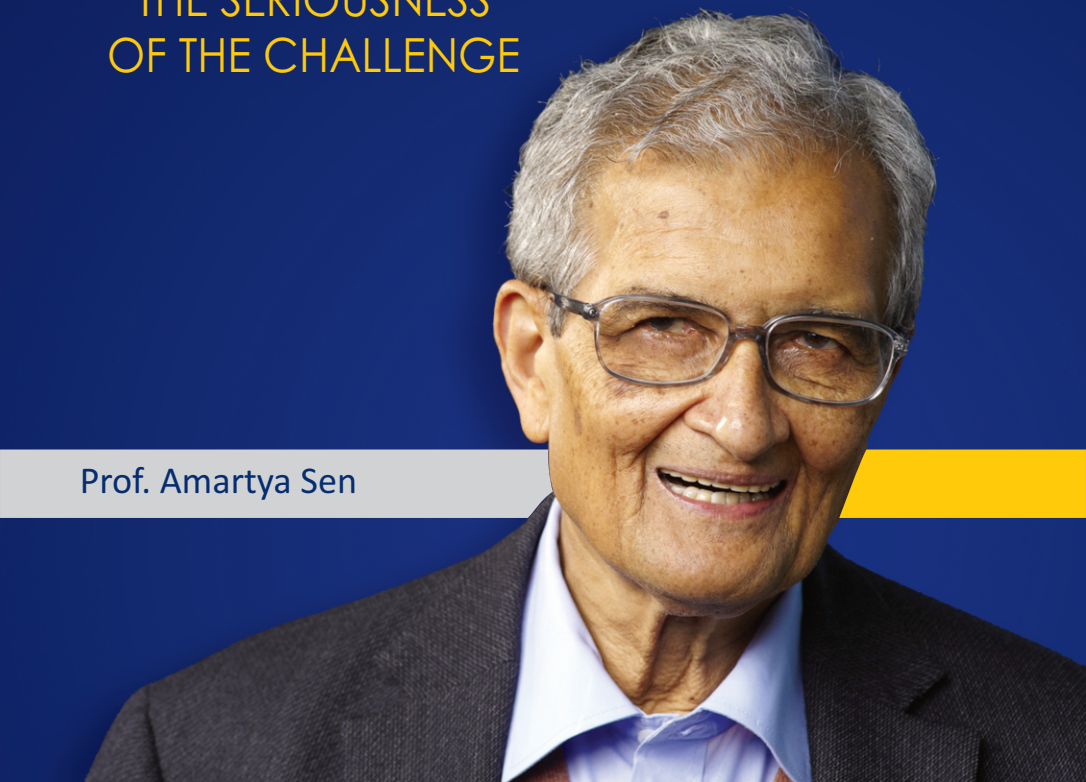
CFI FOUNDATION LECTURE 2012

Cancer Foundation of India

CANCER IN INDIA

THE SERIOUSNESS OF THE CHALLENGE



Prof. Amartya Sen

Cancer Foundation of India

2nd CFI Foundation Lecture

January 2, 2012

Prof. Amartya Sen

Harvard University, USA

CFI Foundation Lectures

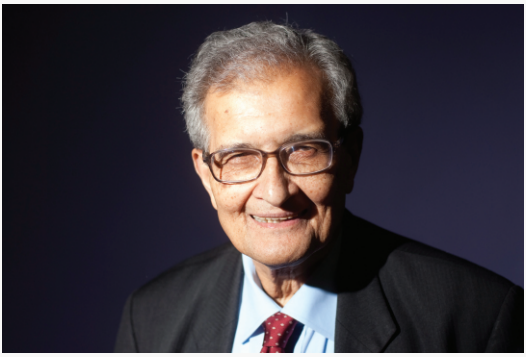
In order to motivate and enlarge civil society participation in the spectrum of issues related with cancer prevention and control in the country, CFI started a series of **Biennial Foundation Lectures** in 2009**.** These are public lectures to be delivered by persons of high eminence who have distinguished themselves in various activities of human endeavour impacting the cause of alleviation of pain and suffering from cancer.

