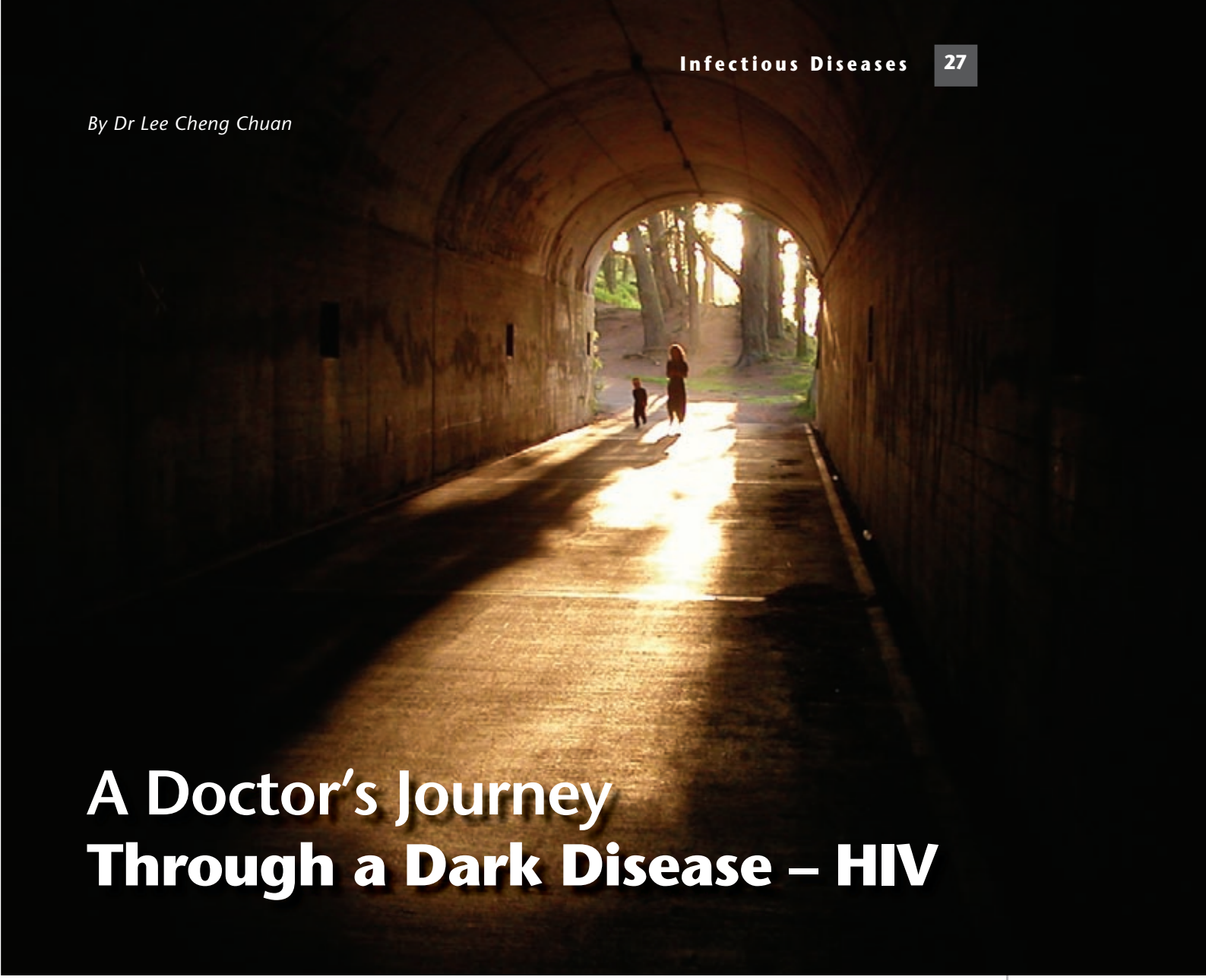

By Dr Lee Cheng Chuan

A Doctor's Journey Through a Dark Disease – HIV

WHEN AND WHAT MADE ME DECIDE TO GO INTO HIV CARE?

Infection with HIV was the new 'plague of our times'. This had a dramatic impact on me. It is arguably the most terrifying disease one could catch. With all the physical, social, ethical, emotional, and access-to-care issues that it embodies, going into HIV medicine allows me to be an activist and a compassionate caregiver. Physicians have a responsibility to help people who are infected and prevent others from getting infected. The opportunity to care for people whom others are fearful to treat really motivates me. Somehow, I knew that HIV care was my destiny. I also wanted to work with interesting and needy patients in a field that would be stimulating and fast changing.

In mid-1994, after passing the examinations in internal medicine, we were asked by the Ministry of Health to fill our choice of specialty. I had put infectious diseases as the top choice. I remember vividly that Professor Chee Yam Cheng called me to his office the next day. He told me that Singapore has only one doctor (A/Prof Leo Yee Sin) trained in HIV medicine and that it needed more doctors to treat HIV infection. There was no formal interview. I got the job immediately!

Since then, there have been no regrets. Treating individuals with HIV has become the most important and life-changing part of my medical career. I could not be anything else but what I am today!

HOW HAS MY WORK CHANGED SINCE I FIRST STARTED?

