

Table 34. Reasons for not participating in the screening programme

Reason	Number	Percentage
1. Shyness	22	3.9
2. Disapproval of husband/partner	8	1.4
3. Disapproval of elders	---	---
4. Both 2 & 3	---	---
5. Fear	137	24.2
6. Negative reports about the programme	9	1.6
7. Not well	15	2.7
8. Feeling that it is not necessary	375	66.3
Total	566	100.0

Table 35. Effect of screening and perceptions about the programme

	Screened		Not willing to participate	
	n	%	n	%
Total women	3349		566	
<i>At screening</i>				
Felt shy	1895	56.6	NA	
Felt uneasiness	328	9.8	NA	
<i>After screening</i>				
Felt happy	2537	75.6	NA	
Felt uneasy and nervous	328	9.8	NA	
Nothing particular	485	14.5	NA	
Felt sorry about not participating	NA		67	11.8
Husband/partner satisfied*	2521	82.5		
Husband/partner sorry*	NA		80	17.1
<i>Perception about the programme</i>				
Will benefit	2615	78.1	13	2.3
Programme is necessary	3031	90.5	135	23.9
Satisfied with services	3250	97.0	NA	

n: Number of cases

* Separated/widowed women having partner, the information of their partner was included

NA – Not applicable

6.5.3 Impact of screening on stage of disease and treatment

Staging of the disease was assessed in the screened arm compared to the control arm and in the clinically detected cases as well as the cases with completion of the treatment of invasive cervical cancer. The number of villages, clusters and number of those eligible from each group are presented in Table 36. The groupwise screen detected cases and clinically detected cases registered are presented in Table 37. The clinically detected cases were the cases that had occurred before the programme reached the people, cases that occurred in those whose screening test was negative and cases that occurred in the non-participants. The groupwise clinically detected cases are presented in Table 38. The stage distribution and detection rate by each arm for the year 2000–2003 are presented in Table 39. The stage distribution and detection rate by clinically detected cases, control area cases and screen-detected cases for the period 2000–2003 are presented in Table 40.

Table 36. Number of villages, clusters and number of eligible women in each arm

	VIA	Cytology	HPV	Control	Total
Number of villages	133	122	115	127	497
Number of clusters	13	13	13	13	52
Female population	114142	108774	115114	103283	441313
Eligible females (30-59)	36874	35193	36938	33696	142701
Examined	26755	25535	27159		
%	72.6	72.6	73.5		

Table 37. Screen detected and clinically detected cases of cervical cancer during the period 2000–2003 (Screening age group 30–59)

Group	Screen detected		Clinically detected		Total
	n	%	n	%	n
VIA	84	69.4	37	30.6	121
Cytology	96	73.3	35	26.7	131
HPV	76	76.0	24	24.0	100
Total	256	72.7	96	27.3	352

n: Number of cases

Table 38. Type of clinically detected cervical cancer cases during the period 2000–2003 (Screening age group 30–59)

Type of cases	VIA		Cytology		HPV		Total	
	n	%	n	%	n	%	n	%
Cases that occurred before the programme reached the people	27	73.0	24	68.6	17	70.8	68	70.8
Cases that occurred in screen negative subjects	2	5.4	2	5.7	–	–	4	4.2
Cases that occurred in non participants	8	21.6	9	25.7	7	29.2	24	25.0
Total	37	100	35	100	24	100	96	100

n – Number of cases

Table 39. Stage distribution and detection rate by each arm of the screen detected cervical cancer cases during the period 2000–2003 (screening age group 30–59)

Stage	Total n	VIA		Cytology		HPV	
		n	%	n	%	n	%
Ia	113	33	39.3	42	43.8	38	50.0
Ib	54	17	20.2	19	19.8	18	23.7
IIa–IIb	33	15	17.9	7	7.3	11	14.5
IIIa–IIIb	25	13	15.5	9	9.4	3	4.0
IVa–IVb	5	2	2.4	3	3.1	--	–
NI	26	4	4.8	16	16.7	6	7.9
Total	256	84	100	96	100	76	100

n – Number of cases, NI- No information

Table 40. Stage distribution of cervical cancer and detection rate by clinically detected cases, control area cases and screen detected cases for the period 2000–2003 (Screening age group 30–59)

Stage	Clinically detected*		Control area		Screen detected	
	n	%	n	%	n	%
Ia	--	–	4	6.8	113	44.1
Ib	14	20.6	10	16.9	54	21.1
IIa–IIb	14	20.6	7	11.9	33	12.9
IIIa–IIIb	30	44.1	30	50.8	25	9.8
IVa–IVb	3	4.4	5	8.5	5	2.0
NI	7	10.3	3	5.1	26	10.2
Total	68	100	59	100	256	100

* Cases that occurred before the programme reached the people

n – Number of cases, NI- No information

There was strong effect of screening in diagnosing the invasive cervical cancer cases, the detection of the cases was high in the intervention group compared to the control arm. In the screen detected group Ia stage cases accounted to 44.1% compared to the control area at 6.8% with no cases in the clinically detected cases group. The difference between the proportion of early stage cases in the screened arm and in the control arm was highly significant ($p < 0.01$). There were 352 cases in the screening age group, more than 70% detected due to screening, 19% that occurred before the screening programme reached the people, 1% occurred in screen negative women they developed the disease after a lapse of a month and near about 7% occurred in non-participants. The graphical presentation of the stage distribution of the screen-detected cases, clinically detected cases and cases from the control area in the age group 30–59 is presented in Figure 18. The treatment details of the cases are presented in Table 41 and age and stage distribution of the cases who did not complete treatment are presented in Table 42.

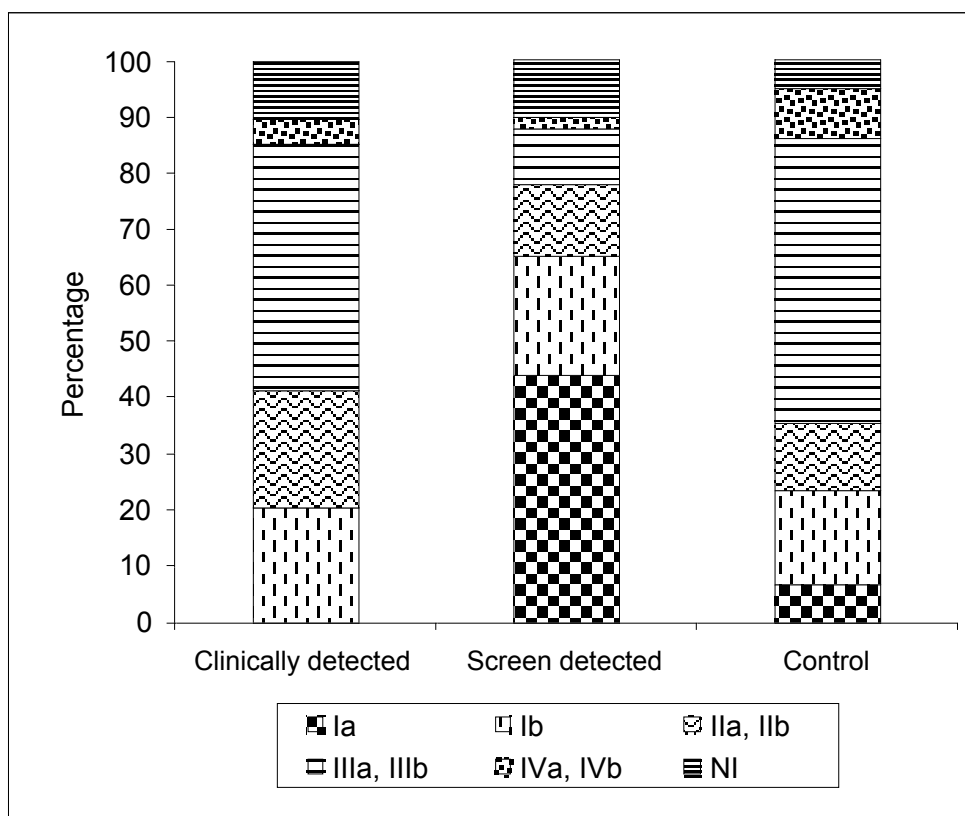


Figure 18. Cervical cancer staging from the screen detected, clinically detected and control area cases.