Along with the Biennial Foundation Lecture a **National Symposium / Seminar** is organized on a subject matching with the accomplishments of the Foundation Speaker. The basic objective of such convention is to bring together various stakeholders such as young medical scientists, health care professionals, academicians, policy makers and industry representatives to update and deliberate on a subject related to cancer and discuss future strategies towards developing holistic dispensation of prevention and cure of the disease in India.

The 1st Foundation Lecture was delivered on 3rd December 2009 by **Prof. Harald zur Hausen, Nobel Prize winner in Medicine 2008,** of German Cancer Research Centre (DKFZ), Heidelberg, Germany. He spoke on ***"The search for infectious agents in human cancers: a continuous challenge"***. Prof. zur Hausen also gave the keynote address at the *Symposium on Cervical Cancer Control in India*, linked to the Foundation Lecture.

The 2nd Foundation Lecture was delivered by **Prof. Amartya Sen**, **Nobel Prize winner in Economics 2002,** of Harvard University, Cambridge, USA, on 2nd January 2012 who spoke on ***"Cancer in India: The Seriousness of The Challenge"***. Prof. Sen also chaired the *National Seminar on Economic and Social Impact of Cancer in India*, linked to the Foundation Lecture. CFI is indebted to **Anil Srivastava** of Open Health System Laboratory, USA for his constant support and encouragement in holding the lecture.

The Foundation Lectures are supported by generous donations from sponsors and donors.



Prof. Amartya Sen

Prof. Amartya Sen was born in Santiniketan, where his maternal grandfather (Kshiti Mohan Sen) used to teach Sanskrit and ancient and medieval Indian culture. After his schooling at Santiniketan, he studied at Presidency College in Calcutta for his B.A. degree in Economics/Mathematics (1951 to 1953). He moved to Trinity College in Cambridge in 1953, and later while doing research for Ph.D, he took time to be in Calcutta. He was appointed to the chair of economics at the newly established Jadavpur University when he was only 23. On a Prize Fellowship he again joined Trinity College and continued research until he joined as Professor of Economics at Delhi School of Economics, University of Delhi where he published his book *Collective Choice and Social Welfare* in 1970. He left Delhi in 1971 to further his research on *social choice theory* at London School of Economics. In later years he taught at Oxford University and Harvard University and also on a visiting basis, at M.I.T., Stanford, Berkeley and Cornell Universities. During this period he published *Poverty and Famines: An Essay on Entitlement and Deprivation* in 1981*, Inequality Reexamined* in 1992 *and Quality of Life* in 1993. He was awarded the 1998 Nobel Prize in Economic Sciences for his contributions to welfare economics and social choice theory and for his interest in the problems of society's poorest members. He received *Bharat Ratna* from the President of India in 1999.

He is currently the Thomas W. Lamont University Professor and Professor of Economics and Philosophy at Harvard University. He is also a senior fellow at the *Harvard Society of Fellows*, distinguished fellow of *All Souls College, Oxford* and a Fellow of *Trinity College, Cambridge*, where he previously served as Master from 1998 to 2004. He is the first Indian and the first Asian academic to head an *Oxbridge* college.

CANCER IN INDIA: THE SERIOUSNESS OF THE CHALLENGE[1]

Amartya Sen

1

J.B.S. Haldane the magnificent scientist and the great geneticist - wrote a poem on cancer in 1964 in Calcutta. He was suffering from rectal cancer himself and died of it in December of that year. Haldane's remarkable poem, which was published in New Statesman, on February 21 of 1964, partly served the purpose, I imagine, of keeping Haldane's spirits up, not with blind affirmative faith but with critical reasoning (as indeed we would expect from Haldane), but it also presented some basic features of cancer as a human problem. I take the liberty of dedicating this lecture to the memory of Haldane whom I came to know after he moved to India - to the Indian Statistical Institute in Calcutta - in 1956. I returned from Cambridge at about the same time, with the unlikely challenge at a young age (I was then 23) to set up a new Department of Economics at Jadavpur University. I did my best to try to fulfil the difficult task I was given, and I was very fortunate in receiving good advice from J.B.S. and his wife, Helen (among other advisors who also helped me).

