



# **6.1. Literature Review**

While cancer remains a leading cause of death worldwide, accounting for nearly 10 million deaths in 2020, the disease burden on India with a mammoth population is significantly high (W. H. Desk 2021)<sup>76</sup>. The International Agency for Research on Cancer (IARC) features that, "1 in 5 people develop cancer during their lifetime, and 1 in 8 men and 1 in 11 women die from the disease" (Cancer n.d.)<sup>77</sup>. Cancer is a generic term for a collection of related diseases which may develop in almost any organ or tissue in the body when there is an uncontrollable growth of abnormal cells formed due to alterations in DNA spread, and damage the surrounding tissues/ organs (Institute, NHI: Understanding Cancer n.d.)<sup>78</sup>. When these cells spread to other organs, the process is called metastasising, which is a major cause of death from cancer (Institute, NCI Dictionaries n.d.)<sup>79</sup>. Cancer is the second leading cause of death across the world among noncommunicable diseases after cardiovascular diseases (W. H. Desk 2021)80. According to The National Cancer Registry Programme (NCRP) 2020, released by the Indian Council of Medical Research (ICMR), it is estimated there will be 13.9 lakh cases of cancer in India in 2020, and that this number is likely to rise to 15.7 lakh by 2025—a 12% increase from current estimated cases—based on current trends, according to the report (NCDIR 2020)81 (ICMR-NCDIR 2020)82. It further adds that breast cancer will be the most common cancer in women, affecting an estimated 2 lakh in India every year; with an increase of 30% over the past decade.

According to the World Health Organization (WHO), most cancer cases are detected only in the advanced stages, when they are untreatable (W. Desk n.d.)<sup>83</sup>. Cancer remains a life-threatening disease that is fuelled by hoax cancer cures and unproven therapies that pose a severe risk to patients' lives, rather than offering them any hope. Misleading information has often allowed it to be equated with sure death in people's minds, thereby bringing about changes in people's treatment-seeking behaviour. According to the NIH National Cancer Institute, "patients using complementary or alternative medicine are more than twice as likely to die as those treated with conventional medicine" (Staff 2017)<sup>84</sup>. The Lancet's paper on oncology, fake news, and legal liability too supports the fact that patients using complementary medicine are more likely to refuse surgery, radiotherapy, or chemotherapy which have minute probability of actually saving lives (Oncology 2018)<sup>85</sup>. The National Institute of Cancer Prevention and Research further underscores that of every two women diagnosed with the disease, one succumbs to it.



Cancer, unlike other diseases, is unique in nature, i.e., while the patient wonders why this is happening to them, the disease manifests itself in more ways than one. Every cancer is unique and depends on how severe it is and what stage it is at to seek the necessary treatment. Therefore, timely screening, treatment and prevention are requisite in understanding and approaching cancer. Globally, the most frequently diagnosed cancers include lung (1.8 million, 13.0% of the total), breast (1.7 million, 11.9%) and colorectal (1.4 million, 9.7%) (Biswas 2014)<sup>86</sup>. With over 1.5 lakh new breast cancer patients recorded in India in 2018, it accounts for 14% of all cancers among women. Today, one in every 28 women (one in 22 women in urban Indian, one in 60 women in rural India) is at risk of developing breast cancer in her lifetime (C. Desk n.d.)<sup>87</sup>.

Given the complex and grievous nature of the diseases, broadly there are four obstacles in seeking proper treatment including:

Misinformation obtained largely by accessing the internet: When fact-checked, it was found that most of the videos propagating cancer treatment are mostly commerce-driven, intending to sell their products with no proven or scientific backing.

Lack of information: Most women are unaware about symptoms of breast cancer. Lack of adequate knowledge in common people with undeveloped personalities that has resulted in fear, confusion and inability to take logical decisions regarding their treatment options.

Stigma of cancer: Apart from myths, social taboos are also an obstacle in dealing with cancer. A diagnosis of cancer is a life-changing event commonly evoking feelings of shock, fear, anger, sadness, loneliness, and anxiety. The big C-word, as it is colloquially known, remains to be a taboo till date. Therefore, people who are diagnosed with cancer are often discriminated & stigmatized that in turn dissuades them from sharing their diagnosis and further seek treatment

Fear of treatment and side effects: The negative perception around cancer especially the misinformation surrounding treatment, side effects, and remission have certainly had an impact on treatment seeking behaviors. An early diagnosis of cancer and proper medical intervention would certainly lead to better prognosis and enhance the chances of disease-free survival.