Table 41. Treatment details of screened detected cases, clinically detected cases and cases from the control group

Treatment	Screen detected		Clinically detected		Control	
	n	%	n	%	n	%
Surgery	117	45.7	5	7.4	8	13.6
Radiotherapy	66	25.8	33	48.5	30	50.8
Other treatment	5	2.0	5	7.4	5	8.5
No treatment	68	26.6	25	36.8	16	27.1
Total	256	100	68	100	59	100

n: Number of cases

Table 42. Stage and age distribution of the cases who did not complete the treatment

Characteristics	<u>Screened detected</u>		<u>Clinically detected*</u>		<u>Control</u>	
	n	%	n	%	n	%
Age group (years)						
30–39	17	25.0	2	8.0	3	18.8
40–49	27	39.7	10	40.0	2	12.5
50–59	24	35.3	13	52.0	11	68.8
Stage						
Ia	22	32.4	--	–	2	12.5
Ib	8	11.8	3	12.0	–	--
IIa–IIb	9	13.2	1	4.0	2	12.5
IIIa–IIIb	6	8.8	15	60.0	7	43.8
IVa–IVb	1	1.5	3	12.0	3	18.8
NI	22	32.4	3	12.0	2	12.5
Total	68	100	25	100	16	100

* Cases that occurred before the programme reached the people
n: Number of cases, NI – No information

The treatment completion was 73% in screen-detected cases, 63% in clinically detected cases and 73% in the control area cases. The cases that did not complete the treatment were from the older age group 50–59 from the control area 69% compared to 35% from the screen-detected cases and 52% from the clinically detected cases. Among the no treatment group there were 44% Ia, Ib stage cases from the screen-detected and 60% IIIa–IIIb cases from the clinically detected group and 44% from the control group.

6.5.4 Determinants of acceptance of treatment in screen positive women

The data of the screen positives who accepted the treatment was taken from the Q1 database and the data on the screen positive women who refused the treatment was taken from the Q2 database. The number, proportion, univariate and multivariate odds ratio (OR) with 95% confidence interval (CI) of screen positive women not accepting the treatment compared to women who accepted treatment are shown in Table 43.

Table 43. Number, proportion, univariate and multivariate odds ratio (OR) with 95% confidence interval (CI) of screen positive women not accepting the treatment compared to women who accepted treatment

Variable	Screen positive not accepted treatment			Univariate		Multivariate	
	Total	n	%	OR	CI	OR	CI
<i>Age group^a</i>							
30-39	103	20	19.4	1		1	
40-49	50	17	34	2.1	1.0-4.6	1.9	0.8-4.8
50-59	33	13	39.4	2.7	1.2-6.3	2.4	0.8-6.9
<i>Education of the women^a</i>							
No education	120	37	30.8	1		1	
Educated	66	13	19.7	0.6	0.3-1.1	0.9	0.4-2.3
<i>Occupation of the women^a</i>							
Housewife	72	23	31.9	1		1	
Agriculture	109	26	23.9	0.7	0.3-1.3	0.2	0.1-0.6
Other	5	1	20	0.5	0.1-5.0	0.4	0.04-4.3
<i>Marital status^b</i>							
Married	169	39	23.1	1		1	
Widowed	14	10	71.4	8.3	2.5-28	12.5	3.2-49.0
Separated	3	1	33.3	1.7	0.1-8.9	1.9	0.1-50.7
<i>Education of the husband^{c*}</i>							
No education	59	16	27.1	1		1	
Educated	108	24	22.2	0.8	0.4-1.6	0.8	0.4-1.9
Not known	5	1	20				
<i>Occupation of the husband^{c*}</i>							
Agriculture	135	32	23.7	1		1	
Other	35	8	22.9	0.95	0.4-2.3	1.2	0.5-3.4
Not known	2	1	50				
<i>Income^a</i>							
< INR 2000 p.m. (US\$<41)	90	29	32.2	1		1	
>=INR 2000 p.m.(US\$>=41)	95	21	22.1	0.6	0.3-1.2	0.2	0.1-0.6
<i>NI</i>	1						
<i>Screening procedure^a</i>							
Understood	155	37	23.9	1		1	
Not understood	31	13	41.9	2.3	1.1-5.1	1.2	0.4-3.5

a For multivariate analysis adjusted with all the variables in the table

b For multivariate analysis adjusted with all the variables after excluding husband education and occupation

c For multivariate analysis adjusted with all the variables after excluding marital status

NI – No information, n- number of cases * Widowed/separated women having partner their information was included INR - Indian Rupees.

In the univariate analysis it was found that among women who were above the age of 49, widowed and women who did not understand the importance of the screening the risk of refusing the treatment was high and significant, while the education and occupation of the women, education and occupation of the husband and income had no effect on acceptance of the treatment.

The multivariate analysis was carried out for all the variables in the table but for the variable marital status, husband's education and occupation was excluded and conversely for the husband's education and occupation because there were no data for the previous husbands of widowed and separated women. The women in the age group 40–49 had 1.9 times risk of refusing treatment (95% CI 0.8–4.8) while women in the age group 50–59 had 2.4 times risk of refusing treatment (95% CI 0.8–6.9) compared to the age group 30–39 and this was not significant. The risk of refusing treatment was low, 0.9 in educated women compared to illiterate women (95% CI 0.4–2.3) and was not significant. The risk of refusing treatment was low at 0.2 (95% CI 0.1–0.6) in the women who were involved in agriculture compared to the housewives and was significant. The risk of refusing treatment in widowed women was very high, 12.5 (95% CI 3.2–49.0) compared to married women and was highly significant. The risk of refusing treatment was 1.9 (95% CI 0.1–50.7) in separated women as compared to married women but was not significant. The education and occupation of the husband showed no effect on the acceptance of treatment. In the multivariate analysis income had an effect on refusing treatment, the risk of refusing the treatment was very low, 0.2 (95% CI 0.1–0.6) in the women having a monthly income \geq INR 2000 (US\$ \geq 41) compared to women having a monthly income $<$ INR 2000 (US\$ $<$ 41), and was significant. The risk of refusing treatment was 1.2 in the women who did not understand the screening procedure (95% CI 0.4–3.5) and was not significant.