I started HIV care in an era of programmed death – we are now in an era of projected normal life expectancy. In 1994, people with HIV had a terminal diagnosis. In the early years, we could

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offer little beyond prophylaxis and treatment for opportunistic infections along with comfort care for those who were sick or dying. Of course, we still have patients with difficult and challenging opportunistic infections and HIV-related diseases to manage. However, most of these patients who are currently in the wards are those who do not come for testing until they have AIDS or have disease progression because they are not on anti-retroviral treatment for various reasons.

With the advent of combination drug therapy including protease inhibitors from 1996, much of our clinical work has shifted from inpatient focus to the outpatient. It is hard to imagine how I could have coped if the miracles we witnessed after 1996 never occurred. Most of my patients are now on some form of anti-retroviral therapy, thanks to the availability of generic anti-retroviral medications that my patients obtained from Thailand. The cost of the drugs there is only one-tenth of the price of the original medications in Singapore.

Many of us have been amazed many times how patients near death become so much more alive after treatment. My longest living patient was diagnosed in 1988 and many of my patients diagnosed with AIDS in the mid-1990s are still doing very well today. Nowadays, most of the HIV work in the developed world is about designing the right anti-retroviral regimen and trying to persuade patients to take their medications. Research has shifted from a desperate search for any effective HIV drug to fine-tuning proven effective therapy.

WHAT'S THE BEST THING ABOUT MY JOB?

From the academic and scientific standpoint, HIV is one of the most fascinating diseases you could imagine. At my workplace, I am also surrounded by dedicated, compassionate and hardworking people who see work as much more than just a job. There are many wonderful volunteers who I befriended. But it is the patients who really nurtured my passion in HIV medicine.

HIV care has allowed me to interact with a whole spectrum of people, including the under-privileged and marginalised groups viz MSM (men who have sex with men), sex workers and prisoners. I learnt that no matter who they are, they are all human beings to be respected and not judged. From the patients, I learned a great deal about the diversity of the human spirit. For many, their will to carry on

"For many, their will to carry on and live even when things are depressing and chaotic really touched me." – Painting by a HIV patient in 1997.

and live even when things are depressing and chaotic really touched me. The loving support some patients got from their children, parents, partners, friends and volunteers is edifying. Now, whenever, I see relatives visiting the patients, instead of avoiding them like in the past when I was a junior medical officer, I will quickly run to them thanking them for coming, knowing that getting them involved and educated about illness improves patient outcome.

The blessings that I receive from my patients and their loved ones are what keep me showing up for work eagerly. Ironically, I feel that I am the one who receives healing from the patients I encounter. Over the years, I have become a better person. I have come to learn about my own fallibility and to appreciate love and not to take life for granted. They have taught me values like courage, hope, determination and humility.

With the multiple treatment options available, I have developed many fulfilling long-term patient-doctor relationships. I have been blessed as the HIV component of my practice has grown more than I could have ever imagined. I am thankful and humbled for referrals from physicians and patients. I calculated that I have now close to 300 patients on my follow-up list, and only about 9% of these patients have passed on.

WHAT'S THE WORST THING ABOUT MY JOB?

The failure to improve health for some patients. We have patients who cannot tolerate medications. I remember a pleasant young man with a lovely wife and young son. He had a zest for life and wanted to live. However, he just could not tolerate any regimen and died eventually. We all also have some patients who are reluctant to take pills and patients who elected to stop taking their much needed HIV medications in order to pay for other necessary family items.

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HIV medicine can be a lonely profession. Not many doctors are interested in this area and it was difficult to persuade doctors to come for our local AIDS conferences. However, attending regional and international HIV conferences, and interacting with so many passionate people who share a similar mission is truly an inspiring and energising experience.

WHAT DO I PROVIDE IN TERMS OF EDUCATION OR COUNSEL FOR A PATIENT WHO IS JUST DIAGNOSED?

Together with our social workers and nurses, we provide individualised HIV education and prevention education to our new patients.

There are patients who do not seem to realise how serious HIV can be and how much an active role they have to take regarding their health. But, of course, to those who are already infected, we want to avoid terrifying people. It is really a balancing act; to patients who are anxious, the first thing I do is to explain that they are not going to die, that HIV infection is a chronic disease and there are effective treatments available. I let them know what is ahead and that there is hope for them.

WHAT ARE SOME OF THE CHALLENGES AND PROBLEMS PEOPLE WITH HIV FACE TODAY?

It is still the stigma and discrimination. People with HIV feel stigmatised by all parts of society, even the medical field. One of the hardest things often is to get patients to comply with the medications. Some suffer from low self-esteem and some come from dysfunctional families. A few are very difficult as they have personality disorders. Nevertheless, we see these cases as challenges, and with love, compassion and patience, some do turn for the better. Other challenges include treatment for patients with multi-drug resistant HIV and continued access to HIV medications.

WHAT SINGLE CHANGE WOULD I LIKE TO SEE IN HIV CARE?

An effective vaccine. Meanwhile, it is encouraging to note that we are gearing up our prevention efforts. There is a need for a multi-sectoral and coordinated response towards prevention. It is also very comforting that some of the medical students I taught have indicated interest in HIV medicine as a career. ■