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The Challenges of India's Rising Breast Cancer Epidemic

Brigette Stickney
SIT Study Abroad

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The Challenges of India's Rising Breast Cancer Epidemic
Brigette Stickney

Azim Khan
Bhagwan Mahaveer Cancer Hospital and Research Center
SIT Study Abroad
India: Public Health, Gender, and Community Action
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Abstract

India is currently undergoing rapid urbanization, which is greatly impacting Indian citizens' health. One of the rising concerns due to the drastic lifestyle and environmental changes that are results of urbanization is the issue of breast cancer. Breast cancer diagnosis rates are rising exponentially, and breast cancer has moved its way up to be the most common cancer in India. Breast cancer mortality rates in India are also some of the worst in the world. This paper analyses the social, mental, economic, geographic, and physical challenges that are present for women diagnosed with cancer in India. It assesses how they decrease the woman's likelihood of receiving early diagnosis and treatment. Late diagnosis is the main reason that the mortality rates are so high. The study also discusses solutions to the problems in the forms of awareness and education. The study was conducted through interviewing oncologists, counselors, social workers, female breast cancer survivors, and males from a variety of professions to understand the challenges that women face in receiving effective and early treatment for breast cancer. These interviews were conducted through Comprehensive Rural Health Project, Koshish, Jaipur Cancer Relief Society, Bhagwan Mahaveer Cancer Hospital and Research Center, and a hostel in Jaipur. The challenges included fear of death, physical effects of treatment, pain of treatment, and lack of education. Through effective increased awareness and education provided to both men and women, these issues can be reduced, and mortality rates can drop despite the rising breast cancer epidemic.

Introduction

Cancer is a growing problem in India. Rapid urbanization has been drastically changing the lifestyles of many Indian citizens and the environments that surround them¹. The number of cancer cases and deaths per year has been hastily increasing in India. In 2017, the number of cancer-related mortalities was about 556,400, and this number is expected to increase by more than seven lakh each year in the upcoming years. The four most common cancers in India--breast cancer, cervical cancer, mouth cancer, and lung cancer--together make up 50% of all cancer-related deaths in the country.² However, breast cancer is increasingly a bigger problem among women than other cancers among men. In 2012, there were 112,000 female patients diagnosed with breast cancer, which is more than double the amount of total men diagnosed (53,000) with common cancers.³ In that same year, there were 70,000 reported breast cancer mortalities which is expected to increase to 76,000 by 2020.⁴ Over 50% of the breast cancer diagnoses in India occur in stages 3 or 4, which leads to a more difficult treatment process with a much lower likelihood of survival.⁵ This late diagnosis is one of the main reasons that India has such a high breast cancer mortality rate in comparison to other countries, and it is continuously growing as the number of women diagnosed with it increases. The high mortality rate can be seen when

¹ Banavali, Shripad. Delivery of cancer care in rural India: Experiences of establishing a rural comprehensive cancer care facility. *Indian Journal of Medical Pediatric Oncology*. [Online] 2015, 36, 128-131 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4477376/> (accessed Oct 12, 2018).

² Chakrabarty, Jyothi. Economic Burden of Cancer in India. *Indian Journal of Public Health Research and Development*. [Online] 2017, 8(3),137-141 https://www.researchgate.net/publication/318109546_Economic_Burden_of_Cancer_in_India (accessed Oct 11, 2018)

³ Nyblade, Laura; Stockton, Melissa; Travasso, Sandra; Krishnan, Suneeta. A qualitative exploration of cervical and breast cancer stigma in Karnataka, India. *BMC Women's Health*. [Online] 2017, 17, 2-15 <https://pdfs.semanticscholar.org/43a6/342655746cde4847d9a4deafdda5fba49ce5.pdf> (accessed Oct 12, 2018)

⁴ Bhattacharya, Papiya. India is staring at a breast cancer epidemic. But do we have the awareness and tools to prevent one?. *Scroll.in* [Online] 2017 <https://scroll.in/pulse/850251/india-is-staring-at-a-breast-cancer-epidemic-but-to-we-have-the-awareness-and-tools-to-prevent-one> (accessed Nov 5, 2018).

⁵ Shah, Sumeet. Breast Cancer India. *The Pink Initiative* [Online] 2018.

comparing statistical data that, “68% of patients with cancer die of their disease in India as compared to only 33% in USA.”⁶ According to a study done by Sanjukta Sharma, a public health specialist stated that, “one of every two woman newly diagnosed with breast cancer doesn’t survive in this country.” The statistics that prove this are shocking, and the root cause of this problem, as described by the author is the social taboo around female health and the fact that breast cancer is associated with both feminine beauty and reproductive health.⁷ As India faces a soon-to-be breast cancer epidemic due to environmental and lifestyle changes that are greatly increasing diagnosis and mortality rates, it becomes increasingly important that India provide education and access while simultaneously breaking down social stigmas to improve rates of early diagnosis that can reduce breast cancer mortality.

Global trends show that urban, developed cities are the most common locations for breast cancer to occur in citizens.⁸ India in the past has had a much lower breast cancer diagnosis rate. However, recently, diagnosed breast cancer cases have been increasing.⁴ Breast cancer is now the most common cancer among urban Indian women and the second most common cancer among rural Indian women. The highest rates of breast cancer diagnosis are in Delhi, Mumbai, Ahmedabad, Calcutta, and Trivandrum.⁹ One of the two directors at Comprehensive Rural Health Program, an NGO that focuses on providing health education and access through Village Health Workers that are empowered women of lower castes, stated that though breast cancer and cervical cancer have been a rare occurrence in rural areas, like Jamkhed, in the past, he has seen

⁶ Banavali, Shripad. Delivery of cancer care in rural India: Experiences of establishing a rural comprehensive cancer care facility. *Indian Journal of Medical Pediatric Oncology*. [Online] 2015, 36, 128-131 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4477376/> (accessed Oct 12, 2018).

⁷ Sharma, Sanjukta. The secrecy and shame around women’s cancers. *LiveMint*, Sep 2018.

⁸ Shetty, Riya. India faces growing breast cancer epidemic. *Science Direct*. [Online] 2012, 379, 992-993 [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(12\)60415-2/fulltext?hc_location=ufi](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)60415-2/fulltext?hc_location=ufi) (accessed Oct 12, 2018).

