



Richa Bajimaya

Memorial Foundation

Newsletter

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क्यान्सरका लक्षणहरु प्रति

सचेत हुनुहोस्

United for a
movement
against **Cancer**

All about Sarcomas

Dr. Janith Singh

Orthopaedic surgeon and Sarcoma Specialist, Norvic International Hospital, Nepal

What is your specialty and where did you train?

Namaste. I am an orthopedic surgeon currently based at Norvic International Hospital. I did my post-graduation from PGIMER Chandigarh. This was followed by a yearlong clinical fellowship in Musculoskeletal Oncology from University of Toronto. During my training, I was based in Mount Sinai Hospital and Princess Margaret Hospital in Toronto. Both hospitals are high volume tertiary cancer care centers catering to the province of Ontario and beyond.

What is Musculoskeletal Oncology?

MSK oncology is a subdivision of Surgery dealing with management of tumors arising from the musculoskeletal system. All connective tissue tumors arising from skin, muscle, bone, cartilage, blood vessels nerves etc are included in MSK oncology. These tumors could either be benign or malignant. The malignant ones are termed sarcomas and are of many subtypes.

How common are musculoskeletal tumors?

Benign soft tissue tumors are fairly common. Benign bone tumors are however not very common. Sarcomas are fortunately rare and make up only 1% of total cancer load. However if you look at age specific incidence, it is one of the commoner forms of cancer in children and young adults. Up to 15 percent of cancers in childhood are sarcomas. While benign tumors are fairly easy to manage, sarcoma management requires a multipronged approach.

Are sarcomas inheritable or communicable?

Sarcomas are largely sporadic and unpredictable. It is not communicable and only inheritable in rare syndromes. Nothing you eat or drink or any specific behavior is proven to have any consistent link with developing sarcoma. Same goes for the benign swellings. Unlike other cancers, tobacco use has not shown to have any consistent link with the risk of developing sarcoma. However, there was one study back in the 90's that showed slightly higher risk of developing sarcomas in individuals consuming smokeless tobacco. Previous high dose of localized radiation is known to cause sarcoma.



What are the signs and symptoms of sarcoma?

Interestingly, these tumors are often easily overlooked for anything from fatty lump, pulled muscle, sprain, "extra" muscle and the likes. Pain is usually a very late symptom or is associated with tumors arising from or near neural structures. The usual complaint is a lump or bump that seemingly grows at a variable rate which could mean days to months or even years. Like I pointed out, awareness is the key.

Are there any danger signs that one should be wary of with those lumps and bumps?

The chances are that a superficial lump which is easily mobile, has distinct borders and is lesser than 5 cms is almost always benign. However, if you can feel a lump that feels a bit deep with fuzzy borders and is fairly large then it is worthwhile getting it checked by a specialist.

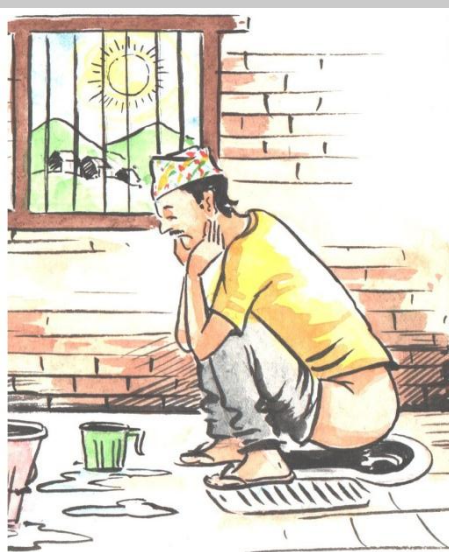
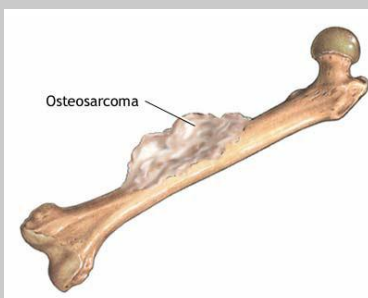
How are sarcomas diagnosed?