[1] *Text of the second Foundation Lecture of the Cancer Foundation of India, given in Calcutta on January 2, 2012. For helpful conversations, I am grateful to Sudhir Anand, Lincoln Chen, Abhijit Chowdhury, Albina du Boisrouvray, Prabhat Jha and Felicia Knaul. I would also like to thank Dr. Urmi Chatterjee for her generous remarks in introducing me at the lecture-meeting, and Professor Maqsood Siddiqi for kindly inviting me to give this lecture.*

J.B.S. was, of course, a towering figure in genetics and in the sciences in general, and had an overwhelming commitment to help widespread dissemination of scientific knowledge and understanding. Haldane had tremendous faith in the future of India, and became an Indian citizen shortly after he came to Calcutta. His political approach was distinctly left of centre and it was powered by a passion for equity and justice (in my youthful way, I found a kindred spirit there). We get very few opportunities to meet a person whom we can admire wholeheartedly, in absolutely every way, and for me, J.B.S. Haldane was one of the few I can easily place in that extremely narrow category.

In this lecture, I shall try to follow Haldane's insistence on seeing the natural and the social sciences in an integrated perspective, and the basic theme of my lecture today is what I would like to call the "social epidemiology" of cancer. I have been told that social epidemiology is not an attractive term, and I think that is a correct diagnosis, but it is descriptive enough for what I want to talk about. I will try to say something on the epidemiology of cancer seen from the social perspective, including, of course, medical understanding, but a lot more, particularly about the nature of the society in which the so-called the "emperor of all maladies" (a fitting description of cancer chosen by Siddhartha Mukherjee) flourishes.

2

Haldane's poem about cancer began with this opening verse:

Cancer's a funny thing:
I wish I had the voice of Homer
To sing of rectal carcinoma,
This kills a lot more chaps, in fact,
Than were bumped off when Troy was sacked.

Haldane was certainly right that various forms of cancer kill many more people in most places on earth than are killed by violent deaths generated by conflicts.

Cancer is not, of course, the biggest killer in India. It is, however, difficult to be sure about the incidence of cancer and of cancer deaths in India because of the incompleteness of our data base. In many poor families, especially in rural India, when people are afflicted by some serious malady, they typically have only a vague awareness of the nature of the ailment. The absence of a comprehensive treatment network in the country also goes with the absence of an adequately complete data base of diagnosis and follow-up.

Cancer has often been seen as a disease that is particularly important in rich

countries. In India the focus of epidemiological attention has traditionally been on other types of medical adversities that kill with abandon on a regular basis across the country - from cardiovascular and diarrhoeal diseases to respiratory infections. There is, in fact, a common presumption that in a poor country where people do not very often live to mature ages, and the forces of mortality come mainly from diseases of the young, and particularly from communicable diseases, cancer is relatively a smaller threat than many other common diseases that afflict a poor and relatively young population. Partly as a result of this presumption, fighting human deprivation tends to be seen as requiring a concentration on other diseases, and the focus of medical attention for the poor often tends to be elsewhere than in cancer diagnosis, cancer prevention, and cancer treatment. The reasoning behind this sense of priority is easy to see. And yet this way of thinking about the problem may well be deeply defective.

First, many cancers hit the young and not just the old. There are of course specific types of cancers to which the young are particularly vulnerable. And there are also relatively young people who fall victim to standard forms of cancer, even though the incidence of these cancers typically rises with age. In my own case, when it became clear at the age of 18 that I did have squamous cell carcinoma on the roof of my mouth, it would have been futile for me to grumble that as a young person I should not have got it. I had the disease and needed the treatment, and I was fortunate enough to get ultimately an effective radiational treatment which - no matter how draconian - seemed to have eliminated the disease.

However, getting the diagnosis was not at all easy: indeed it took all my youthful energy (I was then an undergraduate at Presidency College in Calcutta) to persuade the doctors, beginning with my general practitioner, to persuade them to take

seriously my initially self-diagnosed cancer (diagnosed with the help of examining the unusual lump on my palate and reading books on cancer that a fellow resident at the YMCA hostel, who was a third year student in medicine, got for me from the Medical College library).

