

Body, Illness and its Metaphors

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Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place

– Susan Sontag, *Illness as Metaphor* (1978)

This paper aims to discuss two diseases that have been well documented in Fiji, that can illustrate the concept of our thinking about illness as a metaphor. As Stephen Jay Gould proclaimed, 'We reveal ourselves in the metaphors we choose for depicting the cosmos in miniature'. The two diseases selected are leprosy and cancer, both ancient diseases with powerful social, political and medical overtures. These diseases are often expressed in strong metaphoric language in Fiji. This paper is also prompted by my reading of Siddhartha Mukherjee's Pulitzer Prize winning book *The Emperor of All Maladies – A Biography of Cancer* (2011).

Leprosy is one of the oldest diseases known to mankind. In the Vedic literature in India, Leprosy was called the *Kushtha* as far back as 1400 BC. A good description of this illness and its treatment is given in *Sushruta Samhita* – a book on surgery written 600 BC by the Indian surgeon Sushruta.

In the 18th and early 19th century, before discovery of the bacillus causing Leprosy, this illness was considered hereditary. But gradually as evidence mounted in favour of contagiousness of the disease, this theory was abandoned.

The bacteria that causes Leprosy, *Mycobacterium Leprae*, was discovered by G H Armauer Hansen (1841-1912) from Norway in 1873. It is spread by exposure to a case of Leprosy by prolonged contact (either skin

to skin or indirect contact via clothes). The nose is a major portal of exit of the bacilli via sneezing, blowing, nasal picking and the incubation period of the illness is between 3-5 years. It is a particularly deforming illness with deformities such as claw hand, absorption of digits, mask like face, loss of eyebrows, perforated or depressed nose, ear deformities, gynaecomastia (enlargement of breasts in males) and perforated palate, to name only a few of the disfiguring and de-moralizing physical aspects of the disease.

Throughout history, Leprosy was greatly stigmatized. Among European Christians in the Middle Ages, Leprosy was particularly feared. In nearly all European countries, Churches conducted a ceremony known as 'Separatio *Leprasarum*'. Here the leper was administered rites similar to rites of the dead. According to the rites of Paris, the leper knelt before the altar; his face covered in black veil, he listened devoutly to mass. The officiating priest took a spade-ful of earth from the cemetery and let it fall on the head of the leper saying "'My Friend, this is a sign that thou art dead to the world. *Sis moutuus mundo!*"! And then in consolation he added "*Vivus interim deo*". *Thou shalt live again with God*' (Rosebury, 1971).

The word Leper exemplifies the stigma associated with this disease and the attitude towards those suffering from it. Arguably no other disease, apart from cancer, has had such a derivative cognate as leprosy. This is also true in Fiji and possibly in the South Pacific.

The Hebrew word *sara 'at* (pronounced 'tsaraath') originally signified a state of ritual uncleanness or ceremonial defilement, on par with the ritually unclean who handled corpses or with menstrual uncleanness (S. G. Browne, *Leprosy in the Bible*, 1971; D. Beckett, *The Striking Hand of God*, 1987). To the Israelites, *sara 'at* was a condition amendable only to divine intervention, requiring ritual cleaning, not a medical cure (Browne).

In the New Testament, *Lepra* was the equivalent of *sara 'at*. Thus the two words coalesced and were translated simply as leprosy into English and other translations of the Bible.

It is a basic human trait to fear anything that can cause gross physical harm to the body as does leprosy. This fascination, fantasization and fiction around leprosy has no doubt compounded ideas of stigma and led, in a large way, to the development of 'Leprosy Colonies' in various parts of the globe.

Here in Fiji, a Leprosarium was set up at Makogai Island, east of Suva in 1911. Lepers were perceived as outcasts, unwanted, unworthy people barred from society. The Colony, it can be argued, provided a sanctu-

ary for the lepers, where they could remain shrouded away from the evil forces in society, a sanctuary they could call home, where everybody regarded each other with respect and even find partners to marry. This could never have happened had they not locked themselves in isolation. This Leprosarium accepted people from around the Pacific region and in reality was a Pacific Islands sanctuary. Of the 4500 people treated at Makogai, 2500 were successfully treated and discharged, 1500 died and were buried on the Island while 500 were repatriated back to other Pacific Islands. Makogai, which is synonymous with Leprosy in Fiji, was finally closed in 1969 and patients moved to the P.J. Twomey Memorial hospital in Suva. This closure was largely due to the emergence of Multi Drug Therapy (MDT) which was highly effective in killing Mycobacterium Laprae. Ironically, the P J Twomey Hospital in Suva was later converted to accept another set of patients suffering from a disease that has scourged humanity for many centuries – Tuberculosis. So from Leprosy to Tuberculosis and the fascination with these subjects continue. Leprosy and Makogai was revisited in a locally produced documentary film *The Compassionate Exiles* by Larry Thomas in 1999.