6.6 Discussion

The results indicate that most of the women from the rural area participated in the screening programme. The compliance with the screening was more than 72% in all arms. The compliance with screening was higher than that reported from the rural areas of the developing countries (Nene et al. 1994, Swaddiwudhipong et al. 1995, Nene et al. 1996, Gaffikin et al. 2003a, Sankaranarayanan et al. 2003b). A high rate of participation in the screening programme is essential in reducing the incidence of and mortality from the disease (Ponten et al. 1995, Lazcano-Ponce et al. 1999) but obtaining a high level of

compliance was a difficult task in many countries with and without organized screening programmes (Parkin 1991). More than 70% of the women in the screened population were illiterate (Sankaranarayanan et al. 2005). It was a difficult task to organize the screening programme for the illiterate women. It was possible as the programme staff involved the community leaders, schoolteachers, civic leaders, husbands of eligible women and all the delegates in the villages. The programme provided high quality services. The person-to-person contacts and group meetings created good awareness about the screening. More than 90% of the women received the information on the programme from field workers of the project. The husband's role was also important in the participation of the women. The husbands encouraged their wives to participate in the screening programme. The programme considered the cultural activity of the community, screening programme was not organised on festival days. This is an important factor while organizing the screening programme in the rural population of India.

The risk of not participating in the screening programme was greater in the older age groups, illiterate, widowed, low-income groups and among those who did not understand the screening procedure and its importance. Among widowed women it may be due to a negative attitude towards life due to loss of the husband. Due to a fatalistic approach among illiterate women and due to some personal barriers these women did not participate in the programme. The non-participation in the screening programme in older age groups, low income groups, less educated women and in the women without partners was reported in a study conducted in South Africa (Bradley et al. 2004). The two thirds of non-participants reported that they did not participate, as they did not feel it was necessary to attend the screening. A study conducted in Iceland and in Northern Ireland regarding non-attendance at screening reported that women had a feeling that they did not need the test (Bergmann et al. 1996, Murray and McMillan 1993). Almost one fourth of non participant women reported being afraid of the test. The fear of getting a positive test result and anxiety was a common reason among non-participating women (Kelly et al. 1996, Neilson and Jones 1998, Lobell et al. 1998).

Due to cultural barriers it was difficult for social workers to discuss sex and sex-related issues with the public. Most of the screened women and women not willing for screening did not wash their internal parts after intercourse. The project female social investigator and nursing staff advised them about this but the women did not follow the advise as their houses were small and the bathrooms were open. It was reported that adequate facilities for washing after coitus were not available (Varghese et al. 1999). The population screened was previously unscreened; a negligible percentage of the women had the Pap test. More than half of the women felt shy during the screening as they attended for the first time this procedure. Most of the participating women and

their husbands were happy with the programme and the facility provided for them. More than three quarters of the women felt that it would be beneficial. This shows that the programme was successful in establishing good rapport with the participants by providing excellent services and involving all the delegates from the community. The attitude of the non-participants did not change in spite of the excellent treatment facilities offered to screen positive women and to cervical cancer patients from their own village; about 10% of the women felt sorry that they had not participated in the programme.

The Osmanabad cervical cancer registry has provided cervical cancer staging and treatment details for the year 2000–2003. The results reported here should be considered as preliminary results as the data collection by the registry is not yet complete. In the screening arms the percentage of Ia cases was higher compared to the control arm. The screening has shown the effect of early diagnosis on the cases and the difference between the screened arm and control arm in the proportion of stage Ia cases was highly significant. It was reported that in the screening programme in Sweden (Ponten et al. 1995) the main effect of the screening was a shift from stage II to stage I.

In the overall data for 2000–2003 the ‘no stage’ cases percentage varied from 5 to 17% in all arms, no information on the staging of the cervical cancer in the Indian registry database was reported (Sankaranarayanan et al. 1998a). It may be that these cases were from an early stage. In the survival studies reported for India (Jayant et al. 1998, Shanta et al. 1998, Yeole et al. 1998a) the ‘no stage’ cases survival seems to be higher compared to the regional and advanced cases. The screening programme provided services like transport, medicine and food during the hospital days. In India some government hospitals and a few charity hospitals provide free food and treatment. It may not be possible for other institutes in India to provide such facilities due to limited financial resources. This study would like to recommend that all the facilities mentioned here should be provided in cervical cancer control programmes in the rural areas otherwise programmes may not be successful in achieving the goals. The completion of treatment in CIN was higher compared to the invasive cancer cases. (Sankaranarayanan et al. 2005). The treatment of the precancer lesions like cryotherapy and LEEP therapy are a one sitting or a one-day procedure. The programme called all the screen positive women of the village for treatment on the same day. The programme provided transport and village leaders were requested to accompany the screen positive cases for treatment in NDMCH, Barshi. Women being brought to NDMCH in groups and the presence of village leaders in the hospital gave moral support to the screen positive women to accept treatment. Regarding the acceptance of the treatment of the screen positive women the widowed women showed the highest risk of not accepting

treatment OR=12.5 (95% CI 3.2–49.0) as compared to married women it may be that widowed women may have a negative attitude towards life due to loss of the husband. The risk of not accepting treatment was greater in the lower income group, which was significant. The adverse effect of socioeconomic status on the treatment and survival has been well established (Kogevinas et al. 1991, Mackillop et al. 1997)

More than a quarter of the invasive cervical cancer cases had no treatment. In contrast to CIN cases the patients having invasive cervical cancer have to pass through many procedures like biopsy results, lab test, ultrasonography, physical fitness for surgery and stay of 2 weeks for the surgical procedure or stay of four weeks for the radiotherapy treatment. It was reported that the number of visits to the hospital was a barrier to treatment (Black et al. 1993). We have the same experience, as in the health education project, the early stage cases did not complete the treatment. There were many barriers to completion of the treatment, which is mentioned in the chapter on the health education programme. The studies also reported that removing economic barriers did not lead to a significant increase in screening when other types of barriers were present (Lantz et al. 1997). Due to the screening programme the disease has been detected at an early stage and most of the cases completed the treatment, ultimately it will affect the mortality of the disease. However there were a few cases that did not complete the treatment due to some other barriers. More attention is required with older age group women, illiterate women, low-income women and on widowed women in implementing a cervical cancer-screening programme in a rural area. Involving the village leaders/providing social support and minimizing the number of visits to the hospital can remove the barriers to screening and treatment completion.

The initial results of the RCT and result of the cost effectiveness were published (Sankaranarayanan et al. 2005, Legood et al. 2005, Nene et al. 2007). A screening programme in middle-income developing countries failed to achieve a major impact and to implement screening programmes in developing countries entails many practical difficulties (Sankaranarayanan et al. 2001, WHO 2003, Cronje et al. 2004). The RCT showed that when the resources were available the satellite cancer centre in the rural area with the technical support from the regional cancer centre as well as technical and financial support from the international agency was able to organize the screening in the developing countries. The recommendation of this study is that a cervical cancer control programme should be to detect and treat precancerous lesions in single or two visit strategies rather than detecting and treating invasive disease, given our experience of barriers to completing the treatment.

7. A cervical cancer control plan for rural India

7.1 Objective

Based on the experience of the studies conducted at NDMCH, Barshi to propose a cervical cancer control plan for rural India.

Objective number four of the dissertation is described in this chapter.