Second, even though the preponderance of young people often gets the spotlight in discussions about the composition of the Indian population, the age distribution of the Indian people is not as unusual in the world context as it is sometimes taken to be. There is also increasing life expectancy in India, which is associated with the presence of a larger number and proportion of the relatively old. Even though life expectancy in India is unnecessarily low because of the chaos in our health care system and the limited reach of reliable public health care, it is still well above 64 years already. Parts of the Indian population are, thus, very much in the age group for which the incidence of cancer tends to be sharply rising with age. And that demographic phenomenon will intensify quite rapidly over the future years, especially if a more sensible health care system is pursued by the administrative - and ultimately political leadership, thereby expanding the life spans of Indians.

The third reason for paying attention to cancer in India arises from the fact that there are widespread conditions that tend to be conducive to the development of cancer, even among the Indian young, such as smoking and the chewing of tobacco. Some statistics seem to indicate that about 40 per cent of cancer deaths occurring in India for people in the age group between 30 and 69 are tobacco related.[2] The ways and means of behavioural re-examination have to be a part of responsible

[2] *I am thinking of an unpublished paper by Rajat Dickshit and others, including some people present here today, such as Prakash Gupta and Rajendra Badwe. My understanding of this problem draws a lot on the research work of Prabhat Jha and my conversations with him.*

health policy, including that for cancer, and this avenue of change, through a variety of means, including education, advocacy, incentives and public discussion, could save a huge number of lives and reduce much pain and suffering.

Even as smoking has sharply declined in richer societies such as the United States, it has become more and more prevalent in many of the developing countries, such as China and India. There have even been some predictions based on fairly respectable data that there is the possibility that - unless the present trends towards the intensification of predisposing conditions such as greater smoking in developing countries is reversed - cancer may soon become the leading cause of death in the world. But even as matters stand now, the toll of cancer is extraordinarily large not only across the world, but even in India. It may well be that only about 6 per cent of the deaths that currently occur in India is directly attributable to cancer, but that is still a very large medical challenge, and the size of that challenge is steadily growing.

A fourth reason is that, contrary to the view that is often prevalent in popular imagination in which cancer is often seen as a death sentence, treatment can, in many cases, make a gigantic difference. And in order to get the benefit of what is offered already by science, and to keep pace with the progress of scientific knowledge in medicine, we need a good understanding not just of science (and of the pure knowledge of medicine, crucially significant as it is), but also of the social conditions related to diagnosis, prevention, treatment, care, and rehabilitation. And these are among the central concerns of the social epidemiology of cancer.

3

Public attitude to cancer is itself a very significant variable in the management and alleviation of cancer. There is some inspirational thought in Haldane's poem about cancer.

I know that cancer often kills.
But so do cars and sleeping pills;
And it can hurt one till one sweats,
So can bad teeth and unpaid debts.
A spot of laughter, I am sure,
Often accelerates one's cure;
So let us patients do our bit
To help the surgeon make us fit.

Haldane may have overestimated the medical value of a positive attitude: I have seen contrary statistical evidence on how much or how little difference can be made by mental resistance. I have seen benefits of it even in terms of bearing the burden of treatment in some actual cases, including in my own life: I don't think I could have easily gone through the rigours of 8,000 rads in the mouth (receiving the radiation through holding a lead case with a radium mould inside my mouth for five to six hours a day for seven days), not to mention the damage to normal tissues

flesh and bones that goes with the imprecisely targeted nearly lethal dose of radiation. I have also seen cases in which the most positive and defiant of attitudes did not ultimately help at all (this I saw when my late wife, Eva Colorni, succumbed to stomach cancer in 1985 after an extraordinarily fought battle with a remarkably high spirit that never deserted her). But even if Haldane was too optimistic in thinking that successful treatment of cancer would be materially helped by an affirmative and cheerful attitude, it certainly makes the experience of treatment and its aftermath bearable in a way that pessimism cannot deliver.