⁹ Agarwal, Gaurav; Ramakant, Pooja. Breast Cancer Care in India: The Current Scenario and the Challenges for the Future. *Breast Care*. [Online] 2008, 3, 21-27 <https://www.karger.com/Article/PDF/115288> (accessed Oct 12, 2018).

a spike in diagnosis in recent years. This is largely due to environmental factors and rapid urbanization that is taking place throughout parts of India.¹⁰ Smog and other forms of pollution due to industrialization and farmers's burning of crops are problematic in cell division cycles and are leading to further cancer occurrences.¹¹ These factors are mainly problems in urban areas, but their effects spread out to rural areas as well, and even rural Jamkhed, located 4 hours from the major city of Pune, is suffering from the harmful effects.

There are often underlying social stigmas, fears, and challenges in India that prevent women in seeking diagnosis and treatment even if they are educated on the topic of breast cancer. Despite the fact that so many more women are diagnosed with breast cancer than men are with other common cancers, women are far less likely to receive treatment due to social inequality, stigmas, and accessibility.¹² Once a woman begins experiencing symptoms, such as small tumors developing on her breast and unusual nipple discharge, it is common for her to isolate herself out of fear and avoid medical diagnosis.¹³ If she does eventually seek treatment, it is often in much later stages when it is far less likely for the woman to survive the cancer. One doctor at Cachar Cancer Hospital and Research Centre in Silchar stated "Women sometimes come in with lumps in their breast that are 30–35 cm large. These heavy masses of cancerous cells protrude outside the body, ulcerating or teeming with maggots."¹⁴ She then goes on to say, "if women came to my clinic when their lump was 1 cm rather than 10 cm, it would make a massive difference to their survival."¹⁵

¹⁰ CRHP Director. Personal Interview. Oct 25, 2018.

¹¹ Sharma, Shweeta. Public Health-Environmental Concerns and Chronic Disorders. (lecture, SIT India, November 1, 2018).

¹² Nyblade, A qualitative exploration, 2-15.

¹³ CRHP Village Health Worker 1, 2018.

¹⁴ Shetty, India faces growing breast cancer epidemic, 992-993.

In Gaurav Agarwal and Pooja Ramakant's study, "Breast Cancer Care in India: The Current Scenario and Challenges for the Future," a study was conducted through statistics and data presented by hospitals in Delhi, Mumbai, Ahmedabad, Calcutta, and Trivandrum--the places in India of highest breast cancer diagnosis rates. It states that "almost 50% of [breast cancer] patients present with locally advanced disease," and the majority of patients are in stages III-b and III-a when they choose to seek treatment. "8-10% of patients have TNM stage IV disease at presentation, and only very few (5%) have stage I disease." This shows that more women are willing to seek treatment at the point that their tumors are massive and they are undergoing unbearable symptoms than when they first begin experiencing symptoms. At a variety of cancer centers throughout India, the average tumor size when treatment was pursued was well over 5 cm and most commonly--70% of the time--having stage III of the disease. At the time of this article, no national or regional breast cancer screening program existed in India. Breast cancer screening by examination or mammography was not available outside of research studies or women who actively seek out and pay for it at specialist hospitals. Movements are being made through NGOs--Health for All and the National Rural Health Mission to promote self-examination education for women to be able to self-check themselves free of cost. It states that the 5-year breast cancer survival rates were 62% overall, "90% for stage I patients, 78% for stage II, 57% for stage III, and 22% for stage IV, though the survival data is available based on the follow-up information for 75% patients only," and the 10-year survival rates were 35% for all combined stages, 75% for stage I, 55% for stage II, 35% for stage III, and 5% for stage IV.¹⁵

The director at CRHP along with two of the village health workers stated that fear due to stigmas and financial barriers was one of the main problems that prevented early diagnosis of

¹⁵ Agarwal, Breast Cancer Care in India, 21-27.

cancer among women.¹⁶¹⁷¹⁸ Some of these stigmas revolve around the ideas that cancer is contagious through contact, punishment for wrongdoings in the past, and/or a death sentence that shouldn't be treated.¹⁹ The village health worker at CRHP stated that many times, the women would be separated from their families and be avoided by their community out of fear of contracting the disease and being associated with someone who had angered their god.²⁰ These stigmas often result in isolation, job loss, harassment, and reduced chance of marriage for women with cancer.²¹ However, stigmas are not the only problem, financial burdens and lack of accessibility also play a huge role.

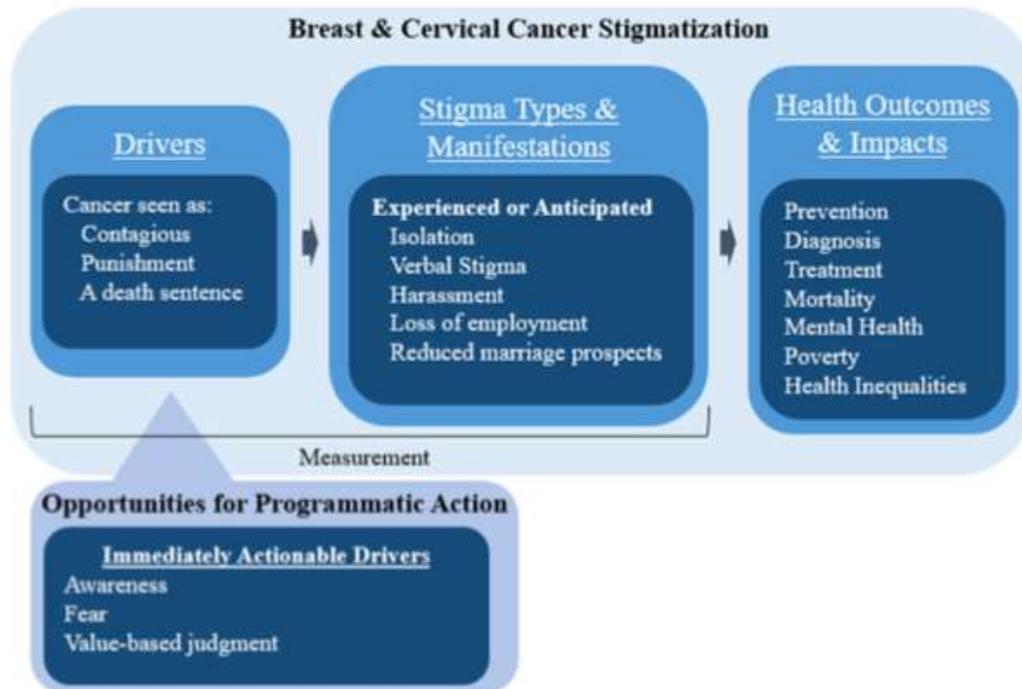


Image 1. Breast and Cervical Cancer Stigmatization.²²

¹⁶ CRHP Director, 2018.