Any lump that feels deep and is large should be subjected to a thorough clinical examination to ascertain how deep it is and where it could be originating from. Once this is done we typically ask for a 1.5 or 3T MRI scan of the affected part which usually means scanning one joint above and one joint below the affected area. Many tumors could be diagnosed solely based on the characteristic signal changes they produce under the MRI. It is a good practice to interpret the findings on the MRI first by you before looking into what the radiologist has to say. If they match, certainty of the diagnosis is raised. Personally I would always ask for the MRI scan on a disk as well because it helps in physically measuring the dimensions of the tumor, its relation to the contiguity and in overall planning of radiation field and surgery.

Once the MRI is done, a biopsy ensues. For soft tissue tumors that are large and superficial or bone tumors with large soft tissue component, tru cut biopsy as an outpatient procedure is adequate. For deeper soft tissue tumors and bone tumors, open biopsies or image guided biopsies are more appropriate. Excisional biopsies are only recommended for superficial tumors that have no suspicious signal changes in MRI. The biopsy specimen is then sent to a Histopathologist who confirms the pathology based on the tissue morphology and the molecular markers. He or she often grades the tumor as high, intermediate or low based on what she sees under the microscope.

What happens once it is diagnosed?

Once sarcoma is diagnosed, it should ideally be discussed in a tumor board where the attending doctors discuss the plan of action. This is usually done before the patient is briefed about the diagnosis. It saves the patient and his/her relative from any confusion that might ensue if any of the treating doctors is unaware of the treatment plan. The patient is explained of prognosis of the disease in terms of survival, recurrence and the morbidity associated with the treatment. All questions regarding the treatment and disease in general should be answered with clarity.



क्यान्सरका लक्षणहरु : दिसा पिसाबमा परिवर्तन—
मलमूत्र परित्यागमा अस्वभाविक परिवर्तन, कब्जीयत
हुनु, गोटा पर्नु, दिसा कडा हुनु वा पातलो दिसा हुनु

Are sarcomas Curable?

Yes, localized, early stage sarcomas are mostly curable. Up to 9 in 10 cases of extremity sarcomas are cured. But then that is western data. Most of the cases in the west are diagnosed early and receive treatment early enough to achieve total cure. Only 1 in 5 patients in the west undergo amputation for extremity sarcoma. In fact in my one year of training we hardly did 3 amputations! We don't have a national data for the same. But from the little that I have seen, patients present very late or are often mismanaged. It is hence imperative to raise awareness about sarcomas at all levels.

In brief how are sarcomas managed?

There is a difference in management of bone sarcomas and soft tissue sarcomas. One thing that is common in both is that only Surgical Management ensures local cure of the disease. Patient with bone sarcomas usually undergo Neoadjuvant chemotherapy and Surgery. This translates to diagnosis of the disease followed by chemotherapy then surgery and back to chemotherapy. With soft tissue sarcomas, it is usually surgery with either pre or postoperative radiotherapy. High volume centers around the world may have variation to this protocol. Surgical management has to ensure wide resection, which means tumor free cuff of normal tissue around the resected specimen. If the latter is not achieved, the chance of recurrence is very high necessitating further surgery or postoperative use of high dose radiotherapy. If the defect caused by removal of the cancer is large it needs to be filled in by a flap or skin grafted. If the blood vessels or nerves had to be sacrificed, they should be reconstructed as well. In bone sarcomas, the resected bone is either replaced by massive allografts or megaprosthesis.

What do you mean by multipronged approach in management of sarcomas?

Sarcoma Management requires a team of doctors. This includes MSK radiologist, medical oncologist, radiation oncologist, MSK Oncosurgeon, MSK trained Histopathologist. Management will also often include Plastic surgeon, Cardiothoracic and Vascular Surgeon and Neurosurgeon depending on the need of surgical management. The usual trend nowadays is establishment of a specialist cancer center where all attendees form a tumor board. They usually hold once a week meeting for discussion of new patients, difficult cases, overall outcome and complications and are also involved in propagating new research activities. This sort of organized behavior drastically cuts down on the complication rates and improves the overall outcome in patients suffering from sarcoma.

What is the cost burden of treating Sarcomas and is there is a way to curbing it down?

It is quite a lot! In fact it is difficult to imagine an average Nepalese family being able to bear the cost of the whole treatment process. In soft tissue sarcomas the expenses are incurred in various diagnostic tests, radiotherapy sessions and perioperative costs. In bone sarcomas, the cost of mega prosthesis itself could be a major setback. The other aspect of bone sarcomas is that it's often the young ones who suffer. Unlike other cancers where we talk of 5 year or 10 year prognosis in a 65-70 year old who is on the other side of 50, here we have teenagers who have long life to live. The possibility of mechanical complications in the long run warranting revision surgeries is undeniable.