This is perhaps not as minor a point as many people, including some medical practitioners, tend to think. Our life consists of a sequence of experiences, and the period of treatment is a part of that sequence. So what we have to look for is not merely the "end result" of whether or not we die from the disease that afflicts us, but also for the life that we lead even as we are battling with our affliction. Or to put it in another way, we have reason to be concerned not merely with the life after our battle with cancer - if there is any life there - but also with the life during the battle, which can in fact be quite a prolonged period. This is not the same thing as singing the praise of palliatives only - though reduction of pain and suffering is certainly tremendously important - but to value the quality of life over one's entire life span. Indeed, the frequent emphasis on some treatment being "only palliative" may well be less conducive to a good life than focusing the attention on people's overall experience, including their concerns and anxieties, their fears and hopes. And Haldane was definitely right to see the role of laughter as a part of the battle against cancer.

4

Let me, however, move away now from the psychological side of the social epidemiology of cancer, without letting it go out of our sight altogether. Given the short time available for this lecture, I cannot hope to provide anything like a comprehensive discussion of social epidemiology of cancer, but it is important to sketch out a few of the salient points.

The relevant issues must include, first, the habits and customs of social life to the extent that they expose us to the dangers of cancer of different kinds. Here smoking is an obvious concern, as is the chewing of tobacco, which I understand is expanding in India, rather than declining. This is such an obvious issue that I need not labour the point, but I should draw attention to an error in reasoning that is often repeated. The point is frequently made that the government must not limit the right of the individual to lead the life he or she wants, so long as the choices made do not reduce the freedom of others. That admonition, in its general form, may be both wise and important. However, we have to recognise the fact that smoking influences the lives of others not just through forcing proximate people to what is called "passive smoking," but also through the medical cost of the treatment of diseases that tend to result from smoking, such as cancer. When the cost of medical treatment is borne by the state directly, the connection is obvious, but even with

private treatment the implicit subsidy provided by the state in supporting the medical infrastructure can be quite large. That may not be reason enough for prohibiting smoking, but the case for strong discouragement (through means such advocacy and taxation) is not something that even such defenders of liberty, as John Stuart Mill, would have found difficult to accept.

A second social concern is the importance of education in general and of medical understanding in particular. So many carcinogenic connections are so imperfectly known that a focusing on the importance of public discussion must be an important need. The neglect of basic education in India, about which we have reason to complain for other reasons as well, has a clear connection with battle against cancer.

A third issue is the need for environmental policy and public discussion on it, including the impact of pollution on our lives in general. This issue too relates to public discussion, since such questions as the necessity of dealing with arsenic in our water, or tar in the air, demand a public engagement, both for guiding our individual life styles and for inducing the public authorities to do what needs to be done to making the environment that surrounds us more friendly rather than hostile.

A fourth concern is the system of health care delivery. India has moved quite prematurely to dependence on the private sector to provide our basic health necessities. While we have emulated post-reform China, with some success, in trying to make gainful use of the global market economy, we tend to overlook the fact that despite China's market-oriented priorities, it has been much more committed - after some initial vacillation - to providing basic health care services

through the public sector. The fact that China devotes 2.7 per cent of its GNP to government expenditure on health care, compared with India's relatively miserable 1.2 per cent, is directly relevant to the significantly higher health achievement of China compared with India: for example it contributes to China's higher life expectancy than India's (life expectancy is estimated to be 73 years in China compared with India's relatively lowly 65 years). One result of the relatively low allocation to public health care in India is the development of a remarkable reliance of many poor people across the country on private doctors, many of whom have little medical training, if any.

Since health is also a typical case of "asymmetric information," when - in particular - the patients may know very little about what the doctors (or "supposed doctors") know and what the doctors give them for their ailments, the possibility of fraud and deceit is very large. In a study conducted by the Pratichi Trust - a public interest trust that I was privileged to set up in 1999 with my Nobel money - it was found that there were many cases of exploitation of the poor patients' ignorance of what they are being given to make them part with badly needed money to get treatment, which they often do not end up getting. This is a result not only of shameful exploitation, but ultimately of the sheer unavailability of public health care in many localities around India.