¹⁷ CRHP Village Health Worker 1, 2018.

¹⁸ CRHP Village Health Worker 2. Personal Interview. Oct 26, 2018.

¹⁹ Nyblade, A qualitative exploration, 2-15.

²⁰ CRHP Village Health Worker 1, 2018.

²¹ Nyblade, A qualitative exploration, 2-15.

²² Nyblade, A Qualitative Exploration, 2-15.

This shows the extent to which fear of cancer diagnosis and recognition in the community as a cancer patient can prevent a woman from seeking help and greatly decrease their chance of survival. However, through education and awareness, women are more comfortable and able to seek treatment. It is essential that these root issues be assessed and targeted through awareness and education to lower mortality rates and increase women's chances of breast cancer survival.

Methods

This study assesses what the social and economic burdens are of breast cancer are, how they impact women's likelihood of breast cancer survival, and how these issues are being combated in order to improve women's chances of survival. The study was conducted in the urban city of Jaipur with Bhagwan Mahaveer Cancer Hospital and Research Center, Jaipur Cancer Relief Society, and Koshish as well as in rural Jamkhed with Comprehensive Rural Health Project. Medical doctors, social workers, support group counselors, village health workers, males from a variety of professions, and cancer survivors were all questioned with semi-structured interviews. Consent was always obtained prior to the interview and patients currently undergoing treatment were not interviewed due to ethical reasons. At CRHP, a translator fluent in marathi, hindi, and english was used to interview village health workers who primarily spoke marathi. In Jaipur, a translator fluent in hindi and english was used to interview two breast cancer survivors who primarily spoke hindi. The interviewees were asked a series of twenty to thirty questions about their perspective on social stigmas with female cancers and how they have seen the challenges presented by cancer diagnosis, treatment, and aftercare impact patients lives. They were asked about a series of common myths about breast cancer and their knowledge of them. They were asked about support and resources provided for these women financially, socially, and mentally. Questions were also asked regarding family structural

changes throughout the woman's experience with cancer and who held the power in healthcare decisions.

Comprehensive Rural Health Project in Jamkhed was worked with initially during a week-long workshop through SIT. Interviews were conducted here to gain a better understanding of breast cancer from a rural perspective. The goal of these interviews was to add diversity to perspective in the paper. Comprehensive Rural Health Project (CRHP) exists to help empower women as Village Health Workers in the local villages to improve awareness and knowledge of breast and cervical cancer. CRHP is an NGO that was created by Dr. Raj and Mabelle Arole in 1970 to provide rural access to secondary healthcare, better health conditions, and improve equity of all people in Jamkhed area through empowering women and people of lower castes in nearby communities. Through the Village Health Workers (VHW), Adolescent Girls Program (AGP), and Women's Self Help Groups (WSHG), CRHP is able to provide resources for the community and greatly improve the ability of the women in the community to get an early diagnosis and receive access to treatment.

Jaipur was chosen as the primary location for this research due to the urban environment and variety of breast cancer patient support and care resources provided in the city that would be ideal for conducting breast cancer research here. Jaipur Cancer Relief Society, Koshish, and Bhagwan Mahaveer Cancer Hospital and Research Center were all used as main contact sources in Jaipur to connect to interviewees for this research. Jaipur Cancer Relief Society is an NGO that was founded in 2000 by Dr. Sudhindra Gemawat, a doctor in radiotherapy at SMS Hospital. The goals of the organization are to provide the resources of cancer awareness/prevention, counseling during treatment, rehabilitation, home care, and financial support. The public hospital that it works under and stemmed off from, Sawai Man Singh Hospital (SMS Hospital), also has a

wing exclusively for female cancer patients and radiology technology and facilities. Koshish is a breast cancer support group dedicated to help breast cancer patients. The Jaipur branch of Koshish was created on December 14, 1997 by 15 members. The organization is composed of breast cancer survivors, social workers, and healthcare professionals that volunteer their time to help motivate, encourage, and serve breast cancer patients. They provide assistance mainly through counseling and financial support.

Bhagwan Mahaveer Cancer Hospital and Research Center was also used as a resource. It is a private hospital and research center that was created in 1997 as an institution focusing on cancer prevention, treatment, education, and research. It includes the departments of Surgical Oncology, Medical Oncology, Radiation Oncology, Radiology, Pathology, and Blood Bank. It contains 200 beds and has a specific wing dedicated to female cancer patients. A variety of cancer support groups also stem from this hospital. It was created to be the first cancer specialized hospital in Jaipur.

Interviews were also conducted with a variety of male visitors at Chillout Jaipur Hostel. At this location, a variety of male perspectives were gained on women's health to better understand their relationship to women's health and how they impact a woman's ability to be successfully be treated and diagnosed early.

Cancer and Death

The initial fear that most women face when confronted with breast cancer is the fear of death. Every cancer patient, doctor, and NGO member spoken with at SMS Hospital and Mahaveer Hospital in Jaipur stated that this is the first and most important challenge to overcome and educate people on. So many people assume that with the diagnosis of cancer comes certain death. This proposes a huge challenge, because if people are unaware of the fact that cancer can

be treated, they will not pursue treatment at all. Often women in India travel to live with their husband's family after marriage. Therefore, it is often seen that the woman's care is mainly the responsibility of her husband's family, and if the husband's family thinks she will die, it greatly negatively impacts her ability to be treated early and effectively.²³²⁴²⁵²⁶

Often, when the husband's family discovers that the woman has cancer, they will neglect her health. They will isolate her and begin making plans for their son to be remarried to a new woman. Frequently, it is thought that it is cheaper and more beneficial to remarry the son to someone new than to pay for his wife's cancer treatment.²⁷²⁸²⁹ The family is especially unwilling to pay for transportation and lose hours of work to provide the woman treatment if they think that the treatment will be ineffective and she will die anyway.³⁰ As found in a study conducted by Nyblade et al, "one group of young women described how a cancer diagnosis would mean that the mother-in-law would begin looking for a new wife for her son. 'If it is between mother in law and daughter in law then mothers in law will be thinking to remarry her son.'"³¹ There is also a trend where the husband cheats on his wife while looking for new prospective wives and sexual satisfaction, since he is not able to obtain it in his current marriage. As Nyblade found in speaking with a female cancer support group that one patient responded to the topic of marital infidelity by saying, "even though men send for the test, ladies don't go because they are scared that if they have disease husband may leave her and go to another lady. So even though they have disease they don't go for the test, they think that they [husband] will not have sexual

²³ Male 1. Personal Interview. Dec 5, 2018.