It would not be befitting to expect anything from the government for sarcoma patients as there are other pressing health concerns that affect a larger population. The most ideal way to curb around this issue would be a well organized insurance system but that seems rather unlikely for many years to come. The other alternative is to develop a sustainable fund for sarcoma. The latter could effectively be used in various sarcoma related activities like treatment, awareness campaign, research and more. Many countries around the globe have well established funds like these and have proved to be successful in propagating the best method of treatment and research of sarcoma at national level. Crowd funding is another exciting avenue in treatment of patients in need.



क्यान्सरका लक्षणहरु : लामो समय सम्म पनि ठिक हुन नसकेको घाउ खटिराहरु



क्यान्सरका लक्षणहरु : अस्वभाविक रुपमा शरीरबाट रक्तस्राव भैइरहनु

In context of Nepal what do you think is the most important aspect in management of sarcomas?

Like I said previously, the most important aspect in management of sarcomas is the awareness of the entity. Since it is rare, it can be easily overlooked, misdiagnosed or mismanaged. The sad truth about sarcomas is that many limbs and lives are lost due to inappropriate surgical management of the disease. In two landmark studies coming from H J Mankin, poorly performed biopsy or surgical procedure was one of the reasons for amputation where limb salvage could have been performed. The awareness should hence be at all levels. The patient and the attending doctor should realize that not all lumps and bumps are lipomas. Surgeons who attempt removal of these lumps should always remember the basic rules of biopsy and always send the specimen for histopathology and make sure to follow on it.

How can Sarcoma care be improved in Nepal?

Since the likelihood of a doctor seeing, let alone managing, a case of sarcoma is really paltry in a community; the experience gained at an individual level is pointless. The only way to deal with this spectrum of rare disease is by the method of collective learning and this is only possible with designated Sarcoma referral center that caters specifically to sarcoma patients. Needless to say, sarcoma care must be done in an institutional basis where all medical personnel required for treatment are available under one roof. This will ensure smooth practice and improved outcomes in the long run. All diagnostic tests should ideally be possible under one roof as well. The necessity of a tissue bank and bone bank in management of sarcomas cannot be exaggerated. With growing number of aging population, the number of procedures besides sarcoma where tissue and bone allografts could be used is ever increasing.



World Cancer Day 2014 (Feb 4, 2014): Richa Bajimaya Memorial Foundation in collaboration with Nepal Cancer Relief Society marked World Cancer Day in Tenzing Park, Kathmandu. The day focused on Target 5 of the World Cancer Declaration: Reduce stigma and dispel myths about cancer, under the tagline 'Cancer is not a curse'. The event included an instrumental session followed by speeches from Guest Speakers which consisted of Karna Shakya, Rotarians, executives of NCRS and others. The event also featured a candle light ceremony and a poster exhibition. The day was remembered for those who lost their lives to cancer, those who were fighting with cancer and those who had won their battle against cancer. A poster exhibition and signs of cancer were presented to the public by Dr. Rajendra Prasad Baral.



National Convention on Students (Dec 22, 2013): Richa Foundation participated in a National Convention on Students' Quality Circle organized by Quest Nepal in association with LRI from 20 to 22 December 2013. We conducted a Cancer Awareness session for the participants. 40 schools from around the nation and one from India had participated in the program.

Laxmi Puja (Nov 3, 2013) : Laxmi Puja was performed with the presence of...



the World Cancer Day on 4th of February at Patan Durbar
e "Debunk the myths". The program began with a musical
Then, candle lighting ceremony was conducted whereby we
. At the end, an informative presentation on the symptoms



Puja was celebrated in the foundation office at Chabahil
presence of few core members.



Interactive session on Sarcoma (March 8, 2014)
by Dr. Janith Singh and Dr. Prabin Nepal



6th Annual General Meeting (Sept 28, 2013): Richa Foundation
celebrated its 6th year of journey at the Foundation office, Chabahil
with its advisors, life time members and friends of RBMF family. On
the very occasion, Prof. Dr. Anjani Kr. Sharma released the 4th issue of
newsletter. Certificate of appreciation was awarded to the trainees -
Abina, and Pema (Thames International College), and new life time
members by Mr. Shyam Sundar Bajimaya.

