

Personal Viewpoint

How Illness Changes an Adolescent's Outlook of Life?

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Abstract

Adolescence, as a transition between childhood and adulthood, is a period of exploration of our identities and roles in the society. Any illness encountered during adolescence brought stress, as demonstrated in my case. After realising the diagnosis of osteosarcoma on my fourteenth birthday, I had a hard time undergoing amputation and 12 courses of chemotherapy. But with the support of my family, friends and medical staff, I endured the pain, psychological stress and worry of recurrence. Nine years have passed and I am now a Year 5 medical student in the Chinese University of Hong Kong. My disease gave me much impact, and the most important change is to learn to treasure our family, friends, health and life. My obligation to cheer up the sick and the desperate drives me to choose Medicine as my future career, and to share as often as I could.

Key words

Adolescent health; Hospitalisation; Illness; Osteosarcoma; Psychosocial impact

Introduction

I am much honoured to be one of the speakers in this Adolescent Health Congress. Facing illness during adolescence definitely imposes great changes on one, be it positive or negative changes. I would be sharing my story with 1000 gifted high school students, their families and teachers, and I have overrun. So this time, I am much more nervous. I am not going to present much information which you might have expected joining this Congress. Instead, I would have another approach. Just sit back and listen. I would be sharing with you my own case of bone cancer, and how it changes me, intellectually, physically and psychosocially.

My Story

My story dated back to 9 years ago, when I was 13 years old. Each aspect of my life was going smoothly – with good

past health, studying well, fond of swimming, long runs, playing basketball and nearly all kinds of sports. Never had I realised what life and death meant to me.

Then one day in Secondary 3, I found progressive weakness over my left knee, especially when walking upstairs and downstairs. Once, I nearly fell from a table at school when I was hanging drawings for my classmates. My mother urged me to visit an orthopaedics private doctor. After a knee X-ray he told me three possibilities, osteomyelitis, a benign or a malignant tumour.

I was not as scared as my mother because I did not think I would get any of these diseases. I was just curious about each instrument around me, and each procedure performed – X-ray, CT scan, bone scan, ultrasound and MRI. My birthday was one week after my hospital admission, so I enjoyed the many birthday celebrations from my parents, classmates, teachers and the principal.

On the eve of my birthday, I underwent a bone biopsy. On that night, my doctor-in-charge and many nurses flooded my cubicle holding a birthday cake in hand. I was so touched to have their blessings, as I knew they must have been very tired after working for a whole day, and I was just an ordinary patient. Two nurses even woke me up at the first minute of the midnight and greeted me Happy Birthday.

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Breaking the News

On my birthday, during the ward round, my doctors told me that I had suffered from osteosarcoma. I was totally shocked and did not believe in the doctors, thinking that they were playing tricks on my birthday. However, when I grasped hold of the X-ray films, I realised there was something wrong with my left knee. Tears rolled down my face and that was the only time I cried during my hospitalisation.

The news of having a bone cancer on my birthday was shocking, and by that time, cancer seemed to be equivalent to death to me. I was worried about my future. Can I continue my studies in school in future? How much longer can I live? Can I walk again? Can I lead a normal life as others even if I can recover? Can I do sports again? My brain was puzzled with questions.

But soon, I knew fears and anger could not change the truth. I had to face the music. Fortunately, my doctor invited another osteosarcoma patient with amputation for over one year to visit me. She has set a good role model to me, letting me know how good I could be, and she gave me a lot of advice regarding the chemotherapy and rehabilitation. Before she left, I told myself, 'I have to walk better than her some days later. And I have to visit other patients and share my story to cheer them up, if possible.'

A Long Battle

I was supposed to undergo eight courses of pre-operative chemotherapy before the limb amputation. Just like others, I bore the side effects of the chemotherapy – nausea, vomiting, loss of appetite, malaise, alopecia etc. Amongst all these, vomiting made me most uncomfortable. I held a record of vomiting over 20 times a day, starting from food, bile-stained contents, water and finally nothing to vomit except a cramping pain. Sometimes, it awoke me from sleep, and then I threw up almost immediately. But I knew I had to eat as much as I could, even though it would be vomited out soon. Or else, I would not have enough energy to overcome the cancer.

Though it was hard for a 14-year-old to bear such suffering, I had not thought of giving up. My optimistic character only partly contributed, more importantly was that I knew I was not alone in the battle. My family, my classmates, my teachers and all the medical staff were backing me up.

However, after three courses of one-week chemotherapy in one month, my doctor told me that my response to chemotherapy was unfavourable. The tumour did not regress but grew instead. Urgent scans were arranged, and amputation surgery was planned ahead of schedule.

My Amputation

The originally planned surgery was Van Nes Rotational Plasty, which was done by amputating most of the femur and part of the tibia as well as fibula. By rotating the ankle through 180 degrees, the calf was connected to the remaining thigh and the original ankle would serve as the knee joint after transposition.

Yet, as the tumour bulk increased in size, the extent of amputation could only be confirmed during the operation. If unfortunate, I might have my whole limb amputated. I was confident in my doctors, so I just hoped for the best, and left the rest to my doctors.