²⁴ Male 2. Personal Interview. Dec 5, 2018.

²⁵ Male 3. Personal Interview. Dec 5, 2018

²⁶ Male 4. Personal Interview. Dec 6, 2018.

²⁷ Koshish President. Personal Interview. Nov 28, 2018.

²⁸ SMS Oncologist. Personal Interview. Nov 13, 2018.

²⁹ Koshish Exec Member. Personal Interview. Nov 13, 2018.

³⁰ Koshish President, 2018.

³¹ Nyblade, A qualitative exploration, 2-15.

relationship with them and they will go to other ladies, if they come to know they have disease. Some people don't tell even if they have stomach ache thinking that people will assume that they have disease, they don't go for test, so they are scared. Almost all ladies will have that fear.”³²

The fear of death and marital infidelity of the women's husbands often results in a complete lack of treatment for already married women, and this has a very negative impact on their mental health and often leads to depression and suicidal thoughts.³³³⁴ It also impacts women who aren't married, because their future chances of marriage become much more slim. Fear of cancer and death also leads to women isolating themselves in their own homes to prevent other community members and family members from discovering their disease.

However, this is not true for all women. Women of higher social standing and economic status tend to remain in their marital relationships. One of the males interviewed stated that his sister is engaged to be married in February. If she got cancer, he does not believe that her engagement would be broken off. He thinks that due to her high level of education and good job in media, her fiance would not break off the engagement.³⁵ This shows that women of higher social standing, higher education, and better careers will often suffer less from marital strain than women of other social standings.

Physical Effects of Treatments

The physical effects of chemotherapy also impact women's marital and social status. An oncologist at SMS Hospital described the impact of hair loss on women undergoing chemotherapy. In India, long, healthy hair is often considered beautiful and desired by men when

³² Nyblade, A qualitative exploration, 2-15.

³³ Koshish President, 2018.

³⁴ SMS Oncologist, 2018.

³⁵ Male 4, 2018.

choosing female mates. A 28-year-old patient that came to SMS with long, beautiful hair that grew past her waist was engaged to be married in three months before she was diagnosed with breast cancer. She had waited a long period of time to be married, and twenty-eight is considered a late marriage age in her cultural context. When her husband found out that she would lose her hair during chemotherapy, he broke off the engagement. He left her to marry another woman. The doctor stated that she had seen multiple other similar cases as well of husbands leaving their wives when they were diagnosed with cancer.³⁶

Short hair or shaved hair on women is associated with cancer. Men interviewed found long hair to be far more desirable than short hair.^{37,38} It is very rare for a woman in Jaipur to willingly shave or cut her hair, unless she has cancer and is undergoing treatment. Therefore, when people see a woman without long hair, they treat her differently. They associate her with disease. Often, if the person is unaware of the science of cancer, he or she will respond to the woman negatively.³⁹ Assuming that cancer is contagious or a consequence of a wrongdoing in the past, the person will keep distance from the woman in an attempt to avoid her or scold and taunt her for her past actions.⁴⁰

One of the breast cancer survivors interviewed kept her head covered with cloth constantly in public. She feared other people seeing her short hair due to her recent chemotherapy, and she didn't like them to see it, because they would treat her differently. They would either show her sympathy or disgust/avoidance.⁴¹ A community leader in Karnataka in a study by Nyblade stated that, "Some women hide the changes in their body. Some fear that if the

³⁶ SMS Oncologist, 2018.

³⁷ Male 2, 2018.

³⁸ Male 4, 2018.

³⁹ Nyblade, A qualitative exploration, 2-15.

⁴⁰ Nyblade, A qualitative exploration, 2-15.

⁴¹ Cancer Survivor SMS. Personal Interview. Nov 13, 2018.

community comes to know about it they will keep her separately, so to avoid all those humiliation women don't discuss such things freely. Only when it reaches incurable stage they will tell."⁴²

When asked what the biggest challenge that women face when going through cancer, one man who worked in pharmaceuticals stated that "more than pain from treatment, they suffer from societal problems."⁴³ Another man also stated that the biggest issue women face with cancer is coming out to society about it, and the physical effects of cancer make it nearly impossible to keep social relationships the same. He stated that he would try to hide her cancer diagnosis from society and would take her to a hospital that would keep it quiet, so that she would not have to deal with social issues. However, if people see her shaved head and weak figure, they will be unable to hide her cancer diagnosis, and she will be constantly confronted by the challenges that society presents to her in social stigmas.⁴⁴

It was found in speaking with a breast cancer survivor at Mahaveer Hospital in Jaipur that when a person is well educated on the topic of cancer and of higher social status, they often show sympathy to the patient when noticing her shaved hair. The woman came from a privileged and wealthy background, so she was able to afford acme care at private hospitals. She was very strong and confident in her ability to overcome the cancer and used it as an opportunity to promote awareness and help others who were also cancer patients. Her friends and family were all well educated on the topic of breast cancer and showed her a great amount of sympathy while she suffered the physical effects of cancer treatment. In her case, this sympathy was not

⁴² Nyblade, A qualitative exploration, 2-15.

⁴³ Male 4, 2018.