India has moved towards reliance on private health care without developing the basic rock of support of basic public health facilities that state health care can provide - and which have been the main force behind every successful health transition across the world - from Britain to Japan, from China to Brazil, from South Korea to Mexico. Even within India, there is a world of difference between (1) the

use of the auxiliary facilities of private health care to enrich a reasonably well functioning state system (as is successfully used in Kerala, where the share of private health care has gone up with the prosperity of the population, but always supported by the solid base of public health care available to all), and (2) trying to rely on private health care when the state provides very little in terms of health facilities (as in the so-called BIMARU states of Bihar, Madhya Pradesh, Rajasthan or Uttar Pradesh).

There is a word of caution in the modern literature on asymmetric information even about trying to make up the gap by subsidizing private health care or trying to provide private health insurance, since the problem of profit-seeking market transaction with very unequal - and asymmetric - knowledge of medical conditions is not a matter only of economic poverty. The diagnosis of cancer as well as the treatment of it demands more humane - and more intelligent - use of the state in collaboration with the market, and the present system of overreliance on the market for health care applies as much to cancer as it does to many other maladies from which the Indian population suffers.

Fifth, the adversities of poverty are pervasively relevant to the curse of cancer, since people who suffer from serious social and economic deprivations tend to be hit much harder by cancer. This happens in a variety of ways: through their lack of opportunity to have regular medical check ups, through their inability to arrange and pay for the needed diagnostics and for reliable medical advice, through their lack of means for securing appropriate treatment, through the unaffordability of expensive drugs, and through the lack of freedom of the poor patient to withdraw from normal duties of job, family work or child care in order to concentrate on treatment and healing.

Since, contrary to an often-repeated belief, most cancers in the world occur in relatively non-rich countries, the challenge of cancer in the presence of general economic and social deprivation is quite central to the battle against cancer in the world. This applies inter alia to breast cancer as well, and in as I shall presently discuss, the penalty can, in fact, be much larger for the cancer of the breast - or of the cervix - because of the coupling of the hardship of poverty with the handicap of gender inequality. It is striking that while the ratio of fatality to the incidence of breast cancer is less than a quarter for what the World Bank calls "high income countries" (the ratio for 2002 is reported to be 23.9 per cent), that ratio is substantially more than one half in "low income countries" (the actual fatality ratio, as given by the World Bank for these poorer countries, is 56.3 per cent).

5

If poverty is a big factor in dealing with cancer, so is gender asymmetry, with unequal opportunities for women. Let me now turn from poverty and deprivation in general to the relevance of gender-based deprivation in particular. While inequality between women and men has many different manifestations, one feature that applies in one form or another to women, particularly in developing economies, is typically a far less acute social awareness of their ailments compared with those of men. There is quite a literature on this for many countries in the world, to which I have tried to contribute myself. When I began my own research on this subject more than a quarter century ago, I was very struck by some extraordinary findings in the hospital admissions data that we studied from two large public hospitals in Bombay. There was definitive evidence that the women just admitted were typically far more ill than men, and girls very much more sick than boys, yielding the inference that a woman has to be much more stricken before she is taken to the hospital.[3]

In another study, dealing with the morbidity of women in a situation of health adversity, in fact in post-famine Bengal in 1944 (for the region of Singur), I

[3] *See my joint paper with Jocelyn Kynch, "Indian Women: Well-being and Survival," Cambridge Journal of Economics, 7 (1983), and also Resources, Values and Development (Cambridge, MA: Harvard University Press, 1984).*

encountered the remarkable fact that in response to a questionnaire about their health, widows hardly reported any incidence of being in "indifferent health" whereas widowers (the men involved) complained massively - more than 45 per cent - about being in just such a health predicament.[4] Since there was not much external evidence that women were in observably less ill state than men, the explanation of this difference in the respective responses has to be sought elsewhere. Indeed the attitudinal difference involved has a direct relevance to the seeking and getting of medical attention.

A second influence in the direction of underrecognition of women's predicaments is the strong cultural feature of discouraging women from expressing their views in general and their concerns in particular. When I encountered the silence of women on their health conditions in post-famine Singur, I remember being reminded of the advice that came from one of the characters in Jane Austen's Northanger Abbey: "A woman especially, if she have the misfortune of knowing anything, should conceal it as well as she can." Breast cancer can flourish much more easily when women are discouraged, in one way or another, of sharing their concerns - and legitimate fears.