Leprosy was in Fiji prior to European contact. Leprosy stones (*Vatuni Sakuku*), which were supposed to be gravestones of persons who had died of leprosy, were owned by keepers of certain clans, who conducted business using the stones to create fear and confusion by claiming that they could infect others using the stones (Becket, 1987). In 1859, Rev. Moore recoded a reputed cure for victims, by being hung head down in the smoke of a burning poisonous tree, *sinu gaga*. The Medical Superintendent at Makogai, Dr Austin, reported that on a stony ridge off the small island of Kioa, a local chief allegedly isolated Leprosy sufferers to ensure a steady supply of *Bokola*, a body prepared for the oven, for unexpected guests. This was considered advancement over the common practice of clubbing them to death, which was possibly Fiji's version of mercy killings to relieve them of their predicament.

Amongst the Fiji Indians, the word *Korhi*, a Nepalese word, is as derogatory as the English 'Leper'. During my medical school training in Suva in the late 1980's I had the opportunity to experience and talk to some leper's who were at the P J Twomey Hospital and I recall one particular Indian man who had his fingers surgically amputated. Upon asking him how he felt living with no fingers, he promptly replied *Beta, Korhi suney se acha hai ki hamar haat kat jaye* (Son, It is better to cut my hand than to be called a Korhi). This conveys the deep stigma associated with the disease in the community.

The discovery of an antibiotic, *Diamino Diphenyl Sulphone* (DDS) or

Dapsone, in 1941 was the turning point in the treatment of Leprosy and it was not until the early 1950's that it became a clinically useful drug and gave new hope to Leprosy patients and then for the next 30 years was the main drug. But due to emergence of Dapsone resistant bacilli, other drugs such as Clofazamine and Rifampicin became available leading to Multi – Drug Therapy (MDT) in the late 1969 and early 1970's. However because of the magnitude of the sufferings of those with untreated Hansen's Disease, it is essential for us to maintain our fight against this disease in the hope that eventually, it may be eradicated. Incidentally, in the early stages of the disease, no suffering whatsoever is experienced.

Most modern health care providers in Fiji have never seen a case of Leprosy. In fact, the word *Korhi* is regarded by many Fiji Indians as a swear word and very few people have an idea that it is in reality a medical disease. Due to the relative small numbers of Leprosy patients and their obscurity in the community, most people in our modern society would not give much thought to this ancient and socially crippling disease and in my own experience few young people have adequate knowledge of this premier anti-social illness of the old world. Indeed the word *Korhi* is lost to the younger generation of Fiji Indians.

Cancer is Leprosy of the modern world. This ancient, feared disease, known for 4000 years, is an epidemic of this century, unprecedented in medical history. The author of the biography of cancer, Siddhartha Mukherjee, has chosen an apt title for his book, *The Emperor of All Maladies*. In Fiji, apart from the non-communicable conditions such as Diabetes Mellitus and Cardiovascular disease, Cancer of the Breast, Cervix and Liver make up the second largest cause of mortality. On a global scale, in 2010 more than 7 millions humans died of Cancer.

Let us begin by giving a brief description of the origin of the word cancer. Around the time of Hippocrates (400 BC) the word *Karkinos* appeared in medical literature, derived from the Greek word 'Crab'. The tumour, with blood vessels sprouting out of it, reminded Hippocrates of a crab dug in the sand with its legs spread in a circle. Later doctors noted that the matted surface of the tumour resembled the tough carapace of a crab's body. Others described a crab moving under the flesh as the disease spread insidiously throughout the body. The sudden stab of pain produced by the disease was like being in the grip of a crab's pincers.

Another Greek word, *Onkos*, meaning a mass or load or burden was interwoven with history of Cancer. Cancer was metaphorised as a burden carried by the body. In Greek theatre, *Oncos* described a tragic mask that was often burdened with an unwieldy conical weight on its head to denote the psychic load carried by its wearer.