⁴⁴ Male 2, 2018.

appreciated. She wished for people to treat her normally. She believed in her own strength and did not want the pity and negativity of others dragging her down.⁴⁵

One breast cancer patient interviewed at SMS hospital was returning for one of her follow ups after treatment. She stated that her family was very worried for her and willing to take her to get treated, especially after the women at Koshish told her family of the news that she could survive the treatment and that it would be free through SMS. She came from a wealthier family and they did not struggle to move to Jaipur for a few months in nearby apartments until her treatment was complete. Her husband's family prioritized her health above remarrying her husband.⁴⁶

The common trend of wealth and higher societal standing had a huge impact on how women were treated when their physical characteristics were noticed. Most commonly, women of lower income and education levels are taunted and avoided due to the thoughts that their cancer is a result of wrongdoings or is contagious. They were commonly isolated and neglected by their families due to the family's fear of contracting the illness. Their husbands were remarried. However, women from higher income and higher education levels are often shown sympathy. Their families help ensure that they get treated. This fear of going through treatment suffering socially from physical effects often is one of the factors that lead to women having delayed treatment and not surviving breast cancer.

Pain of Treatment

Chemotherapy not only creates physical differences that impact how women are treated socially, the fear of the pain during the treatment also plays a role in delayed diagnosis and

⁴⁵ Cancer Patient Mahaveer. Personal Interview. Nov 19, 2018.

⁴⁶ Cancer Survivor SMS. Personal Interview. Nov 13, 2018.

higher mortality rates. A breast cancer patient at SMS Hospital said that she greatly feared the pain that she would face during chemotherapy. It was one of the biggest factors that swayed her to not seek treatment. However, her mother was willing to convince her to undergo chemotherapy, because she needed to take care of her two young children. Her fear of not being able to care for her children was greater than her fear of the pain. Her case of breast cancer was very aggressive, and she had to undergo treatment for five years. She went through 7 breast operations and multiple chemo treatments. Finally, she was free of cancer and able to provide support and help to other women diagnosed with breast cancer. She joined Jaipur Cancer Relief Society as a social worker and a counselor and is very thankful that she is able to use her experience to help others.⁴⁷

A few of the men interviewed stated that they thought that a huge challenge that women faced in breast cancer was pain. They knew that chemotherapy induced a lot of pain. If the men fear for the pain that their wives, mothers, and daughters will go through, it will likely also affect the women and cause them to fear it as well.

This fear of chemotherapy is also a factor in mortality rates. Even if a woman is able to go through diagnosis and treatment despite social and accessibility challenges, she still might refuse it due to the knowledge of the pain and suffering that she will experience.

Lumpectomy and Mastectomy

Along with hair loss and pain, breast removal is also a fear. Breast conservation surgery (lumpectomy) is rarely practiced in India due to the radiation therapy equipment and early stage diagnosis required to successfully conduct the surgery.⁴⁸ Breast conservation surgery is a

⁴⁷ JCRS Social Worker. Personal Interview. Nov 13, 2018.

⁴⁸ Koshish Exec Member. Personal Interview. Nov 13, 2018.

procedure in which the entire breast is not removed. Often the resulting physical differences after breast conservation surgery only include a small dimple in the breast, but radiation therapy is often necessary post-surgery and the tumor must be under five centimeters in size. (American Cancer Society) In Delhi, a study was conducted that showed that 88.7% of patients that underwent surgery had their entire breast (skin, breast tissue, areola, nipple, and underarm lymph nodes) removed via modified radical mastectomy, while only 11.3% underwent breast conservation surgery.⁴⁹

If a woman loses her breast, it can often result in a husband's infidelity. It is also an easily spotted sign of a woman having had breast cancer in the past, unless a woman is able to cover herself with a padded bra or other form of padding. Being able to hide the hollow in her chest effectively can be costly. However, some programs, like Koshish, provide free bras and pads to patients of low income that can't afford them. Koshish provides one pad and two bras that fit the pad per breast cancer patient in an attempt to reduce the social challenges that the women face due to their mastectomy.⁵⁰

Comfort and Confidence

Due to the fear caused by social stigmas, steps must be taken to provide access to someone that they feel comfortable talking with about health issues. This can greatly increase women's ability to be educated on early breast cancer symptoms and help them find empowerment in discussing their bodily health to actively pursue treatment if symptoms begin. One method of making women feel more willing to seek help when they recognize cancerous symptoms is to educate a female from the local community that women feel comfortable talking

⁴⁹ Agarwal, Breast Cancer Care in India, 21-27.

⁵⁰ Koshish Exec Member, 2018.

with to help them get treatment. Women feel embarrassed to be examined by male doctors who might discover that they have cancer.⁵¹ Many women throughout India are often embarrassed to reveal information about their own bodily health even to close friends and family, so they are very unlikely to seek medical assistance from unfamiliar doctors who they feel less comfortable with than family and friends.⁵²

This was evident in many interviews with female cancer patients. One patient was interviewed in front of a male doctor and her husband. This greatly decreased her willingness to answer questions. Though she wanted to participate in the study, her answers were very short and did not shed light on social stigmas or challenges she faced due to the uncomfortable situation in being interviewed on her health with men in the room.⁵³ Particularly, it was difficult for her due to the sexualization of women's breast. If she felt so uncomfortable speaking in front of them, it must have been extra difficult to address her symptoms and health concerns with them. Also, a list of twenty women was given by Bhagwan Mahaveer Cancer Hospital and Research Center to do interviews with, but only two were willing to be interviewed due to the fact that they were uncomfortable discussing their experience with breast cancer.

When interviewing one of the male interviewees, he stated that the main difference between men having cancer and women having cancer is that men can talk to anyone about their health. Women are limited to only talking to sisters and mothers, and even with these female family members, they sometimes still are uncomfortable talking about bodily health. However, men are able to much more easily discuss their own health issues and access healthcare resources to treat them. Female health has a shamefulness attached to it that male health does not.⁵⁴

⁵¹ PTI, India Facing Breast Cancer Epidemic, 2017.

⁵² Sharma, Sanjukta. The secrecy and shame around women's cancers. *LiveMint*, Sep 2018.

⁵³ Cancer Survivor SMS, 2018.

⁵⁴ Male 2, 2018.

According to a study at the University of Portsmouth, methods that are traditionally used to spread breast cancer awareness in other countries, such as the United States, have little effect in increasing diagnosis and treatment rates in India due to underlying social and cultural differences.⁵⁵ Therefore, methods through the use of community health workers to teach both men and women can be initiated to increase education and awareness and lower mortality rates. Providing resources, such as the village health workers at CRHP, ASHAs, Avengari workers, and NGO support groups, can help reduce the amount of women that wait to seek treatment until it's too late. The health workers hold power in breaking down stigmas and encouraging women to feel more at ease in seeking diagnosis and treatment through discussion. They also teach them how to check themselves and be aware of symptoms for early diagnosis.