When I woke up from the anaesthesia, the first thing I did was to look at my leg. Part of it was still there, and I could even move my toes at that time! I was further reassured after seeing my parents' smiling face.

After the Operation

After the operation, nine further courses of chemotherapy followed. I was getting more used to the side effects, but still vomited much. The last course of chemotherapy in July just signified the start of my long term rehabilitation.

I underwent physiotherapy and trained myself as hard as I could, so that I could be fit enough to go back to school in September. I was most excited to see my improvement – getting used to my prosthesis, walking, climbing stairs and started playing simple sports.

My Changes Brought by the Illness

Family

Although I have suffered a lot in the disease, I know my parents suffered even more. They were very sad knowing the news and witnessing my suffering, but they tried their best to stand as strong as they could in front of me, and kept encouraging me to have faith and be ready to struggle. They resigned from their work to look after me. Preparing

soup, bringing me lunch and dinner, staying in the hospital with me, taking care when I vomited or felt sick. They have devoted entirely to me. My elder brother, though very busy with his schoolwork, still squeezed his time to visit me, and even turned down their school picnic to stay with me.

After my return to school, my mother kept helping me in various aspects, taking my schoolbag, bringing me lunch in the canteen. Without their support, I would not have lived till now, sharing with you here. Indeed, my mother related my symptoms to cancer even before visiting the doctor, just because she had visited another cancer patient with similar complaints a long time ago.

Before the illness, I did not spend enough time with my family, but after having cancer, I know family is the most valuable thing in my life, and I am glad that our family relationship has been much closer.

Values of Life

Standing at the edge of death, I realised life is invaluable. Very often, we take life and health for granted, but no one knows when we are going to lose it, and it would be too late to learn to treasure only by then. So, I have learnt to treasure everything I have, my life, health, family, friendship and each opportunity. It is more important to know what we already have than what we have not.

I was missing school during my stay in hospital. For the first two weeks, I was still working on the homework brought by my elder brother from school. Soon, I knew my battle was a long one, so I wished I could go back to school earlier. I treasured my chance to study, so I worked very hard. I was glad that my effort was not in vain. I got distinctions in all my subjects in the HKCEE and HKALE.

Receiving four Outstanding Students Awards and three Outstanding Disabled Persons Awards recognised my effort, and served as another motivation for me to work harder.

Diversity

I grasped hold of every chance I had to learn. For music, I was an 8th grade pianist in Secondary 4, and held a Performer's Certificate in Solo Piano by Secondary 5. In Secondary 7, I represented Hong Kong and China in a cultural exchange and musical performance program to the United States and played the piano at the Consulate General of the People's Republic of China in Washington.

I have a strong passion in Mathematics since young, as it can train my logical thinking. My addiction to it intensified after my disease, and I was awarded numerous prizes. I competed with our mainland's talented young

mathematicians in the Chinese Mathematical Olympiad and won the Bronze Awards for two years. Going a step further, I represented Hong Kong twice in the International Mathematical Olympiad. The climax was in Secondary 7 when I won a Bronze Medal in the 41st International Mathematical Olympiad in South Korea.

Physical Limitation

I was a bit worried whether I could participate in sports again, and for the first two years, I was just playing very mild sports like table tennis. Under the encouragement of my classmates, I started to challenge myself by picking up sports which I had previously learnt like badminton and basketball, and started to learn new ones like tennis and squash. In Year One in the university, after joining the Hong Kong Sports Association for the Physically Disabled, I picked up swimming again. In two years' time, I won a lot of local and international awards in swimming. In 2002, I even represented Hong Kong in the 8th Far East & South Pacific Games for the Disabled (the so-called Disabled Asian Games) held in Pusan, South Korea, and was the swimming team captain. I also learnt wheelchair fencing and got a First Runner-up in Junior Foil Open in Hong Kong.

To me, my amputation definitely hinders me from joining some of the sports. I could not take part in long runs which I love very much, and I would be tired or have pain if walking for long. I could not walk as nicely as others and had some hindrance in my daily life. Yet, I would comfort myself by saying, 'Even a healthy person cannot take part in all sports. I am just selecting those I can, and there are already a lot of them.'

A Wish to Share

Having overcome the disease, I have learnt a valuable lesson, and I was much more grown up.

Seeing the desperate patients, I felt in myself a responsibility to cheer them up, and lead them to think in a more positive way, and be persistent in their therapies. Therefore, I often visited patients, especially young cancer patients, to share what I have faced, and how I overcame all these. Nearly all of them got encouraged, seeing light of recovery, or understanding their meanings in life.

I had shared more than 80 times in patients' support groups, rehabilitation institutions, youth organisations and more than 20 secondary schools, spreading the message of positive life attitudes, "Never give up; Treasure what we have."

Teenagers are at an age just starting to explore their

values in life and their positions in society. They can be easily distracted, give up easily when facing difficulties, or lose their confidence after one or two failures. I wish my experience could inspire them to think more, and understand they are much more fortunate than many deprived ones in other parts of the world.