Coping with Oncology Through Poetry

Corazon A Ngelangel

Head, Oncology Section, Jose R Reyes Memorial Medical Center

"Few physicians deal with death and grieving as often as oncologists," said Dr. Laurie Lyckholm (Virginia Commonwealth University School of Medicine, USA). Frustrations with limited treatment success and continuous exposure to fatal illness make oncologists particularly vulnerable to stress and burnout. Oncologists must foster their own emotional well-being to be able to cope.¹

In psychology, coping²⁻⁴ is expending conscious effort to solve personal and interpersonal problems, and seeking to master, minimize or tolerate stress. The term coping generally refers to adaptive or constructive coping strategies, reducing stress levels. Art Therapy is such a coping strategy. Through creating art and reflecting on the art products and processes, people can increase awareness of self and others cope with stress and traumatic experiences; enhance cognitive abilities; and enjoy the life-affirming pleasures of making art.⁵

Poetry is a form of Art Therapy. In the 1940s, Margaret Naumberg⁶ blended ideas about psychoanalytic interpretative techniques and art to develop art as a tool to help "release the subconscious by means of spontaneous art expression...and on the encouragement of free association... the images or in the case of Poetry the words... constitute symbolic speech...meaning".

A decade later, Edith Kramer⁷ defined an art therapist as one who is able to bring "subconscious material closer to the surface by providing an area of symbolic experience wherein changes may be tried out, gains deepened and cemented. The therapist must be at once artist, therapist, and teacher..."

Art therapy can be for one's own coping as well as a prescription for others.

Poetry is a way of letting go, a way of relaxation, and a way of self-expression. Oft I get asked how I cope with my chosen field of specialty – cancer medicine. I reflect on the question and have in my mind Poetry as a way of coping.

One time, I was asked to write something on cancer prevention – it was so technical that I choose to write the following (abbreviated form):

*Buwan-buwan, Kanser ay hadlangan
(Cancer prevention forever)*

*Ganito parati Enero hanggang
Disyembre (January to December)
Para ang Buhay maparami.
(Life greater not lesser.)
Cancer-studded Lifestyle
Huwag mare! Huwag pare!
(No ma'am! No sir!)
Be aware and take care
Too late is never
To change is forever.
Lifestyles to change,
Lifestyles to maintain...
For richer
Never for poorer
A life without cancer...*

Oftentimes I get asked why I have ventured into a field of specialty like cancer medicine – I usually say it must be ... as the poem 'A Thousand Reasons for Living' states:

*"...Leave the Father free Himself to
weave the pattern of your days."*

Occasionally, my cancer patients ask me if it is okay for them to go for alternative medicine. I had written my answer accordingly:

*The body cannot heal
If the mind is ill.
Hence, keep the mind healthy
To make the body heal.
Forget not your psychosocial
counselor
Nor your medical doctor.*

Sometimes cancer patients at their moment of receiving bad news try to keep their emotions buried inside them in public – to which I wrote:



क्यान्सरका लक्षणहरु : एक्कासी मांसपेसीमा कडापन हुन जानु वा डल्ला डल्ली देखिनु वा स्तनमा गांठो महसुस हुनु

*It is alright
for a patient to get angry,
It is alright for a patient to cry,
get depressed, laugh, hurt,
or have any other feeling... But above
all
take a moment to SMILE
And FEEL the SMILE in every bit of
your being...*

The great Jonas Salk once said, 'The mind in addition to medicine has powers to turn the immune systems around...'

At times, cancer patients ask me at what stage of cancer they are in. I usually in silent hope would pray...