Various factors such as the exorbitant price of the treatment and reluctance to deal with the side effects of standard treatment options such as chemotherapy force patients to choose unproven therapies and miracle cures that often result in deadly outcomes. It is indeed a great regret how years of scientific advancements that can result in remission and saving of lives can be easily undone by resorting to either inaction or reliance on unreliable and unscientific methods.

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#### 6.2. Common Myths and Misconceptions

**MYTH:** 

Cancer is almost and always fatal.

01

**FACT:** Not all cancers are fatal. While survival rates have been improving over the years, mortality depends on other factors like detection stage, type of cancer, parts of the body affected, etc. In fact, improved treatment options have made it possible for thousands of patients to be cured of the disease.

**MYTH:** 

All cancers can be contagious.

02

**FACT:** Apart from cervical cancer (caused by human papilloma virus) and liver cancer (caused by hepatitis B and C viruses), none of the other forms of cancer are contagious.

**MYTH:** 

Lung cancer is prevalent only among smokers.

03

**FACT:** Smoking undoubtedly increases the risk of lung cancer, but other pertinent factors like heavy exposure to asbestos, radon, uranium, arsenic, genetic pre-disposition, passive smoking and lung scarring from any prior illness can all lead to lung cancer.

MYTH:

Every abnormal growth is cancerous.

04

**FACT:** Benign tumours do not possess the capability to metastasise. In case of any clinical problem, these can be surgically removed.

MYTH:

Cancer is predominantly a hereditary disease.

05

**FACT:** Genetic predisposition is an important factor that contributes towards development of cancer, but all cancers are not hereditary. Only 5-10% of all cancers are attributed to genetic defects and the remaining 90-95% result from environment and lifestyle (Preetha Anand 1 2008)<sup>88</sup>.

MYTH:

Sugars feed cancer.

06

**FACT:** Sugar consumption does not directly imply the spread of cancer. Excess intake of sugar can lead to obesity and can, therefore, enhance the risk of cancer. (Biswas, 2014)\*\*.

MYTH:

Biopsies and surgery aggravate cancer.

FACT:

Bioposies are one of the most effective detection tools for cancer. It is a safe procedure that provides valuable information on the cancer diagnosis and also enable doctors to tailor the treatment. (Biswas, 2014) 6.

**MYTH:** 

Drinking hot lemon water or three spoons of organic coconut oil daily in addition to not taking sugar can cure cancer.

08

FACT: No research studies were found to substantiate the claims of curing cancer with a sugarfree diet, and drinking hot lemon water and organic coconut oil.

MYTH:

Supernatural factors and ill fate influence cancer.

09

FACT:

People often attribute an illness to supernatural factors, ill fate and witchcraft. These affect the wellbeing of patients due to delay in decision-making and seeking medical care.

MYTH:

Cancer research is fruitless.

10

FACT:

Oncology, the study and management of cancer, is the fastest evolving branch of modern medicine today. Though the cause of cancer is still a mystery, the advanced interdisciplinary research has increased the scope of fighting the disease. Cancer research has brought in a number of new molecules that have helped to blend the targeted therapy, hormone therapy along with better surgical options, radiotherapy and chemotherapy to improve the disease-free survival of cancer patients (Biswas, 2014) 6.





# 6.3. Case Study- Tragic Demise of Malayalam Actor after Prolonged Battle with Cancer

In 2016, Malayalam actor Jishnu Raghavan passed away after battling cancer for two years. Having suffered from throat and lung cancer, the actor battled between hope and despair but unfortunately lost the battle to a vicious relapse. As in the case of famous personalities, actor Jishnu too was offered a lot of advice that included unscientific cures, personal anecdotes and wishful thinking that did not necessarily align with Western medicine.



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He attempted different remedies like local traditional plants including Lakshmi tharu (simarouba glauca) also known as the paradise tree and Mulathu/Mulethi (graviola). He took to Facebook to share his experience with his fans about how the belief-driven and not scientifically endorsed cures put him in a precarious spot. He left a note saying while altruistic suggestions of the loved ones are one thing, holding out any expectation of cure is another thing, especially when one is battling for life.