7.2 Infrastructure

India is a big country with more than 1 billion population, 72% of whom reside in the rural areas. The model proposed to control cervical cancer in India is that Regional Cancer Centres (RCCs) take the initiative to develop the community centres (CC) for cervical cancer prevention in the town hospitals or in the district hospitals or in the centres, which are involved in Cancer Atlas project. These community centres can start cervical cancer preventive services in the rural areas by providing health education and easy access to screening, diagnostic and treatment facilities.

In India there are 25 regional cancer centres, 210 institutions having more than 345 teletherapy facilities across the country (Gupta et al. 2006). Altogether 105 centres participated in the programme of the development of the Cancer Atlas for India (Nandakumar et al. 2004). Most of the town hospitals, district hospitals and the centres involved in the Cancer Atlas project have pathology and surgical facilities, the human resources like surgeons, gynaecologists, pathologists, nursing staff and technicians are available and they are working for regular activities of the hospital. These existing infrastructure and human resources can be used for the development of community cancer services in hospitals. At present the staff is not trained in the techniques of health education, screening, colposcopy and the surgical procedures for preinvasive lesions and they can be trained in the centres that are actively involved in the cervical cancer prevention programme. In India the following centres have been actively involved in cervical cancer prevention programme (Sankaranarayanan et al. 2003a, ICPO-ICMR Annual Report 2003).

Tata Memorial Centre, Mumbai, Maharashtra.

Nargis Dutt Memorial Cancer Hospital, Barshi, Maharashtra.

Chittaranjan National Cancer Institute, Kolkata, West Bengal.

Bhagwan Mahaveer Cancer Hospital and Research Centre, Jaipur, Rajasthan.

Christian Fellowship Community Health Centre, Ambillikai, Tamil Nadu.

Regional Cancer Centre, Thiruvananthapuram (Trivandrum), Kerala.

Institute of Cytology and Preventive Oncology, ICMR, New Delhi.

The responsibility for a cervical cancer control programme could be assigned to the regional cancer centres and to the gynaecologist or pathologists of the hospital. The regional cancer centre should develop the network of community centres for cervical cancer prevention. The human resources from these centres can be trained and resources can be provided.

Due to the support of the regional cancer centre TMC, NDMCH Barshi provided the preventive services for cervical cancer in 959 villages covering 0.7 million female population (346 villages of the registry area covering 0.2 million female population, 116 villages from the health education programme covering 0.1 million female population and 497 villages from the screening programme covering 0.4 million female population). The studies conducted at NDMCH, Barshi and the results reported here are useful guidelines for cervical cancer control in rural, India.

7.3 Method

The health education programme in Barshi provides a model. It consisted intensive health education on the risk factors of the disease and included preventive measures against the disease and providing easy access for diagnosis and treatment. One community centre can cover a female population of 200,000 in the nearby rural area. Apart from the existing staff, four field staff members to educate the women and to motivate the symptomatic women to undergo diagnosis and treatment at a detection clinic or at community centre was need to be appointed. One field staff member can be made responsible for 50,000 female populations. For the implementation of the programme the area can be divided into zones. Health education can take place person-to-person, in school, in-group meetings and by video show. The symptomatic women above the age ≥ 30 can be motivated to attend for diagnosis at the primary health centre by organizing a detection clinic or at the CC.

A follow-up round can be implemented after six months in that zone, in the follow-up round we propose the method used by the Rural Cancer Registry Barshi of identifying the symptomatic cases and referring cases to NDMCH i.e. to bring the symptomatic cases from the village for diagnosis at the community centre. The second round (health education by video, group meeting and organizing the detection clinic at the PHC) can be organized after every three years. A similar programme for other zones can be organized.

The village leaders and husbands of the women should be informed in advance about the facilities that the organizer is providing. Consent to the examination must be obtained from the participating women. A woman participating in the detection clinic should have her report explained after the screening. Medicine as per the complaints of the participants to be provided for those women attending at CC or detection clinic. The VIA test has the potential to be a cervical cancer screening tool in the developing countries setup (Sankaranarayanan et al 2007b). The VIA screening criteria and treatment of precancerous lesion should be followed as mentioned in IARC manual (Sankaranarayanan and Wesley 2003d, Sellors and Sankaranarayanan 2003). The results of the VIA screening test and the colposcopy diagnosis are available immediately and women can be encouraged to undergo immediate treatment of cryotherapy if needed. The advantage of the VIA test is that participants will get the screening results immediately and the loss to follow-up will be minimal. The screen negative women must be informed that the test is negative, but in case of future symptoms related to the disease a women should attend the community centre. If the test is positive and women underwent colposcopy guided biopsy the results should be informed to the women by house visit. The cases diagnosed as CIN I, CIN II and CIN III from the same village can be treated at the same time and village leaders/close relative should be requested to accompany women for treatment. The treatment in the group accompanied by a village leader or close relative will give the women moral support. The precaution to be taken after the treatment by cryotherapy/LEEP should be properly explained to the woman and her husband. It has been reported that cryotherapy procedure done by nurses under the supervision of a doctor is safe and acceptable to the participant in rural India (Sankaranarayanan et al. 2007a). The success rate with LEEP in women treated for the first time is around 90% (Sellors and Sankaranarayanan 2003). The screening programme should focus on detecting and treating the precancerous lesion in single or two visit strategies rather than detecting and treating invasive disease given our experience showing poor compliance with treatment. The number of visits to the hospital for invasive cervical cancer cases should be minimized.

The localised cases can be treated by surgery at CC. The advanced cervical cancer cases should be treated at the level of radiotherapy centre/at RCC. The RCC should provide the necessary facility to the patient attending for the treatment from CC. The field staff should be assigned the responsibility of taking the women to the radiotherapy center and provide moral support to the patient during the treatment. The field staff has to act as a bridge between the community centre and the community. The patient who is unwilling to undergo treatment should be motivated by the village leaders and they should be provided with social support either by a close relative or some accompanying person from the village.

The cervical cancer incidence and mortality can be monitored by establishing a cervical cancer registry with the help of field staff by using the rural cancer registry method or with the help of an existing cancer registration centre of cancer atlas project. The method for cervical cancer control to be adopted is presented in Figure 19.

7.4 Programme cost

For the costing purposes the invasive cervical cancer incidence rate has been calculated to be 23 per 100,000 PYRS in a rural area of India (NCRP 2005). The screen positive rate of VIA 14%, biopsy rates around 10% and detection rate of 0.9% for CIN 1 and 0.7% for CIN 2–CIN 3 (Jayant and Nene 2003, Sankaranarayanan et al. 2005) have been considered. It is expected that around 4000 cases will attend in a year for the examination from a female population of 0.2 million. The 0.2 million female populations will be covered by twelve primary health centres. Under each primary health centre a detection clinic will be organized. According to our experience in a health education programme around 230 women will participate in one clinic ($230 * 12 = 2760$ women) according to our experience in rural cancer registry in a year around 100 symptomatic women will be identified from one primary health and these women will attend at CC ($100 * 12 = 1200$ women). From 4000 screened women, 560 (14%) will be screen positive and biopsy rate will be around 10% from the total screened i.e. 400 biopsies. Given the detection rate of CIN 1, 36 cases will be diagnosed and most of them will be treated by cryotherapy. Given the detection rate of CIN II and CIN III, 28 cases will diagnosed and these cases may need LEEP treatment, in addition to that 1.7% unsatisfactory colposcopy/ lesions extending into canal and few CIN I and condyloma cases from screen positive will be also be treated by LEEP (Sankaranarayanan et al. 2005, Sellors and Sankaranarayanan 2003). However for the costing purpose it is expected that 50 cases will need LEEP treatment. It is expected that 46 cervical cancer