*Ang aking buhay ay inyong diary,
Diyos ko...(My life is Your diary My
Lord...)
Kayo na ang gagawa sa mga antas
ng aking buhay...(Author please the
stages of my life...)*

Aloud I try to impart to them what Ann Landers wrote –

*"Expect trouble
as an inevitable part of Life
And when it comes,
hold your head high
Look it squarely in the eye and say,
I will be bigger than you,
you cannot defeat me."*

One day I got the kick of my life in my early years of medical training when a patient under my care at the Intensive Care Unit with all the tubes in the nose, the mouth, the vein, suddenly woke up and smiled and got on to complete recovery after chemotherapy from malignant lymphoma – big bulky nodes in the neck and chest. She was saying something in not so many words but more in her smile, her touch, her prayer. She was glad for being alive even for just that moment. I tried to put her state of mind in this poem as I presented her case in a medical conference:

*From my nightmare
YOU woke me up...
I saw the sweet song of the birds
I heard the dew on the morning leaf
I felt the color of the rainbow
on my skin...
If this was only for a day, a week, a
month, a year or two or more...
Dear GOD, then after then,
welcome I YOUR embrace...*

Indeed oncologists must foster their own emotional well-being to be able to cope with such a clinical practice ...and indeed, poetry matters. AD Peterkin of Toronto Mount Sinai Hospital

Department of Psychiatry wrote, "The inadequacy of medical language and technology in describing the intensity of experience shared by healers and those they care for is one compelling reason that leads physicians to take up the pen⁸⁹".

Here now, we share in the next pages our subconscious, by means of spontaneous art expression and free association, a sample of our poems our essays... our reflections constituting symbolic meaning, "allowing for comfort and escape and also invoking rattling confrontation⁸⁹".

Canker! Cancer!*

By Susano B Tanael

*Canker! Cancer! burrows deep
into the flesh for its keep.
What infernal entity
can own its identity?*

*It waits around in silence-
a corporeal existence?
It attempts to disfigure-
a success or a failure?*

*What makes it move step by step?
What makes it grow inch by inch?*

*Does it have a vulture-grasp?
Does it wait till the last gasp?*

*A twisted mouth and a lip
can suck blood without a nip?
A spittle from a bogey
can melt the flesh of its prey?*

*When it lies close
to the base of his meat
it pushes its host to seek retreat.
When it blocks
the hollow tubes of his life
it clears the path to His eternal life.*

*Canker! Cancer! Still to bore
into the core of his bone.
Your Immortal Origin
did not will your mortal sin.*

*Taken from Susano B Tanael's book of poems *Ambiguities of the Body on Illness and Healing*, CreateSpace Independent Publishing Platform United States of America, 1 November 2013.



क्यान्सरका लक्षणहरु : प्राय अपच हुनु वा खाना निल्नमा गाब्रो हुनु

Tayo na sa Center Mag-pasuri at Magpa-acetic*

By Cora Ngelangel

*Nanay, Ate, Tita
Ale, Ale, Tayo na*

*Nag-aanyaya sa iyong diwa Kinikimkim
sa loob ng dibdib Lumalabas ang pag-
nanais Makatikim ng pag-aaruga*

*Pumanaw ang araw at dilim Buhay mo
ay walang katiyakan Kailan mo, kailan
pagbibigyan Sarili ay alagaan
Tayo naaaa.....
Tayo naaaa....*

*Tayo na magtungo sa center
Magpasuri at magpa-acetic Alisin ang
hiya at ang takot Ibigay ng buong buo*

*N'ay! Pasuri, pa-acetic
Kanser! Ay maiiwasan
Tita! Pasuri, pa-acetic
Mister! Ay sumama ka na lang*

*Nanay, Ate, Tita
Ale, Ale, Tayo naaa...*

*Ate! Pasuri, pa-acetic
Kanser! Ay malalabanan
Ale! Pasuri, pa-acetic
Mister! Ay sumama ka na lang*

*Tayo na sa center – magpa-acetic Tayo
na sa center – mag-pasuri Tayo na sa
center – magpa-acetic Tayo naaa*

*(Mom, sister, aunt
Hey lady, hey ladies...
Come on... Come on*

*Inviting you sincerely
Care for yourself willingly*

*Days swiftly turn to nights
Life can be so uncertain so fight
Make the time
Gift yourself A caring so fine...
Mister, do come along
Come on...
Come on...*

*To the health center we go
Hesitancy aside
A check-up abide*

*Have acetic acid wash
Cervical cancer quashed*

*Let's Fight cancer
Let's go...let's go...\
Come on...Come on...)*



क्यान्सरका लक्षणहरु : कोठी वा मुसामा एक्कासी परिवर्तन हुनु, आकार बढ्नु, रंग फरक हुनु