With its origins in Central & South America, Lakshmi tharu or the paradise tree found in parts of Kerala and Karnataka is believed to treat the side effects of chemotherapy, certain malignant cancers, dysentery, malaria, etc. Mulethi or liquorice root, on the other hand, is a sweetening agent used for medicinal purposes to cure various issues including sore throat, hair loss to now cancer, and is endorsed by Ayurveda and Chinese medicine. While these indigenous plants and roots do possess medicinal properties and consuming the concoctions can provide a certain relief to the effects of the aggressive treatments, there is no scientific evidence to prove that they will cure the disease, in this case, the cancer itself.



In fact, although most oncologists are on board with patients seeking traditional/alternate treatments to recuperate and boost their immunity, they have always cautioned that the traditional remedies must complement and not replace actual scientific treatment. As in the case of every cancer patient battling the disease, to quote journalist and cancer survivor Chitra Subramaniam, "Science matters in cancer treatment, so does faith and in that order" (Subramaniam 2016)<sup>89</sup>.

Jishnu's cancer diagnosis was a misfortune and that is perhaps what incited his fans to prompt traditional medicine. However, Jishnu Raghavan advised caution to his fans against raising false hopes and expectations.



# 6.4. Experts Speak



#### DR GEETA KADAYAPRATH

She is a surgical oncologist with over two decades of experience, specialising in breast cancer surgery. Dr Geeta pioneered the establishment of sentinel lymph node biopsy and oncoplastic breast surgery as standard procedures in Max Hospital. She has spearheaded the formation of Breast Support Group, a forum that extends 'Care Beyond Cure' to breast cancer patients twice a month.

### DR VINAY DESHMANE

He is a surgical oncologist and a specialist in breast cancer. He is the Medical Director of the Indian Cancer Society, and the editor of the Indian Journal of Cancer. He is amongst the first to have developed a specialised breast cancer treatment centre in the country. He has pioneered the development of breast endoscopy and oncoplastic breast surgery in the country. He is associated with the Breach Candy Hospital Trust, P. D. Hinduja Hospital and the Asian Cancer Institute, and has an experience of over 30 years in this field.





01

Of all the major ailments and diseases, cancer is often associated with immediate fear and imminent death. What are the things that people should know/be wary of?

Dr Deshmane: It is natural to be scared when you hear the word cancer, the big C as it is known. This is a natural phenomenon; you are scared of things you don't know. While everyone hears about cancer, it doesn't mean that every family has had or will have a patient with cancer. Cancer does not happen overnight. Cancer is basically an uncontrolled growth of cells similar to a software problem in your cells. Each cell has a normal lifespan; it grows, multiplies, divides. And when its function is completed, it dies. In cancer, the cell doesn't die. This is generally a very slow process, because our body has protective mechanisms. When things go wrong at the cellular level, they are corrected. It is when these mechanisms that protect us fail, that the cells start multiplying and become cancerous. This process takes many years. So, it is important to realise that cancer does not necessarily mean imminent death; there are so many treatments that are available. Detecting it early, and treating it effectively allows you to live a good, long life. And if caught early, one can lead a normal life doing practically everything that one wants.

**Dr Geeta:** Cancer has got these negative connotations, and this is something that has been handed over from generation to generation. But the fact is that the information that things have changed in these areas has not percolated down as quickly as this misinformation has that cancer means imminent death, which is untrue. And once you're diagnosed with cancer, what happens is there is a lot of panic and the panic essentially arises from the fact that most people go about with this notion that cancer is not curable; that whatever you do, it will come back and you just have a few months or a year or two years. And in many cancers, things have changed dramatically.

So, one thing I would suggest is that if someone is diagnosed with cancer, panic should go out because otherwise what happens is that any decision that you make in that state of panic is likely to be wrong, or incomplete, in the sense that the time that is spent to understand what is happening with this disease is very, very important. Broadly speaking, when you're diagnosed with cancer, there are three elements to it. The three stages of cancer treatment are diagnosis, followed by pathology and staging, and then treatment.