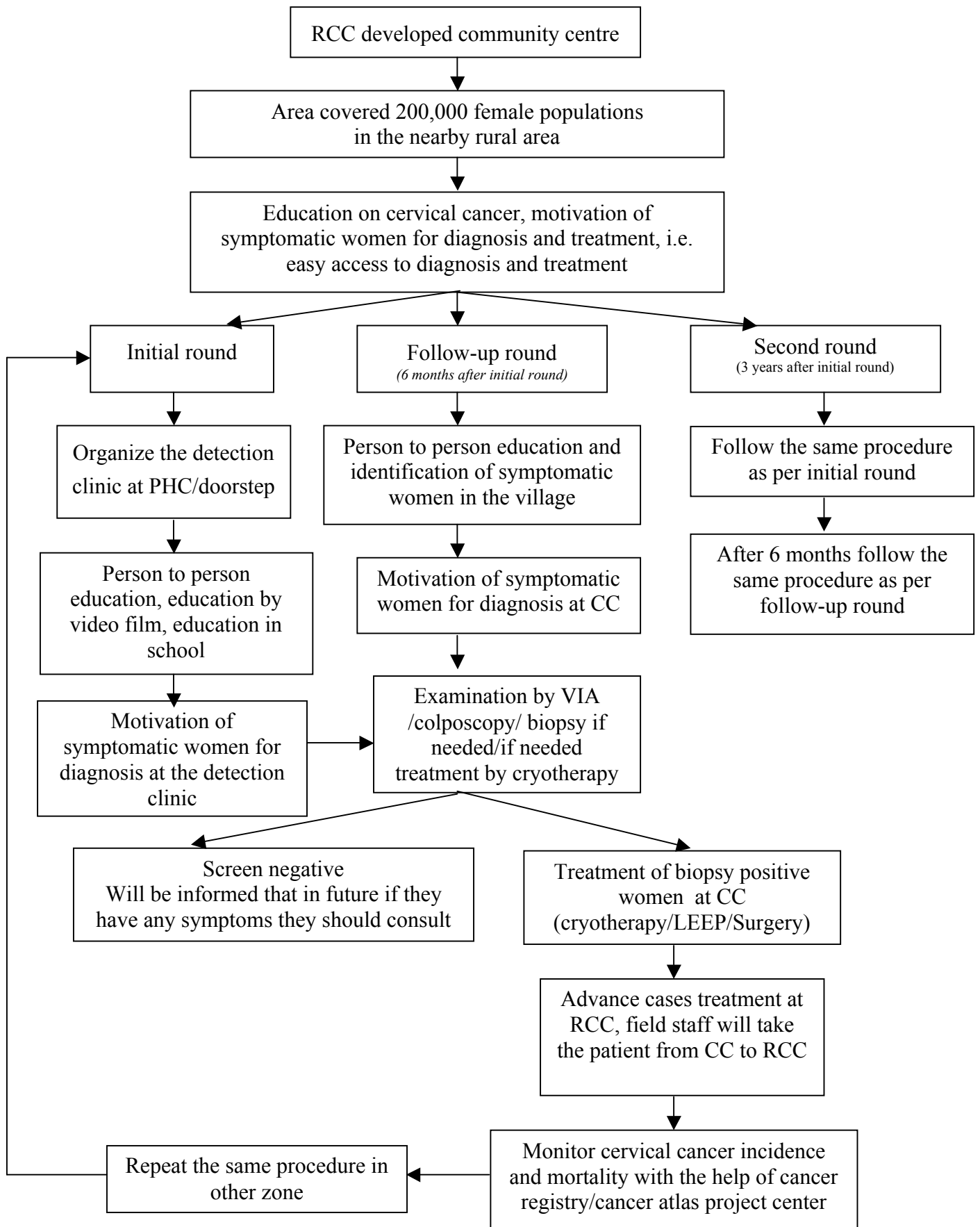


Figure 19. Method proposed for cervical cancer control in a community health center

cases will occur in a year in the female population of 200,000 as per incidence rate 23 per 100,000. According to our experience in the health education project around 45% (Ia, Ib, IIa) cases will be diagnosed at localized stage and some cases after LEEP may require surgery particularly CIN 3 cases so for the costing purpose 30 cases of surgery are to be considered. As per our results of health education project around 40% (20 patient) regional cases may require radiotherapy.

The gynaecologists, medical officer and nursing staff are required in the field clinic as well as during the follow up of precancer cases in the hospital. Other staffs are required for the diagnosis and treatment purpose. The cost is estimated as a supportive salary from the programme as per the work done. The amount required for staff training and salary of support staff is mentioned in Table 44. The cost is taken from health education project database and from the cervical cancer screening programme database

The cost of the equipment required is noted in Table 45 and the yearly running cost of the programme in Table 46. The treatment cost for follow up cases after surgery and the cost of radiotherapy treatment is not considered as the funds will be collected from different sources for the treatment. In all the studies conducted at NDMCH Barshi it was observed that the financial barriers to the patient and his family members in the completion of the treatment. To overcome these problems funds were collected for the treatment of poor cancer patients attending NDMCH. NDMCH received funding from different sources, in the accounting year 2003–2004, NDMCH received Rs. 5,671,916 (US\$118,165) (NDMCH Cancer Patient Funding report for the Year 2003–2004). Just as the way NDMCH collected the funds from different sources the CC centre has to collect the funds for the treatment of the patients. The patients who will undergo cryotherapy at the detection clinic/CC the cost of these cases considered under the laboratory material and chemical (For 1 cryotherapy Rs. 100, expected that 36 cases will need cryotherapy). The nurses will provide the cryotherapy and the cost of their work is also consider. Some cases may require hospitalization after cryotherapy/LEEP, for such patients separate provision is made under the heading of patient medicine and hospital cost, hospital cost of the surgical patient and the cost of medicine which will be used in field clinic/CC for symptomatic women is also included.

Table 44. Amount required for staff training and salary for support staff

Staff	Unit cost as per the work	Amount in INR	Amount in US\$
<i>a Training</i>	All staff training	30,000	625
<i>b Salary</i>			
Surgeon	LEEP (50 LEEP in a year Rs. 200 per LEEP) Surgery-30 Rs. 3000 per surgery	10,000 90,000	208 1875
Anaesthetist	Rs. 75 Per LEEP Anesthesia charges Rs.900 per surgery –30 surgeries	3750 27,000	78 563
Pathologist	Rs. 60 per case (400 biopsies + 50 LEEP + 30 surgery) - 480 (Rs. 40 per biopsy, Rs. 130 per LEEP, Rs. 200 per surgery)	28,800	600
Gynaecologist	Rs. 15 per participants (4000 in a year)	60,000	1250
Medical Officer	Apart from hospital salary Rs. 2000 p.m.	24,000	500
Technician	Rs. 10 per case (480 cases)	4800	100
Nursing staff	Apart from hospital salary Rs.700/- as an extra 4 nursing staff	33,600	700
Assistant	Four staff -Rs. 250 per staff	12,000	250
Field staff	Four staff -Rs. 3000/- pm.per staff	144,000	3000
Total		467,950	9749