*Written to serve as the Cervix Cancer Visual Acetic Acid Wash Screening Campaign Theme Song for the Philippine Department of Health by the UPCM-DOH Cervical Cancer Screening Research Team

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Elixirian Experience

Dipti Timilsina

20 years old, away from home, surrounded by teenagers who for one or the other reason smoke and drink alcohol yet I am motivated to choose healthy lifestyle. I don't need to control myself or try hard to stay away from unhealthy life style. It is most probably because I have conscious and unconscious deep awareness about cancer and its causes. Well, we all know about cancer and its causes, all my friends do but there is a difference between knowing and being aware. As an Elixirian I am aware- to the extent that I can incorporate the information I have into my life and I can also try to convince people to do the same.

I mentioned above that people around me smoke and drink alcohol so, as an Elixirian isn't it my duty to convince them not to? Yes, it is. But it is also true that it is very difficult to shape the mind that's already been shaped. Not that it is impossible but it sure is challenging. This is why Elixir club is momentous and can make a significant difference. It is a club of young people and being affiliated to this club in one or the other way can guide the young minds to the right path at the right time.

I have been Elixirian for almost 5 years now. When I reflect back my first few years in Elixir club, I remember it was so much easier to convince and aware my friends about ill-effects of tobacco consumption then it is now. I have also noticed that my friends who have been affiliated to Elixir club even if just as audience are mostly non-smokers. It cannot be a mere coincidence that most of my friends who smoke were never a part Elixir club. Thus, over these 5 years I have seen it for myself that Elixir club does make a difference.

When I first started as an Elixir it was only established in my school- Ideal Model School. I remember being deeply fond of the club because we could organize several events and competitions.

Though we were established under Richa Bajimaya Foundation we could take a lead and put forward our ideas. And we were always supported and guided by our seniors of Richa Foundation. Now I know that throughout the journey of Elixir club I was learning a life time lesson but at that time it was a fun thing for us. We were spreading awareness through drawings, debates, documentary and so many other interesting means.

Today Elixir club is spread over several schools; a huge number of youth are a part of it. They certainly have reached out to a great deal of people. It makes me smile because I know for sure that in our society more number of people than ever have been informed and aware about issues like cancer and tobacco consumption. I as an Elixir will always remain an Elixir and promote awareness in whatever small way I can.

Cancer Experience

Aarati Poudel

Hematology/oncology fellow (2014-2017)
SUNY Upstate Medical University, USA

Cancer is a traumatizing diagnosis. Recently, one of my close relative had to go through this trauma. As a budding oncologist, I could not be less involved.

It was tough for me to appropriately acknowledge what was going on. After few conversations via telephone, some medical terminologies by patient's family and few scanned documents, few things were clear. This 10 – year old kid was suffering from acute lymphocytic leukemia, with few bad prognostic signs. After initial investigation, decision was made to take kid to New Delhi, India for chemotherapy. After 70 days of hospital stay, including 17 days of Intensive Care Unit stay and few rounds of chemotherapy, complicated by cardio-respiratory arrest, he expired.

Few things came to my mind, during this long and tough process.

Leukemia is a kind of blood cancer. Treatment of this particular kind of cancer requires years. Treatment is available in Nepal. It was not because of possibility of different treatment/medications that he was taken abroad. It was merely because of pressure from society.

This left parents who were in New Delhi without any support. They could never see their near and dear ones during those difficult times. Let alone talk about sufferings for parents when they had to run errands to arrange blood for innumerable blood transfusions. I am not saying that having a second opinion from any place is wrong, but if options are available, why is it so difficult for us to fight against society and give treatment in home town? In this particular case, doctors here in Nepal had given a clear plan, and verified that the treatment is going to be same.

When I talk to those unfortunate parents now, their unanimous answer revolves around “at least we tried, there is no way people can blame us for not taking him to proper place”. I understand their feelings. But my real point here is, let's try and do everything that is possible for your own satisfaction, not for people/society. Not just for this particular case, but in each and every step. This change in culture can make a difference.

Overall, cancer is a threatening word for the society. There are lots of gaps in the knowledge about cancer in general population. There are cancers that you die from, and there are few cancers that you die with. There are few cancers that are preventable, and there are few cancers for which answer to “why me?” is unknown.



क्यान्सरका लक्षणहरु : लामो समय सम्म पनि
खोकी ठीक नहुन