One village health worker at CRHP stated that in order to reduce shameful stigmas around cancer treatment and women's feelings of embarrassment in discussing it, she told all of the women in her village that they would receive free medication for cervical pains if they came to see the CRHP doctor at a specific day and time. Forty to fifty women came to the center to get the medication. The Village Health Worker gathered them into a room, eased their fears through talking with them, and showed them to the doctor who gave them free pap smear tests. They found that four women had cervical cancer. The woman was able to advise them on how to receive treatment and provide support for them. All four of the women were successfully treated, and the cancer was permanently removed. Through this event, as well as educating women in the Women's Self Help Group and the Adolescent Girls' Program (two groups focused around educating females on health), she was able to reduce stigma and fear of cancer in women, and make women more aware and more able to access tests/treatment. Often women and their families think death is certain if tests come back positive for cancer, but she helped teach them

⁵⁵ PTI. India Facing Breast Cancer Epidemic. *Lifestyle, Health, and Wellbeing*, Aug 2017.

that it is treatable. Now women feel far more comfortable checking themselves and coming to her if they notice any unusual discharge or lumps on their breast that might signal breast cancer. She effectively broke down stigmas in her community. The Village Health Worker is able to send them to the hospital to get tested with lab equipment if she finds that their symptoms are signifying cancer, and they are able to get early diagnosis and increase their chances of survival.⁵⁶

By building up women's confidence and education in their own health, they become more comfortable in seeking care and are more willing to learn about symptoms and active prevention/treatment. This village health worker successfully increased the confidence and comfort of the women to improve their will to seek treatment.

A breast cancer survivor at Bhagwan Mahaveer Cancer Hospital and Research Center stated that the primary reason she was able to get through cancer was her confidence in herself and her optimism. She was depressed the first two days of finding out that she had cancer. Her massage therapist noticed a solid lump in her breast and advised her to go to the doctor. She didn't want to initially, but after the therapist persisted she agreed to go. She was diagnosed with breast cancer stage two at age forty-nine. Initially, she was depressed. However, she soon overcame her fear and sadness by doing research on her own. She became confident that she would overcome her cancer, and was able to talk about it freely and seek treatment. She states that she owes a large portion of her ability to overcome cancer to her confidence and optimism throughout the process. Often people were confused that she had breast cancer, because she came across as so positive, confident, and healthy. She now holds awareness events to help increase education and encourage other women to remain confident and optimistic throughout the cancer treatment process. Her awareness events have been very successful in empowering women with

⁵⁶ CRHP Village Health Worker 2, 2018.

breast cancer to actively seek care and discuss their health. She has also been on TV and has been interviewed for multiple articles and papers to spread her story and increase women's sense of empowerment in their own health.⁵⁷

An oncologist interviewed at SMS Hospital and the women interviewed in Koshish also highlighted the importance of confidence. In order to give a woman the will to fight the cancer and actively go for treatment, she must be confident in her ability to get rid of the cancer and talk about it. That is one of the points that Koshish emphasises. The breast cancer survivors that counsel the current patients act as examples of strong women who have overcome breast cancer before. They are able to build the confidence of the women currently going through the same issues and challenges that they went through earlier on in their lives and act as a support system that builds the woman up to believe in her own strength and power to go through social and physical challenges that come with breast cancer. They teach them that they can make it through the difficulties and come out, "even more strong and more beautiful than before." This makes them more ready to go through treatment and fight for survival. Confidence is a key element in survival. If women don't believe in their ability to withstand social pressure and overcome cancer, they have a much lower rate of going for treatment and surviving, and one of the best ways to improve this is to build strength in numbers by meeting other women who have survived cancer and become even more strong.^{58,59}

Through the use of CRHP's village health workers and empowered breast cancer survivors that spread awareness on their own or in support groups like Koshish, women are able to become more confident in discussing their own health issues and actively seeking treatment

⁵⁷ Cancer Patient Mahaveer, 2018.

⁵⁸ SMS Oncologist, 2018.

⁵⁹ Koshish Exec Member, 2018.

when issues begin. If women are more comfortable in discussing their health issues, breast cancer treatment can be diagnosed much earlier on and survival rates can be improved greatly.

Male Influence on Female Health

Though helping women feel more comfortable and confident in seeking medical help is essential in improving instances of early diagnosis, targeting the women alone is not fully effective in making the social change to remove stigma around cancer. Men often hold a much higher position of power in families and often are very influential in women's health.

Unfortunately, women's health is not commonly viewed with high importance among the men and older women in their house. Therefore, the males in the communities must also be targeted to make the social change to increase the amount of women that are able to seek diagnosis and treatment. Due to the patriarchal society, it is essential that men be educated and aware in order to ensure that women are aware and able to receive early treatment to reduce mortality rates.

Every married man interviewed, stated that he would be in charge of his wife's health if she began experiencing breast cancer symptoms. He would be the one who determined where and when she went for care. There was a trend that the husband was in charge of his wife's treatment. If the woman was an elderly mother and her husband was dead, her son would take care of her, and if the cancer patient was an unmarried female without children, the father would take care of her. Most of the men stated, though, that it would not be solely their decision to determine their wife's care. They would also value input from her family in choosing where and when she is diagnosed and treated. Above all, every man stated that they would trust the doctor's word fully in what he or she recommended to be best. ⁶⁰⁶¹⁶²⁶³

⁶⁰ Male 1, 2018.

⁶¹ Male 2, 2018.

However, when asked about the symptoms of breast cancer, only one male interviewee was able to identify any symptoms. This man worked as a lawyer, but he did not know any women who had breast cancer. He was very well educated and had learned about it through a documentary that he had watched. The symptom that he was able to identify was, “lumps in the breast.”⁶⁴ The rest of the men from a variety of professions, including rickshaw driving and pharmaceuticals either asked to not answer the question or openly stated that they did not know of any symptoms.⁶⁵⁶⁶⁶⁷

Though the men are in charge of female health, they are often unaware of the symptoms. If women are uncomfortable discussing health issues and men are not informed on what the symptoms of breast cancer are, this can easily result in delayed treatment. Though all of the men interviewed stated that they would be concerned for the female’s health in a breast cancer scenario and try to find the best care for them, it would be impossible to obtain early and effective diagnosis and treatment if the woman can’t come to them with their health concerns, and the men can’t identify the breast cancer symptoms. “Even educated professional women do not discuss private matters about their bodies with their husbands, fathers, or brothers, so it’s essential to direct health messages towards men to increase their awareness and willingness to discuss the problem.”⁶⁸ Even if the women are educated on the cancer symptoms and comfortable in discussing the information with other women, their fear in discussing it with their husbands is often still present. Therefore, it is essential that men be educated on the symptoms of breast cancer. Though these men were aware of many of the common breast cancer myths and

⁶² Male 3, 2018.