Misinformation about cancer in several local languages is far more accessible to common people than authentic information. As doctors, how do you address these myths and guide the patients or their loved ones in the right direction?

**Dr Geeta:** There is a lot of information online and patients usually come armed with some information. But as doctors, we have to put everything into perspective and tell them what the right way to move ahead is. So, the myths can start from the time of doing a biopsy or not doing a biopsy; patients think that a biopsy means that the disease is going to spread. But that is not true. For instance, in breast cancer, biopsy is the start point. You must have a diagnosis before you can decide how to deal with it. But there are other cancers where you should not do a biopsy, like in the cases with gallbladder or ovarian cancer, where you should not stick a needle. This common misconception about biopsy makes patients procrastinate, so they don't have a diagnosis, which in turn leads to delayed treatment. And obviously, the outcome also suffers in the bargain. Then there is also this myth that those without a family history of cancer

will not get the disease. But one should understand that family history and genetics contribute to only 5-10% of cancers and that the remaining 80-90% of cancers occur without a reason, what we call sporadic cancers. Therefore, the important thing is once you know that there is something wrong, you should visit your doctor and seek advice, which is where the balance is going to be. And that is where you're going to make your decision on how to go ahead with treating the disease. One thing that one should know about cancer is that your first chance is your best chance. And you should not whittle it away by spending time, energy and money on so-called magical cures and not getting anywhere and then finding yourself in a position where you will feel very disadvantaged and not able to get the kind of outcomes you could have had, had you gone to the right place at the right time.

03

What are your views on alternative medicine to counter cancer, especially when people are intimidated by surgery and chemotherapy? How should people go about seeking the right kind of treatment?

**Dr Deshmane:** In a place like India, where all of us grow up with alternative medicine and it is a way of life for many people, most of our patients will, at some point, take alternative medicine, because where there is hope, people tend to reach out for that hope, and alternative medicine offers that promise. There are patients who delay their treatment and take these treatments for a period of four to six months and only when they do not find an improvement, they return to allopathic treatment. But unfortunately, in some of these patients, the tumour advances, and what could have been treated more effectively has to be treated more aggressively. I'd like to say that if there is any truth that any of these treatments have been highly effective, then it will be a matter of practice all over the world. So, if there is any magical substance out there in alternative



medicine, the success of such a practice would have spread like wildfire. And in today's era of instant communication, no one can put a lid on it. So, yes, most patients will opt for alternative medicines. I personally don't have anything against people taking alternative medicines as long as they also follow what is accepted, proven medical treatment at the same time.

04

Breast cancer is the number one cancer that affects women of all age groups and across economic strata. How can women be wary or more aware of this given that there are home-based tests?

**Dr Geeta:** Even today, 70% of our breast cancers are picked up in advanced stages. So, our challenge is to reduce the number of stage fours that we see and bring them to a stage two and to convert the number of stage threes to stage ones. And that is possible only if women are aware of their own breasts. Therefore, breast self-examination, I would say, although very underrated in the West, is of prime importance for a population like ours, where access to screening mammograms is poor. So, you should be doing a breast self-examination every month.

The trouble is that our women are so loath to touching themselves, and it is only when the disease is so big and visible that they come to the doctor. So, getting into the habit of examining yourself once a month, three days after your periods are over in those women who are having their periods is very important. Familiarising yourself with your breasts essentially means that you will be able to pick up an abnormality if it were to happen. And for those women who have stopped having their periods, they can possibly start examining themselves on the first of every month or a day that coincides with their birthday or anniversary. The essential idea is that you do it diligently and regularly every month. So, this is a weapon that you have in your hand, and this is what can bring about early diagnosis as far as breast cancer is concerned.

**Dr Deshmane:** As you rightly said, it affects women across economic strata. And what's really been happening in the last two to three decades is that because of rapid urbanisation, we are seeing a larger number of breast cancers. However, the good news is that it can be treated extremely effectively, without removal of the breast, and it is possible to live a long life if you detect this cancer early. The easiest way is to do something called breast self-examination, which simply means that you get used to the feeling of your own breasts by palpating it once a month. The best time is that after your periods, and if you feel any lump in the breast, which persists despite having one or two periods, then you should seek a doctor's attention. The other way is by undergoing mammography. Mammography is an effective tool for diagnosing early cancers. There is something called a breast MRI, which may be used in women who have a significant family history and in young women with dense breasts. Only 7-10% of breast cancers are related to transmitted breast cancer genes. These genes are transmitted through families and cause the basis for these cancers. So, most cancers in the community are sporadic.