I should add here that while poverty and gender each contributes individually and separately to the adversity of cancer, the impact of the two together can be quite devastating because of the coupling between the two, particularly in socially backward regions in the world. An underprivileged, poor woman is handicapped in her battle against cancer in a way that the purely medical details of the cases involved can hardly begin to capture. The society can indeed be a big player in medical battles.

[4] *See my Commodities and Capabilities (Amsterdam: North-Holland, 1985; republished, Oxford University Press, 1998), Appendix B.*

A factor relevant for women, related particularly to breast cancer, deserves a special mention here.[5] I refer to the dependence of children on the afflicted mother. This is among the principal adversities of the predicament of breast cancer, which can have a strongly adverse effect on the lives of children even as it ruins the lives of mothers. There are, it seems to me, at least two distinct issues involved here. The first is the way that children's lives and accustomed routines may be inescapably disrupted during treatment of the mother for breast cancer, and of course much more radically in case of her fatality.

A related concern is the impact on the mother of the recognition that her children would not only suffer from her reduced ability of to help and to participate in their lives, but that the young beings could also be petrified by the anxiety about the mother if they could understand clearly what exactly was going on. The necessity for mothers to go on pretending as if things were perfectly normal, and to go on doing family duties that could somehow be performed, adds a huge burden to the seeking of adequate medical intervention and to the ability to concentrate on the recommended treatment that women with cancer badly need.

[5] My understanding of this issue is much influenced by the results of research at Harvard Global Equity Initiative, led by its Director, Dr Felicia Knaul, whose own research on the subject of cancer in developing countries has been among the definitive contributions in the field.

6

To conclude, what I have been calling the social epidemiology of cancer raises some deeply difficult issues, not least in India. Along with medical advancement, progress in the understanding of social predicaments can be extremely important. There is some real urgency in the matter given the wide prevalence of the disease and the positive possibility of helping to change the adversities that ruin so many lives. Hippocrates might have been right to argue that the primary obligation of medical practice is to do no harm, but the obligation of the society to do some good cannot but be important as well. The emperor of all maladies deserves a well reasoned and well-organized confrontation. We cannot get there unless we try.

Cancer Foundation of India, Kolkata

Cancer Foundation of India (CFI), Kolkata is a voluntary organization (NGO) dedicated to cancer prevention and control in the country.

The Foundation has 4 focal themes which include **(i) Cancer Communication,** to disseminate authentic information on cancer risk factors and their prevention by developing new communication strategies and advocacy methods. **(ii) R & D in Cancer Prevention & Control,** on topics of critical interest to the country such as epidemiology, lifestyle associated risk factors, chemoprevention, cancer vaccines, early detection methods and tests. **(iii) Development of Human Resource,** in cancer prevention and control by holding workshops, training programs, seminar/symposia/conference and capacity building of medical and paramedical professionals, and **(iv) Patient Service & Support,** by providing clinical and psychosocial support services to cancer survivors.

CFI has received grant in aid for its projects from national and international health research support agencies such as **IARC** (WHO), Lyon, **WHO**, Geneva, **American Cancer Society**, USA, **Bloomberg Initiative**, USA, **Department of Science & Technology (DST)** and **Department of Biotechnology (DBT)**, **Ministry of Science & Technology**, and **Indian Council of Medical Research (ICMR)**, Min. of Health Research, Govt. of India. CFI is recognized as a Scientific and Industrial Research Organization (SIRO) by DSIR, Ministry of Science & Technology, Government of India for R&D work in cancer.

CFI is supported by a large number of clinicians, scientists, social workers and health care volunteers committed to a holistic approach to cancer control in the country. CFI's Management Committee is currently headed by its founder **Prof (Dr) Maqsood Siddiqi**, former Director of Chittaranjan National Cancer Institute and later that of Bose Institute in Kolkata. **Ms. Sutapa Biswas** is the Secretary & Executive Director of the organisation.

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