⁶³ Male 4, 2018.

⁶⁴ Male 1, 2018.

⁶⁵ Male 2, 2018.

⁶⁶ Male 3, 2018.

⁶⁷ Male 4, 2018.

⁶⁸PTI, India Facing Breast Cancer Epidemic, 2017.

knew that they were false, such as breast cancer is not contagious or a result of past wrongdoings, it was not pushed that they be prepared to help with early diagnosis in helping identify breast cancer symptoms in the women in their lives. If men can identify the symptoms as well, then the women in their lives can receive earlier diagnosis and decrease mortality rates.⁶⁹⁷⁰⁷¹⁷²

Every man interviewed, with the exception of one, stated that he would be interested in learning more about breast cancer. They recognised their power in the situation and how being educated could benefit the women in the community. The one man interviewed said that he would be able to be a “helping hand” to any person in the community that was experiencing breast cancer symptoms if he was able to be more educated on the topic.⁷³ Two of the men actively sought out more information on breast cancer. One found it through watching documentaries, and another found it through conversing with an oncologist that he spoke with while driving his rickshaw.⁷⁴⁷⁵ Therefore, it is essential that education on breast cancer is pushed. The men interviewed were willing to learn about it and wanted to help, but they had to seek out the information on their own. If it is presented to them in a way that is easy and accessible, more men could play a part in early breast cancer diagnosis and treatment.

Thankfully, there are currently a number of organizations working to educate men. One of the groups is Koshish. In Koshish, a variety of past breast cancer survivors work as counselors. These counselors not only counsel the patient, but they also counsel the family and educate the men in charge on the woman’s health. This is very helpful in creating male

⁶⁹ Male 1, 2018.

⁷⁰ Male 2, 2018.

⁷¹ Male 3, 2018.

⁷² Male 4, 2018

⁷³ Male 2, 2018.

⁷⁴ Male 1, 2018.

⁷⁵ Male 3, 2018.

awareness when women feel uncomfortable confronting males for help to increase likelihood of effective and early treatment and diagnosis.⁷⁶

Similarly, Jaipur Cancer Relief Society holds a variety of events for men and women to educate them on a large amount of cancers, including breast cancer. By focusing on including both men and women in the events, it raises mens awareness as well.

CRHP targets men through the Adolescent Boys Program and the Farmer's Club where they teach men in the villages about the value and importance of women and their health. They also teach them of the science behind breast cancer and that it is not contagious or a result of wrongdoing.⁷⁷ Country-wide, community nurses are reportedly the most effective method of improving early cancer detection among females through their education of the male community members and breaking down of social stigmas.⁷⁸ In teaching men to prioritize women's health more and educating them more on breast cancer, the women are more often able to seek out medical diagnosis and treatment earlier to decrease likelihood of mortality.

Financial Burden and Accessibility

However, even if a woman along with the rest of her community is educated by trustworthy community health leaders on breast cancer and is able to gain early diagnosis through the reduction of social stigmas and increased awareness, she still needs financial stability and access to a treatment center with an oncologist in order to receive treatment. In talking with the director of CRHP, it was discovered that theoretically most cancer treatments are supposed to be free, but a variety of other elements factor in to make it very costly.⁷⁹ The doctors who created

⁷⁶ Koshish President, 2018.

⁷⁷ CRHP Director, 2018.

⁷⁸ PTI, India Facing Breast Cancer Epidemic, 2017.

⁷⁹ CRHP Director, 2018.

CRHP stated that in the beginning of the creation of their system, “the poorest of the poor did not come to us. They had no money to pay for transportation to the hospital and no one to take care of their children at home. Their relatives could not afford to lose a day’s wages to come with them. Often, there was simply no extra sari to wrap themselves in.”⁸⁰ Transportation, lost work hours, and medication payments can quickly add up, especially for those who are less financially stable or from rural areas that are great distances from treatment centers.⁸¹ This often prevents them from receiving or seeking treatment at all.

Multiple men interviewed stated the importance of financial security in effective treatment. Most of them believed that in being wealthy, people are able to afford better care and are often more educated and aware of breast cancer. However, they believed that issues in receiving care were far more prevalent to those who were poor and in rural areas. Though treatment is free at public tertiary care facilities, challenges are still presented in time and transportation that is taken to get to the facilities for treatment. They also listed off a variety of celebrities who had breast cancer and were successfully treated due to high quality care and early diagnosis. However, most of the women that they knew personally who had breast cancer that were not of wealthy status, did not survive the cancer.⁸²⁸³

This shows the value of wealth in treatment. Even though treatment is free, and medication costs were reduced by the government of Rajasthan by 70% in 2017 (other political leaders are doing similarly), other expenses still play a huge role in breast cancer treatment.⁸⁴ If a

⁸⁰ Arole, Mabelle, Arole, Rajanikant. Jamkhed: The Comprehensive Rural Health Project. Repro Prints Pune. 1994.

⁸¹ CRHP Director, 2018.

⁸² Male 2, 2018.

⁸³ Male 3, 2018.

⁸⁴ Male 4, 2018.

patient can't afford to lose work hours and transport to the hospital, they likely will not be treated or diagnosed early enough to combat the cancer.