05

As someone who treats cancer patients, how should patients go about seeking treatment from the starting to the end and eventually get better and overcome this disease?

Dr Geeta: Being in a positive frame of mind is a huge plus; I am a witness to that because I run this breast support group in my hospital. And I've seen my patients thrive on the kind of positivity that emanates out of that group. This feeling of isolation and loneliness and feeling singled out as that one person who's got cancer goes when they interact with so many other women who've had cancer and see how they bounce back and live life much better than what they used to before cancer. The tips that they share, the positive vibes that they share, the kinds of modifications that they have brought to the lifestyle that they share, the kind of things that they do to fill themselves with positivity that they share it's a kind of hand-holding that not even a clinician can do. Because it makes more sense for a patient to hear from people who've been through the experience. I always tell my patients that they have to take one step at a time. So don't think that it's going to be eight-and-a-half months of torture, or one year of torture. Don't plan too much into the future; just focus on doing one thing at a time. It is important to focus on the treatment because you must realise that your goal and my goal at the end of it is the same and that is to get past this disease and cure you of the disease. And whatever it takes to get there, we have to commit ourselves to doing it.

06

What do you think is the way forward in debunking cancer-related misinformation? How should we sift the facts from the myths that are widely available both online and offline?

Dr Deshmane: I think the most important aspect is for patients to start understanding what cancer is. They are bound to read like everybody now reads on the internet, or tend to ask family and friends, but when they hear things, they must run these past their doctor. Only experts can help you sift the fact from the myths. They must also realise that common sense will always tell us that if there is something which is working, or highly effective, this sort of a truth especially related to cancer cannot be hidden anywhere in the world today. Everyone would get to know of it; it would have been in the newspapers and mass media by now. In fact, every few months, you will hear something about a magical drug coming up and then you don't hear too much of it later. So, there's always a new treatment on the block but again, most of these therapies, treatments, and alternative medications have not stood the test of time. So, it is very important to be logical in your thought process. Have belief in your doctor and trust in them. Finally, it is most important to realise that cancer can be cured or treated very effectively if detected early. So, listen to your body, and if there is something which worries you, seek medical advice.





#### 6.5. Conclusion

Cancer research has made a lot of progress over the past few decades and continues to do so today. Yet, cancer-related misinformation percolates to people through both online and offline vectors. Given how simple the images read or the videos play to convey the inaccuracies, especially to people who are looking for that one ray of hope, misinformation has proved to be influential in patients seeking treatment and their behaviour. Therefore, there is a massive need to be tuned in to this conversation as cancer can happen to anyone, and so, having the right information becomes crucial in the fight against it. As such, believing false information has many harmful effects, especially given the fatal nature of the disease. The complexity and diffusion of misinformation ranges from word-of-mouth to magical cures or herbal remedies to science journals based on a germ of truth or possess a minute anti-cancer characteristic. However, one must be careful to not fall for these unscientific treatments and lose time by replacing a more established and scientific treatment. As Dr Geeta Kadayaprath says,

Your first chance is your best chance. And you should not whittle it away by spending time energy and money on the so-called magical cures and not getting anywhere and then finding yourself in a position where you will feel very disadvantaged and not be able to get the kind of outcomes you could have had had you got to the right place at the right time.

The antidote to uncertainty is awareness. Dr Vinay Deshmane pitches in,

Awareness is the first step to tackle the challenges of cancer. Being aware of the body and symptoms would mean early detection which in turn implies effective and less aggressive treatment. The last block of this chain would only suggest the inverse relationship of effective treatment and death rates, i.e., more effective the treatment,

fewer will be the deaths due to cancer.

Added to this would be the role of the medical fraternity, governments, fact-checkers and social media giants to ensure and promote the visibility of public-health campaigns related to cancer, especially preventive measures and risk factors. While it is true that misinformation enjoys broader coverage than fact, the public must be educated to verify online and offline cancer misinformation by pushing the accurate content through relevant public-health communication.