1 US\$= Indian Rupees 48, INR – Indian Rupees

Table 45 The cost of the equipment required for the programme

Equipment	Number in quantity	Cost in INR	Cost in US\$
Colposcope	2	126,000	2625
Cryotherapy	2	25,000	521
LEEP	1	225,000	4688
Gynecological equipment (Speculum, biopsy forceps etc)		10,000	208
Computer + Printer	1	40,000	833
TV +Video	1	15,000	313
Sound system	1	5000	104
Other laboratory equipment		10,000	208
Total		456,000	9500

1 US\$=Indian Rupees 48, INR – Indian Rupees

Table 46. Annual running cost of the programme

Expenses	Cost in INR	Cost in US\$
Field staff travel (From CC to the village Rs. 3000 per month for four field staff)	36,000	750
Health education programme by Jeep (Rs 5 per km and average 100 km per village, school + village programme 125 programme in a year)	62,500	1302
Mobile van for conducting the clinic programme (yearly 12 clinics) Rs. 10 per KM average 100 KM for a clinic	12,000	250
Staff refreshment during the programme	5000	104
Laboratory materials and chemicals	12,000	250
Patient transport and food (100 cases per month Rs. 50 per patient transport and food, 20 patients have to be referred for RT at nearby centres @Rs.500 per patient / 100 follow-up patient after cryo/ LEEP cases @ Rs.50 per patient)	75,000	1563
Patient medicine and hospital cost (Rs 3000 per operation, Rs 800 per LEEP, Rs 10,000 reserve for any complication, Rs.10,000 medicine for field clinic)	150,000	3125
Data processing and printing	8000	167
Other costs	5000	104
Total	365,500	7615

1 US\$= Indian Rupees 48, INR – Indian Rupees

For the development of the community centre the requirement is Rs. 486,000 i.e. approximately US\$ 10,125 (Staff training + equipment) and for running the programme the requirement is Rs 803,450 i.e. approximately US\$ 16,739 (Staff salary and annual running costs). To cover the female population of 0.2 million we need Rs.1, 289,450 i.e. approximately US\$ 26,864. The yearly increment cost is not considered, as we do not have to spend money every year on the staff training and the purchase of the equipment. The cost may be lower if the institute has a mobile van, jeep, TV, video, sound system and computers. To begin the cervical cancer prevention programme by the community centre it will cost around Rs. 7.50 (US\$ 0.16) per female for 0.2 million female population.

In India 25 regional cancer centres and 210 centres provides the radiotherapy services in different areas (Gupta et al 2006). There are 105 centres, which have actively participated in the cancer atlas project (Nandakumar et al. 2004). There are 315 centers (210 radiotherapy centres + 105 cancer atlas project centre), most of the centres having available infrastructure like surgical facilities and pathology facilities as well the human resources like surgeons, gynaecologists, pathologists, nursing staff and technicians are

available and they are working for regular activities of the hospital. These existing infrastructures can be used for the development of CC. For the planning purpose instead of 315 centers, 300 centres are considered for the development of CC. Most of the cancer atlas project centres have reported that cervical cancer is either the first leading cancer or second leading cancer in females in that area and these cancer registration networks of the country can be utilized for the implementation of the cervical cancer prevention programme. Each of the regional cancer centres should develop 12 community centres by utilizing their own funds or applying for the funds to ICMR or from IARC or to the Government of India for cervical cancer prevention. In addition to the available infrastructure there is a need to appoint four field staff members for interaction with the community. The amounts required for the 300 centres are presented below in Table 47.

Table 47. Amounts required for the 300 community centres

Project cost	Cost of 1 Community Center	Cost for 300 Community Center
a. Staff training	Rs. 30,000 (US\$ 625)	Rs. 9,000,000 (US\$ 187,500)
b. Equipment cost	Rs. 456,000 (US\$9500)	Rs.136,800,000 (US\$ 2,850,000)
c. Staff salary	Rs. 437,950 (US\$9124)	Rs.131,385,000 (US\$ 2,737,188)
d. Project running cost	Rs. 365,500 (US\$ 7,615)	Rs. 109,650,000 (US\$ 2,284,375)
Total in INR	1,289,450	386,835,000
Total inUS\$.	26,864	(US\$ 8,059,063)

1US\$= Indian Rupees 48, INR – Indian Rupees

The expected output of the programme is estimated on the basis the results of the health education programme and screening programme conducted at Barshi. From 300 community centres it is expected that 13,800 new cases will be diagnosed at a rate of 23 per 100,000 (NCRP 2005) (i.e. in one CC it is expected that 46 new cervical cancer cases will be diagnosed at a rate of 23 per 100,000 and in 300 centres it is expected that $300 * 46 = 13,800$ new cases of cervical cancer will be diagnosed), 10,800 CIN 1 and 8,400 CIN 2 and CIN 3 cases will be diagnosed (i.e. in one CC it is expected that 4000 women will be screened 9 CIN I and 7 CIN 2–CIN 3 cases will be diagnosed at a rate of 1000 women screened, from 1 CC it is expected that 36 CIN 1, 28 CIN 2 and CIN 3 will be diagnosed. From 300 centers, $300 * 36 = 10,800$ CIN I, $300 * 28 = 8400$ CIN 2–3 cases will be diagnosed). The programme will provide excellent facilities to the participant and due to help from the village leaders and according to our results in the screening programme (Sankaranarayanan et al. 2005) it is expected that more than 80%

precancer cases will complete the treatment. According to our results mentioned in rural cancer registry Barshi and of health education programme around 55% invasive cervical cancer cases will detect at early stage and around 70% of invasive cervical cancer cases will complete the treatment. Due to completion of treatment survival will be improved and we can prevent death from the disease. The expected output from the community centre is presented in Figure 20.