The lack of doctors and tertiary care centers in rural areas is a major cause for cancer patients having to travel such long distances and spend large amounts of money to gain treatment. Over 70% of India's population lives in rural locations, but 95% of India's cancer treatment centers are urban, and very few doctors travel to rural locations to provide treatment. In a WHO report in 2008, it was discovered that there is only one doctor for every ten thousand Indians, and most of those doctors (80%) work in private sectors in cities, because that is where they can make the most money.⁸⁵ A large portion of Indian doctors also travel abroad to work as doctors in the United States or elsewhere where they can make a much larger income. As seen in a visit to a Community Health Center and a Primary Health Center in Bahraich, India, limited numbers of doctors are often trying to treat huge numbers of patients that line up on benches outside of their offices. The supply is much smaller than the demand. A doctor spoken with at the Community Health Center stated that if he could have any additional resource to provide better care, it would be more medical staff. Though they had a variety of cancer tests to run on patients, they had no oncologists, and patients had to travel far away to gain access to an oncologist. The doctor spoken to in Bahraich also discussed how it is very difficult to draw doctors in to provide care to rural communities due to the lack of money and resources provided to them.⁸⁶ This creates a huge financial burden for patients in rural communities without access to treatment and doctors. Houses with cancer patients spend 36%-44% more than other houses of

⁸⁵ Shetty, India faces growing breast cancer epidemic, 992-993.

⁸⁶ CHC Doctor. Group Interview. Sep 19, 2018.

similar demographics in order to pay for treatments and travel expenses. Most families have to borrow money to be able to afford to seek treatment.⁸⁷

A female oncologist at SMS hospital stated that though breast cancer is more of a challenge in a distant rural community, it is far less common there. Though women struggle more in rural communities to receive treatment and survive cancer due to lack of education, accessibility, and finances, breast cancer rates are much lower in rural India than urban India.⁸⁸ The Director of CRHP shared similar opinions in regards to the lower rate of breast cancer patients in rural areas.⁸⁹ However, there are opportunities for the people to receive financial assistance to travel to more urban areas for care. The government has been actively working to provide more resources to make breast cancer treatment more financially and geographically accessible.

Though the government is beginning to implement financial assistance in transportation costs and loss of work hours due to travel, many people are unaware that these opportunities exist, and choose to not receive treatment thinking that they will not be able to afford it. As a village health worker stated at CRHP, women often will not seek treatment if they have children and are struggling financially due to the fact that they would rather have money to pay for their children to eat rather than to seek cancer treatment.⁹⁰ It is essential that the women and their husbands be educated on the available financial assistance in order to obtain it. The government is also working to build and provide more tertiary care and cancer treatment facilities in rural areas, but the lack of availability of oncologists and other medical professionals that work there

⁸⁷ Chakrabarty, Economic Burden of Cancer in India, 137-141.

⁸⁸ SMS Oncologist, 2018.

⁸⁹ CRHP Director, 2018.

⁹⁰ CRHP Village Health Worker 1, 2018.

is still a major problem.⁹¹ The director of CRHP as well as the president of Koshish emphasized repeatedly that everything can be free with care and treatment, but people need to be aware of it, seek it out, and have the paperwork for it. People below the poverty line can get free transportation, treatment, and medicine, but the lack of awareness and information on how to access it is limited.^{92,93}

Conclusion

As breast cancer diagnosis rates continue to rise dramatically along with mortalities in India due to environmental factors and changing lifestyles, a breast cancer epidemic occurs. It is essential that India finds a way to reduce women's health stigma, spread awareness, and create accessibility for women to be diagnosed and treated early to have a higher chance of surviving their cancer. One oncologist in a tertiary care center stated, "If women came to my clinic when their lump was one centimeter rather than ten centimeters, it would make a massive difference in their survival."⁹⁴ Therefore, researching how to overcome social stigma, to educate women and their communities, and to improve financial access to tertiary treatment is very valuable in decreasing the breast cancer mortality rate as the diagnosis rates continue to skyrocket. The most effective ways of doing this are educating both men and women on breast cancer through the use of community workers. From breast cancer survivors that build female confidence and empowerment in their own bodily health to male farmers who teach the value of women's health, finding people of similar backgrounds that the cancer patients and their husbands can relate to is essential in effectively breaking down of the shamefulness of breast cancer and increasing

⁹¹ CRHP Director, 2018.

⁹² Koshish President, 2018.

⁹³ CRHP Director, 2018.

⁹⁴ Shetty, India faces growing breast cancer epidemic, 992-993.

awareness and early diagnosis. Programs like Koshish, Jaipur Cancer Relief Society, and CRHP need to continue to educate communities. By making the information easily accessible to everyone and pushing it on both the men and women in society, social stigmas can be reduced, and cancer treatment can begin in earlier stages to increase life expectancy. Particularly people of lower education, income, and social standing need to be targeted, because judging from interviews, women of higher social and economic standings suffer less from the challenges that come with breast cancer. Hopefully, India will be able to overcome the challenges and combat the increasing number of breast cancer cases by increasing survival rates through awareness and education, so that fewer women lose their lives to breast cancer in the future.

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Limitations

One of the biggest limitations of the study was the fact that many people were uncomfortable discussing the topic of breast cancer. Due to the shamefulness associated with women's health and the sexual association of breast, many women and men interviewed were embarrassed to discuss the topic, unless they were involved in healthcare or breast cancer support/awareness. Though a list of twenty breast cancer survivors was given by Bhagwan Mahaveer Cancer Hospital and Research Center for this study to be interviewed, only two were actually willing to participate in the study. Many women feel uncomfortable being interviewed on their health. One breast cancer patient was interviewed in front of her male husband and a male doctor. This greatly decreased her openness to answering the questions. She held off on many of the questions, because she was uncomfortable answering them in front of men. However, this was valuable information for the paper, because it showed the impact of the shamefulness on women's health and contributed to the understanding of the research topic.

Another limitation was the language barrier. Due to the limited knowledge of Hindi, a translator was necessary for a few of the breast cancer survivor interviews. This caused some valuable information to be lost in translation.

There was also a limitation in the switching of organizations worked with for the project. The initial primary organization was Jaipur Cancer Relief Society. However, the organization needed to be switched after a few days to Bhagwan Mahaveer Cancer Hospital and Research Center, which took up a decent amount of time, because in switching over, applications and information needed to be processed for almost a week before interviews could begin.

Recommendations for Further Study

It is recommended that in future studies the topic of caste and socioeconomic size be addressed in analyzing patients experiences with breast cancer. Most of the people interviewed in this research were of higher socioeconomic status and from the city of Jaipur, and those of lower status were difficult to find. It would be valuable to gain the perspective of women who are breast cancer survivors in rural communities as well. Women in urban communities benefit a lot from geographical location and closeness to free resources. However, women in rural communities have very different experiences due to the lack of resources nearby and lower income to travel to them.

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