Hippocrates set about to explain illness by proposing that the body was made of 4 types of fluids called humours: black bile, yellow bile, blood and phlegm. In a healthy state these fluids were in perfect balance while in illness there was an excess of one fluid. This has become an often used metaphor in literature for bodily ailment or human temperament. Claudius Galen, a Greek doctor (around AD 160) expanded Hippocrates *Humoral Theory*. He also described illnesses as imbalances of various fluids. Jaundice was overflow of yellow bile, while tubercles were excess of phlegm, cancer was an internal overdose of black bile in a systemic state clogging up the body and bubbling out in tumours in frustration and that was why it was inevitable and hopeless in treating cancer surgically – the cancer could be cut out, but the bile would flow right back.

Hence for many years, the Galean theory was so metaphorically seductive that generations of surgeons developed the motto 'Do not be led away and offer to operate'.

Galen, of course, was biologically wrong as to the origin of cancer, yet he was correct in another aspect - cancer *was* a systemic disease, a humoral illness, constantly mobile in a crab like manner, moving insidiously from one organ to another.

Around the late 1800's, a German researcher Rudolf Virchow who was a professor at Wurzburg, set about describing human diseases in simple cellular terms. His 'Cellular theory' stated that human bodies were made up of cells and that cells only arose from other cells. Cancer tissue, he discovered, exhibited an uncontrollable, pathological and autonomous will to divide. This aberrant cell division resulted in hyperplasia with a mass of tissue that invaded organs and spread from one organ to other (metastases) distant organs.

William Stewart Halsted, a brilliant surgeon in the late 1880's, who would later become the patron saint of cancer surgery, named his 'theory' of cancer with the Shakespearean phrase 'The Centrifugal Theory' that cancer spreads in ever growing arcs from a simple central focus in the body. Breast cancer, he declared, spun out from the breast into the lymph nodes ('Sentinels) under the arm, then cart-wheeled through the blood into the bone, liver and lungs. A Surgical Warrior's job was to contain this centrifugal spread by cutting as much as possible and treating early breast cancer aggressively. He went on to develop the famous Radical Mastectomy procedure for breast cancer whereby the breast, chest muscles and arm pit sentinels are removed in the hope of removing all the cancer seeds.

This surgery went on to be very popular both amongst surgeons and cancer victims in large part due to the use of the word Radical. In Latin

this meant 'root' and thus radicalism was a psychological or manic obsession meant digging out the buried, hidden and mysterious roots of cancer. In spite of its resultant gross cosmetic defects, the question posed was – 'Which woman, when confronted with Cancer would choose a non radical surgery, with a low chance of cure, compared to the radical method of digging out the roots of this disease?' The writing was on the wall. However it was to be discovered soon that in spite of radically cutting away the cancer tissue, it would eventually grow again in some other part of the human anatomy. The Surgical Engineers had failed in curing cancer. Curing cancer was, thus, somebody else's problem. A novel method or procedure was urgently required to take over from the defeated Surgeons.

In 1896 a year after Wilhelm Rontgen discovered Xrays, Emil Grubbe (a medical student in Chicago) was inspired to use Xrays to treat cancer. Radiation oncology was coined to describe the latest branch of Cancer medicine whereby radiant energy could deposit energy deep inside tissues thereby inhibiting cell division and thus killing rapidly dividing cells of cancer.

The 'neutron beans' (x-ray machines delivering radiation) were analogous to 'millions of tiny bullets of energy' in a thrilling victorious metaphorical description of finally overcoming the crab which had for endless time refused to release its claws from the body and soul of humans. It soon came to be realized that x-rays were only useful to treat cancer that had invaded tissues locally. Radiation was relatively useless in curing cancers that had metastasized. The crab was still faster than a human being.

Around the 1950's and 1960's came the trials of drugs that could inhibit cellular growth. One form of cancer that responded to drugs was Wilm's Tumour, a form of kidney cancer. Lung metastasis from this tumour could be reduced by using these drugs. However it was realized soon that cancers treated with a single drug would become resistant to the drug, resulting in transient relapses followed by devastating relapses. Subsequently another idea would arise – could cancer be treated by a combination of 3–4 drugs? Combined chemotherapy could offer synergistic effects on killing cells. The rationale was that since different drugs elicited unique resistance mechanisms from the cancer cells and produced different toxicities, using a combination of drugs would dramatically lower the chance of resistance and increase cell killing.