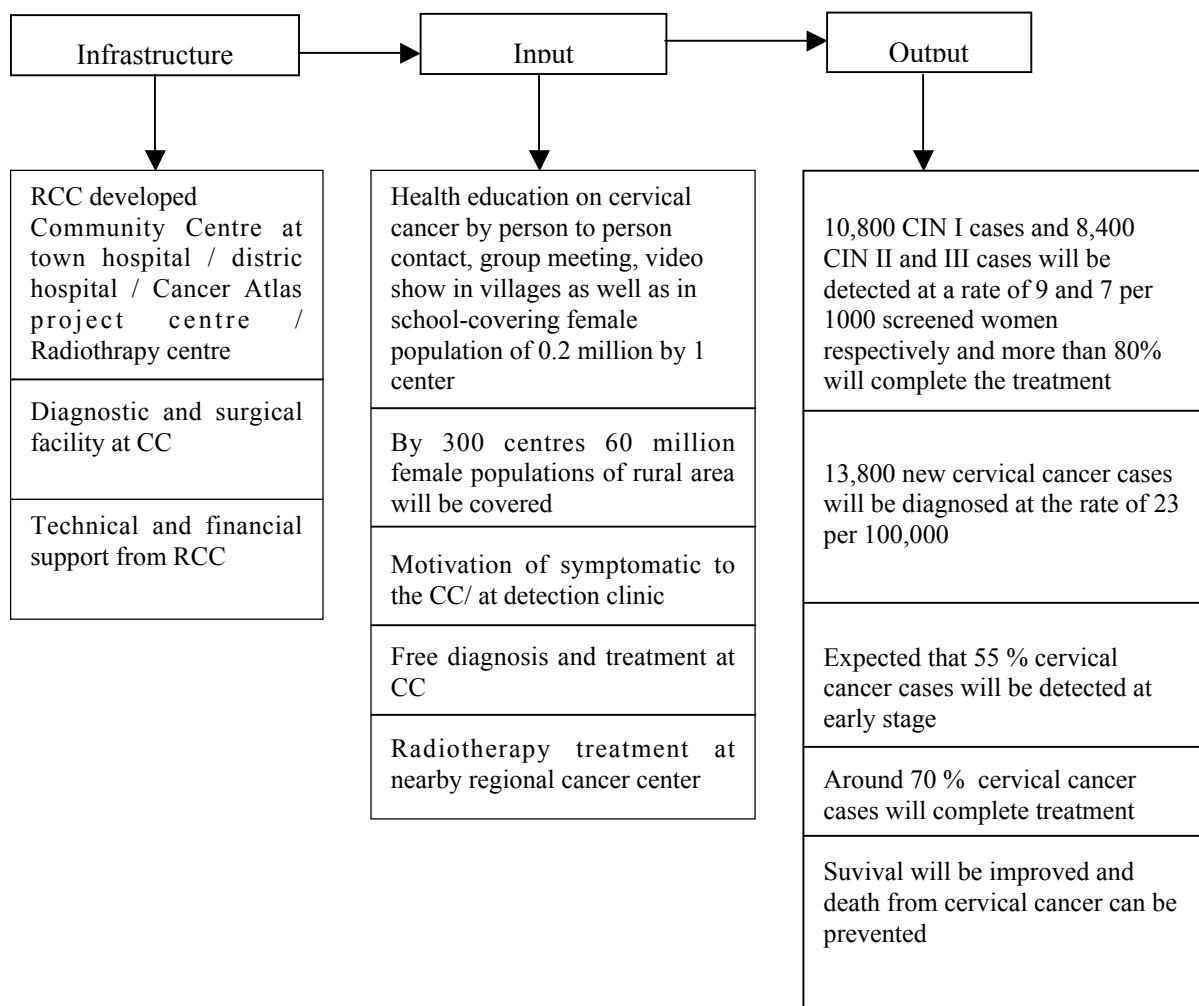


Figure 20. Expected output from the 300 community centres

7.5 Discussion

In India 360 million women live in the rural areas of the country, if we implement the cervical cancer prevention programme in the 300 centres by using the available infrastructure and human resources then 60 million (6%) women from the rural areas of the country will obtain the services for cervical cancer prevention. To start the cervical cancer prevention programme the cost will be around Rs 7.50 (US\$ 0.16) per woman. The cost will be much lower in the subsequent years, as the CC has to sustain activity with the newly developed infrastructure and available manpower. Such an expense is probably affordable and justified in India. The total health budget is about US\$ 20 per person and cervical cancer is number one in cancerous diseases in women especially in the rural parts of India. The cervical cancer prevention programme conducted in Brazil has used the method of visiting door to door contacts with women for education and giving information on the project by radio broadcasting, also easy access to diagnosis, treatment and providing some incentive to the participants has worked effectively in a poor population (Mauad et al. 2002). The three-year cost of this programme was reported as US\$ 29,245 for 1,384 women. The cost reported here for 4,000 symptomatic cases for a year is US\$ 26,864. In the study (Mauad et al. 2002) it was reported that the carcinoma in situ cases were reluctant to undergo treatment and they have to motivate these patients by house visits by a doctor. In all our studies at NDMCH it was observed that women participated in the programme but the major problem was the completion of the treatment. In the rural cancer registry Barshi 49% cervical cancer cases have no treatment while in the health education programme no treatment was 43% in the intervention group while 35% in control group, while in the screening programme more than 80% of women with high-grade lesions completed the treatment and no treatment reined by 26.6% in the screen detected invasive cases. Social support from the village leader or a close relative and absences of financial barriers are useful component for completion of treatment.

The regional cancer centre has to monitor the activity of the community centre and needs to play major role in sustaining the activity of the CC. The periodical quality control and regular staff training has to be organized for the community centres. For the cases referred from the community centre to the regional cancer centre, RCC should provide all the facilities. The need for the development of the community centres by the regional cancer centre in the rural areas of India for cancer prevention was emphasised by Desai (2002). Health education on the disease and easy access to diagnosis and treatment is essential for the prevention of cervical cancer (Sankaranarayanan et al. 2000).

The cervical cancer control plan based on health education, easy access and motivation to have the disease detected and treated and the main focus on diagnosing the precancer lesion at community centre can be replicated all over India, this will play a major role in cervical cancer control for rural India. It is fairly realistic to expect similar development for around 300 community centers on the basis of interest shown in cancer monitoring evaluation and control. However, even complete success would cover only 6% of the rural Indian female population. The Nargis Dutt Memorial Cancer Hospital Barshi was started as a community centre by the Tata Memorial Centre, Mumbai in 1982 and has provided comprehensive cancer control services to a large rural population (Stewart and Kleihues 2003). To control cervical cancer in the rural areas of India the NDMCH should be considered as a model, this model can be replicated all over India, so over the years these centres will provide comprehensive cancer control services to the rural population of India.

8. Summary

The present study was carried out at Nargis Dutt Memorial Cancer Hospital (NDMCH), Barshi, in Solapur district of Maharashtra State in India. Based on the experience of the studies conducted at NDMCH, Barshi, this dissertation focuses on the prevention of cervical cancer and describes the infrastructure, resources, and manpower needed in the rural area of India. An attempt has been made in this dissertation to show how a community centre can be developed for cervical cancer control in rural areas with support from the regional cancer centre.

The Population-Based Rural Cancer Registry, Barshi, is the first rural cancer registry in India, established at Nargis Dutt Memorial Cancer Hospital in the year 1987 by the Tata Memorial Centre, Mumbai, and the Indian Council of Medical Research, New Delhi, under the National Cancer Registry Programme. The registry has generated useful data on cancer incidence, mortality, and prevalence by its unique case finding methodology in the community and raised cancer awareness in the population.

Cervical cancer as the leading cancer site with age-standardized incidence rate of 27 per 100,000 PYRS, age-standardized mortality rate of 18.6 per 100,000 PYRS for the period 1988-2000, and a prevalence of 96.0 per 100,000 as on 1st January 2003 was reported. The method developed by the Rural Cancer Registry, Barshi, for raising cancer awareness and identifying the symptomatic cases in the community by the trained field staff and motivating them for diagnosis at the detection clinic or at the NDMCH, Barshi, has worked effectively in registering the cancer cases. Due to this method, the cervical cancer cases were detected at an early stage and the survival of these cases has been improved. Barshi registry has paved the way for the cervical cancer control programme in rural India. The Rural Cancer Registry has created the necessary infrastructure for conducting epidemiological studies. However, to assess the burden of cervical cancer in the rural area, there is a need of more rural cancer registries in India as 72% of the population is rural. The Rural Cancer Registry will play a major role in planning and monitoring the cervical control programme.