The audience's encouraging response has positive feedback on me. When they told me they were inspired by my sharing, or even had their life changed, it motivated me to share more. A patient even did exactly what I had done before. She was a bone cancer patient and refused surgery. After I visited her, her worries were gone and she promised she would undergo the surgery. What was more, she told me she would visit other patients to encourage them. I was delighted to know that after her amputation was done, she really involved herself actively in visiting other patients.

Besides sharing, doing voluntary work also broadened my horizons. I enjoy serving the mentally disabled, the elderly and the children. And I was also an Ambassador of Suicide Prevention Services, Hong Kong Cancer Fund Strike for a Cure and participated in various youth organisations.

My Goal

Quite a lot of teachers and Mathematics professors suggested me to study Math or computer science, both of which I enjoyed and have spent a lot of time on.

Yet, after having the illness, I have made up my mind to be a doctor in future. In my nine months of hospitalisation, I have met a lot of good doctors and health care staff. Besides celebrating my birthday, my doctor had played chess with me. Doctors and nurses visited me at home in the Chinese New Year, and even invited my whole family to join their wedding, with me playing the piano. I have started to learn how to be a good doctor since then - not just treating the disease, but also the patients' hearts.

Now, I am in the fifth year in the medical school. I look so much forward to graduating a year later, and probably working in Paediatrics if I have a chance.

Psychosocial Impact and Self Image

Although I am an optimistic and persistent person, my disability did bring me some stress.

I remembered the first few times when I was returning home from hospital, sitting on the wheelchair my mother was pushing. I felt embarrassed to have eye contact with the passers-by. I was a boy with hair loss and limb amputated sitting on a wheelchair.

When I returned to school, the 7-minute walk before my amputation took me more than half an hour with the prosthesis. Most passers-by focused their eyesight on me, no matter whether I was walking or sitting for a short rest. Some even stood halfway on the stairs, turning their heads around, looking at me for more than a minute. I just hated their staring so at first I avoided looking at them, then I would not know they were looking at me. Soon, I understood more. I talked myself into thinking that they looked at me out of the wish to help.

But then, another problem arose. My mother kept carrying the schoolbag for me. I often requested to hold it myself, as I thought that was a bit embarrassing. But soon, I thought that having my mother's accompany was a blessing.

An accident three months after I returned to school brought me the greatest impact. I slipped in the toilet at home, and my doctor diagnosed a fracture in my ankle that had undergone surgery. It was near Christmas and two weeks later, I would be back to school for exams. I hoped so eagerly that my fracture could heal in two weeks, but definitely impossible. I took the taxi to school each morning, with a plaster on my fractured left leg.

At the beginning of the school term, although I was very weak and wearing a cap, I was still wearing a prosthesis and seemed like a normal guy. But now, everyone saw that my leg was amputated and I was hurt. I just told myself to be brave and more careful next time.

The disease definitely brings much stress to me, and it is important to share these feelings with family or friends.

Conclusion

It has been more than nine years since my last chemotherapy. During this period, whenever I have bone pain or weakness in the other knee, I would be worried whether it could be a recurrence. Although the disease left me some permanent disabilities with half of the limb amputated, the normal knee already undergoing mild degeneration, tinnitus and mild hearing loss at high pitch, and still frequent vomiting, I am glad to have recovered. And my gain is much more than my loss.

I learn to treasure our life, our health, our family, and everything we possess. I live a brilliant life, with a bit of achievements in many areas. More importantly, I know why I live, to live for the goodness of other people, and to encourage the desperate. No matter how long my life will

last, I will not regret, as I know, living to the fullest does not mean the longest but should mean the most meaningful.

I would conclude with a picture I drew in Secondary 3, the year right after my return to school. The idea was modified from an oil painting by Van Gogh. With a church in the laputa, which is a 'floating city' in the Japanese cartoon

movie, and dark sky at the corners of the picture, I mean when we are facing difficulties and challenges, we have to try our best to overcome, and persist in what we believe is true. Even though solving these problems may be as difficult as building a church in the laputa, without trying, we will not know we can actually break open the dark sky.



Figure 1 Breaking through the darkness – a drawing in Secondary 3.

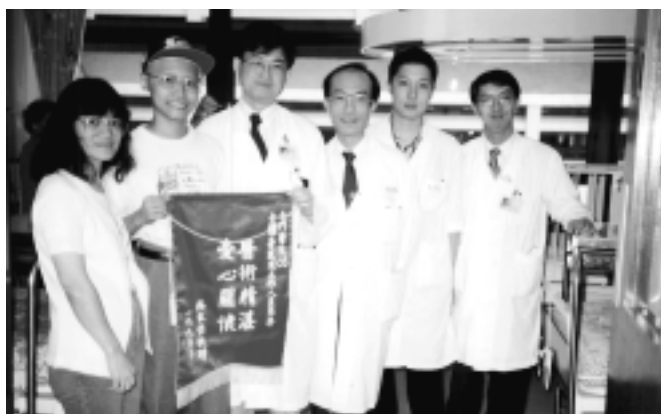


Figure 3 Twelve courses of chemotherapy completed.



Figure 2 Birthday celebration with medical staff – the night before news-breaking.



Figure 4 Participating in International Swimming Competition – overcoming physical disability.



Figure 5 A blessing to share my experience.