The idea of using multiple drugs in treatment was borrowed from Tuberculosis, another socio-political disease of the 19th century in which multiple, antibiotics were utilized to get rid of this societal scourge with relatively good success. The Chemotherapy War had indeed taken a new

turn – its apparent magnificent success against childhood Leukemia and Hodgkin's disease were like the first explorations of a vast unexplored territory. It was similar to the 1969 Apollo II landing on the moon. If the moon, thousands of miles away from humans, could be conquered, then surely a disease that was residing within the human body could also be overcome! With the start of the space age, Cancer would thus emerge from its dark shadows of medicine into the public glare. It was no longer a whispered-about disease.

In 1930's the world was preoccupied with the horrors of external threats - bombs, wars, aliens from outer space. By the 1970's this object of horror had internalized and Cancer epitomized this internal horror. It was the re-birth of an enemy that was within, an internal Alien. The obsession with this disease and the public imagination would eventually capitulate into political determination to begin an organized response to cancer, including more research and a quest for universal causes and universal solutions. Cancer, thus, was missing not merely a medical cure but a political one. The army was now on a march, with the enemy firmly in sight.

In the 1970's, as confidence grew that Cancer could be eliminated, attention focused on surgery again. Could surgery be conducted for breast cancer without leaving the woman in a state of disfigurement and emotional scarring? A trial was therefore conducted which recruited 1765 patients in 34 centres in the USA and Canada. Its aim was to test if Radical mastectomy (designed by William Halstead) offered any advantage over other, less disfiguring forms of surgery.

Patients were grouped in three sections – one treated with radical mastectomy, second with simple mastectomy (removing only the lump in breast rather than the whole breast) and third with surgery followed by local radiation. Results were unexpected and shocking – a rate of breast cancer recurrence, relapse, death and metastasis was statistically identical among all groups. The radical mastectomy group had paid the price heavily in morbidity – cosmetic disfigurement, relationship issues, continuous swelling of the arms (lymphedema) without gaining any benefits in survival or recurrence. Ruthless and incessant cutting away and mutilation of body parts to get rid of cancer had failed miserably. This particular form of radical surgery is rarely done today in many parts of the world. In Fiji and other developing countries, where local radiation therapy is often absent or limited, this mutilation and maiming continues - could it be to boost the morale of local surgeons, who operating with such limited resources, achieve an inner sense of satisfaction by believing they have done the best for their patient by attacking the cancer aggressively and

mercilessly while hoping that there was no metastasis - an analogical ritual that would rid them of cancer and propel them into health? If so, such surgeons have truly transformed themselves from their roles of Surgeon to Shaman. From action men, wielding knives, to hopefuls, hands folded in prayers.

Around the mid 1980's, a procedure known as Autologous Bone Marrow transplant (ABMT) was developed. In this procedure bone marrow (containing blood forming cells known as Stem Cells) of the body was harvested and frozen. Then the remainder of the bone marrow was blasted by high level of drugs. The frozen bone marrow was then thawed and implanted into the same person. This procedure allowed very high doses of chemotherapy to be pushed into the body as the frozen bone marrow cells were spared the brunt of chemotherapy and therefore could be usefully regrown after being implanted. Cancer was the enemy of human kind and if force was needed to control it, then force would be unleashed. The Cancer War was still very much alive.

The mechanistic understanding of cancer cell's gained momentum in the 1980's spearheading yet another war on Cancer – the Genetic War. As early as 1940's it had been realized that a gene was a unit of inheritance that carried a biological trait from one cell to another. Physically the genes were carried within the cell in the form of chromosomes while chemically genes were made of DNA (deoxyribonucleic acid).

In order to target the two traditional Achilles heel of Cancer – local growth and rapid cell division – a detailed understanding of cancer cell behaviour was paramount. Cancer cells grow because of mutations in their DNA. These mutations activate internal Oncogenes and inactive tumour suppressor genes thus causing accelerated growth of cancer cells. These oncogenes and tumour suppressor genes operate in different pathways, their effects having mediated by kinases which turn off some pathways while turning on other pathways. Thirdly, the cancer cell has the capacity to resist death signals, to metastasize throughout the body and to cause growth of blood vessels by altering similar processes that occurs in normal cells.

Over the past 30 years more and more oncogenes have been steadily discovered such as *myc*, *rb*, *ras* and *neu*. If you imagined the inside of a cell as a crab, then these oncogenes would occupy the central portion of the crab, radiating threads in every directions and controlling cell growth and death.