It was felt that the stage shift in cervical cancer observed in the Barshi registry was due to the raising cancer awareness in the women due to registry methodology, which involved education, motivation of symptomatic women for diagnosis and treatment, and close contact with the community. This proposal of the effect of health education on cervical cancer was tested in a study during the period 1995–2002 in two subdistricts in

the vicinity of Barshi. In the intervention area, intensive health education and easy access to diagnosis and treatment facility were provided, while in the control area, no health education on cervical cancer was given except that the women received a routine health message from the government health services. The overall awareness level was raised from 12% to 52% ($p < 0.001$) after the first round of intervention. The awareness level was much better in educated women than in illiterate women. The awareness level in the women with primary education increased from 27% to 66% ($p < 0.001$), and in the women having secondary education, it increased from 24% to 81% ($p < 0.001$) after the first round of the intervention. In the intervention area, the cases were detected at an early stage (55%) compared to the control area (30%) ($p < 0.05$). The five-year observed survival of the cases from the intervention area was 49%, while in the control area, it was 40% ($p > 0.05$). Due to the effect of intervention, the incidence in the intervention area was higher than the control area with RR of 1.25 (95% CI 1.18–1.32), but there was no difference in the effect on mortality between the two areas with RR of 1.02 (95% CI 0.94–1.00).

The reduction in mortality in the intervention area was not observed probably due to delay or no treatment. The treatment compliance in the intervention area was lower (57%) compared to the control area (65%). Among the untreated cases, the early cases, uneducated women, and low-income group women were more common in the intervention area than in the control area. The early cases, Ia and Ib, from the intervention area completed the treatment (52%) compared to the control area (95%) with the difference between the two groups being significant ($p < 0.01$). The localized cases were diagnosed at the field clinic or at NDMCH. When these women were invited for the treatment, their approach was that they were not ill and did not want any treatment. The villagers' attitude was that until the disease became severe enough that they were unable to work and bed ridden, they would consult the doctor. The number of hospital visits, transportation problems, and financial barriers were further important factors for not completing the treatment.

A randomized controlled trial was organized to address the efficacy and cost effectiveness of different screening methods, such as one-time VIA, cytology, or HPV testing, in reducing the cervical cancer incidence and mortality. The programme was initiated in October 1999 and 79,449 women were screened.

To study the compliance and perception of the women towards the screening, 10% of women from randomly selected villages were contacted personally. The women in the screening programme were aware about it due to person-to-person invitations by the field staff and to intensive education about the disease and importance of the screening.

The women from the rural area accepted the screening by VIA, cytology, or HPV. Women who were young, educated, married, belonging to a higher income group, and those who understood the screening procedure participated in the screening programme. Those who participated in the programme reported that their husbands had encouraged them to participate, and they were happy with the services provided by the organizer. Widows refused the screening and their compliance with treatment was poor. The common reason given by the women who had not participated in the screening programme was that they felt such a test was not necessary for them (66%) and another reason was fear of the test (24%). The other reasons reported were shyness, husband's disapproval, not well, and negative rumours about the programme. The washing of the vagina after sexual intercourse was poor in screened women and also among those who were not willing to undergo screening. More than 75% women did not wash the genitalia after sexual intercourse.

In the screening area, the stage Ia cases were reported in the range between 39% to 50%, and in the control area, it was reported only of 6.8%. Altogether, 27% cases from the screen-detected cases, 37% clinically detected cases, and 27% cases from the control did not complete the treatment. The percentage of cases that did not complete the treatment were 44% from the early stage cases from the screen-detected group, 60% of late stage cases from the clinically detected group, and 44% from the control group. The compliance to the treatment was poor in low-income group women.

A cervical cancer control programme, whether it is based on health education or screening, should focus on detecting and treating the precancerous lesion in single- or two-visit strategies rather than detecting and treating advanced stage cases as our experience indicates that treatment compliance is poor. In spite of the free treatment, failure to provide subsidized facilities for transport, food, and medicine, and also lack of motivational efforts in social support during treatment are likely to account for the failure of a cervical cancer control programme. Social support, either by a close relative or village leaders, is essential for the completion of the treatment. The findings of this study indicate that improved public awareness of the risk factors of the disease, its symptoms, diagnosis, and treatment methods lead to early presentation and high compliance with screening in the control of cervical cancer even in the existing framework of health facilities.

Based on the experience of the cervical cancer control studies conducted at NDMCH, Barshi, a cervical cancer control plan for rural India is outlined. To reduce the burden of the disease, the regional cancer centres in the country could develop the community centres in the town hospital, district hospitals, in radiotherapy centre, and in

the centres, such as those actively involved in the cancer atlas project of India. Success was assumed to be possible with regional cancer centres active support and monitoring.

The method suggested for cervical cancer prevention by community centre is intensive health education and providing easy access to diagnosis and treatment as well. The community centre can use the available infrastructure and human resources to some extent. Apart from the existing staff, there is a need for field staff to coordinate the activity within the community.

The estimated amount for the development of a community centre is Rs. 486,000 (US\$ 10,125 – for staff training and equipment), and annually, Rs 803,450 (US\$ 16,739 staff salaries and annual running costs) for running the programme. The total cost will be Rs. 7.50 (US\$ 0.16) per woman per year with services to 0.2 million female population by one community centre. In India, there are totally 25 regional cancer centres, and also there are 210 radiotherapy centres and 105 centres of cancer atlas project, which is around 300 centres. If each regional cancer center develops 12 community centres covering 0.2 million female population per CC, this will cover a 60 million female population. This is only 6% of the Indian rural female population of 360 millions. This is a practical indication of the magnitude of the unsolved cervical cancer problem in India.

The Nargis Dutt Memorial Cancer Hospital Barshi was started as a community centre by the Tata Memorial Centre, Mumbai, in 1982 and has provided comprehensive cancer control services to a large rural population. To control cervical cancer in the rural areas of India, the NDMCH should be considered as a model, and this model can be replicated all over India, so over the years, these centres will provide comprehensive cancer control services to the rural population of India.

9. Abbreviations

ACCP	Alliance for Cervical Cancer Prevention
ANS	Age Not Specified
ARCRRS	Ashwini Rural Cancer Research and Relief Society, Barshi
ASCUS	Atypical Squamous Cell of Undetermined Significance
ASR	Age Standardized Rate
BDO	Block Development Officer
CI	Confidence Interval
CC	Community Centre
CIN	Cervical Intraepithelial Neoplasm
CR	Crude Rate
DCO	Death Certificate Only
HBCR	Hospital Based Cancer Registry
HPV	Human Papilloma Virus
HSIL	High grade Squamous Intraepithelial Lesion
IARC	International Agency for Research on Cancer, Lyon, France
ICD	International Classification of the Disease
ICMR	Indian Council of Medical Research, New Delhi
INR	Indian Rupees
LSIL	Low grade Squamous Intraepithelial Lesion
n	Number of cases
NA	Not applicable
NCCP	National Cancer Control Programme
NCRP	National Cancer Registry Programme
NDMCH	Nargis Dutt Memorial Cancer Hospital, Barshi
NGO	Non Governmental Organisation
NI	No Information
OR	Odds Ratio
PBCR	Population Based Cancer Registry
PHC	Primary Health Centre
PYRS	Person Years at risk
RCC	Regional Cancer Centre
RCR	Rural Cancer Registry
RCT	Randomized Controlled Trial
RR	Relative Risk
RT	Radiotherapy
TMC	Tata Memorial Centre
VIA	Visual inspection after application of 3-5 % acetic acid
VILI	Visual inspection after application of Lugol's iodine
WHO	World Health Organization

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