Apparently there is hope in sight for humans to eliminate cancers. The creation of drugs specifically targeted against these oncogenes and suppressor genes would allow doctors to sit in their office and control cell

behaviour and growth of cancer cells. It would be like playing God, some would argue, sitting in the heavens and controlling every activity that occurs in the universe. Humans now have the potential to do the same with a disease that has ravaged through its biological, social and political framework over the ages. Could the Genetic War be the conqueror of this modern Leprosy?

Targeted therapy of Cancer with development of drugs that had specific inhibitory effects on oncogenes took off in the 1990's. The discovery of the *Her-2* oncogene in breast cancer in 1987 opened up a plethora of clinical research. Some patients of breast cancer have an amplification of this oncogene and are tagged *Her-2 positive*. This is one of the most aggressive and progressive variants of the disease. The discovery of a new drug, Herceptin in 1990, which was in fact a humanised antibody that attacked and inhibited the *Her-2* oncogene, took the bull by its horn. In 2003 two large multinational studies were initiated to test this new antibody drug and the results were astounding - the overall survival in women treated with Herceptin increased by 33%.

Another oncogene, *Bcr-abl* was discovered in the 1980's. In chronic myeloid leukaemia (CML) cells (a rare form of leukaemia) this oncogene would cause a kinase to unleash a cascade of events in the cells leading to frenzy, with cells dividing in an uncontrollable manner. This led to a feverish hunt for selective kinase inhibitors and over the next decade, a series of trial and error experiments and painstaking research developed a drug, Gleevac, specific to the CML oncogene.

Patients with CML and treated with Gleevac now live an average 30 years after their diagnosis compared to 3-5 years if left untreated. This has increased the prevalence of CML (number of patients alive with CML at any given point) and turned, paradoxically, a once rare disease into a common one.

Although the majority of CML patients maintained a long lasting remission to Gleevac, gradually it was noted that cancer cells were becoming resistant through various mutations, such as changing the structure of the *Bcr-abl* oncogene and thus creating a new protein oncogene that could not bind to drugs but nevertheless still able to stimulate growth of cancer cells. In other cases cancer hid and found sanctuary in areas of the body which were relatively inaccessible to drugs such as the Cerebro spinal fluid (fluid surrounding the brain and spinal cord). Furthermore cancer cells synthesized proteins that could destroy the drugs created by humans. Hence newer drugs were introduced in a cat and mouse game where when the cancer outgrew that drug, next generation drugs had to move to the front line of the battle. It is an incessant battle, moving and running to

keep pace with this illness, lest it runs away, sweeping the soil beneath our feet.

In 2003, the Human Genome Project, consisting of about 20,000 genes was completed. This led to the Cancer Genome Atlas which is a list of every gene mutated in the commonest forms of cancer. Genomes of cancers such as the ovary, pancreas, lungs and melanoma have been sequenced along with their mutations. We also know of the 13 major pathways through which cancer inducing signals move through cells and thus more than 20 signal blocking drugs are in clinical tests to determine the various combinations that would kill cancer cells while sparing normal ones.

So is the end to the Cancer War in sight? Cancer, as we now know, is deeply entrenched into our genome. Mutations (caused by random errors during cell division or carcinogens) in oncogenes, produce an unregulated growth of cancer cells. Just as human stem cells are capable of regenerating organs (for example the human hematopoietic stem cell in the bone marrow is capable of regenerating the whole blood after blood loss) cancer stem cells act as a persistent reservoir of regenerating cancer cells after chemotherapy kills the bulk of cancer cells. If human stem cells are regarded as immortal, so are cancer stem cells except that the latter cannot be deactivated. Cancer is a desperate expansionist organism that thrives in the modern world by a similar and almost parallel lifestyle - successfully invading, setting up colonies in hostile landscapes, hiding in one organ then moving to another. It is still a great colonizer, an emperor of bodily ailments.

If humans thought that they are at the end of Darwinian evolution, well think again! The ability of cancer to live so inventively, to outwit, outlive and still survive all assaults that humankind can impart is a testament to a new species developing, one that will be more suited to survival than we are. The War on Cancer needs to be redefined with its aims and objectives mutated. This war cannot be won by eliminating death but rather by prolonging the game of treatment, resistance, recurrence and even more treatment and thus forever altering the way we imagine this ancient, yet modern illness.

Finally, let me quote from Siddhartha's book that expresses how deeply thought-out are the metaphors in his book :

Diseases desperate grown
By desperate appliances are relieved
Or not at all

William Shakespeare, *Hamlet*.