

The Four Tiers of Health Psychology and Parkinson's Disease

Geraldine Tan

Parkinson's Disease. is caused by degeneration in the brain that interferes with motor transmission signals. Parkinson's Disease is the 2nd most common neurodegenerative disorder after Alzheimer's disease in Singapore and is set to rise due to our aging population. The Parkinson's Disease Foundation in America found that as many as one million Americans live with Parkinson's disease, which is more than the combined number of people diagnosed with multiple sclerosis, muscular dystrophy and Lou Gehrig's disease. Approximately 60,000 Americans are diagnosed with Parkinson's disease each year, and this number does not reflect the thousands of cases that go undetected. More than 10 million people worldwide are living with Parkinson's disease. Incidence of Parkinson's increases with age, but an estimated four percent of people with PD are diagnosed before the age of 50. Men are one and a half times more likely to have Parkinson's than women.

It was the turbulent teenage years when my mother was first diagnosed. I recall that I was about 14 years old when that occurred. The thought of my mother having any sort of illness in those years was surreal. She was only in her early forties then. She was diagnosed with "juvenile Parkinson's". That was a great blow for her to receive that and to be told that it is a slow degenerative disease. I recall her recounting what was told to her that she would have shuffling and mask-like features. A few symptoms that the disease will bring. She was given a number of medications to take, vitamins, and even encouraged to go for physiotherapy.

Parkinson Society Singapore in 2015, estimates that some 4,000 people suffer from the disease in Singapore. It affects about three in every 1,000 seniors, aged 50 years and above. From 2013 to 2015, the Parkinson Centre has seen the number of clients grow from 250, to 700.

Most common symptoms of Parkinson's are uncontrollable shaking of the limbs, stiffness and difficulty in walking. The severity of symptoms for Parkinson's is classified into five stages. Stage one is the mildest form, where unusual symptoms may occur but they do not interfere with daily activities. In stage two and three, tremors and stiffness may become more noticeable, and loss of balance can occur. It is usually in stage three that falls are most common. It is in stage four and five that Parkinson's patients may lose their independence. They may have to rely on a walker or wheelchair, or in the more severe cases, are not able to live by themselves. Poor coordination can also lead to swallowing difficulties. Neurologists say this affects between 45 and 95 per cent of patients.

My Mother's Experience

There is little recollection now the reason my mother had to seek help. And she was in Stage One. Again, I need to reiterate that it was totally unexpected and there was no warning. What happened after the diagnosis was a crushing defeat of her realization that she would eventually be reliant on others and the helplessness is being felt acutely even until today. During that period, we were dependent on the doctors to provide the information as Information Technology was not as easily available as it is now.

The support group was set up in 1996 a few years after she was diagnosed and she was encouraged to go for it. But the years in-between she moped and reclused herself. My father was busy with work and at the peak of his career. And my mother was a stay-at-home-mum working freelance as a nurse. Her diagnosis paralyzed her for a while and she refused all jobs thinking that she is not able to manage crisis if they were to occur. It was tough as I was going through my teenage phase. I was attempting to seek my identity while she was dependent on my presence, actually, I think she was clinging on to my presence.

Spirituality came in as an escape for her. She became more religious and a fervent in her beliefs. She then pushed it onto us, me I think and left me confused. Many “friends” then attempted to speak to me about the bible and wanted me to attend their church. I eventually went to back to Catholicism and was baptized.

All these times, the information was provided by the medical personnel and often we had no one to ask or turn to. By the time the support group had formed, my mother had gone through rather depressive bouts, obsessive bouts and even manic phases. Her manic phases were really funny as she would buy loads of lovely clothes and wear them. Looking back, she must have felt her end time was soon. The support group was supposed to be another avenue resource for the patients. However, as my mother was going through her manic clothes buying phase and dressing up, she was lauded for her “positivity” and “acceptance”. She felt good that she was helping others but in my perception, it was not useful for her and they had missed her manic coping style.

Not too long after, she cycled into another depressive cycle and by that time I was in Junior College and she complained of feeling “electric currents” along her leg. Tests were ran and nothing was found. She claimed she could hear God speaking to her and I kept telling the doctors that I think it was something more but I had no idea what it was. The doctors would not listen as I was really too young. Going with my intuition, I did not refute when she told us but gave her a lot of concrete anchoring of touch, of words and visuals. We passed that stage and I was researching about Parkinson’s and the treatments. Lo and behold, there is no cure! The words were ringing yet again. One would have thought that after so many years that there was still no cure! There was stem cell research but it was far away from Singapore.

Up till this point, in 1998, there was still little public knowledge and publicity about Parkinson’s. I recall that the boxer Muhammad Ali was diagnosed with that, but many people

blamed it on his boxing career. And Charlie Sheen who was also diagnosed, had his lifestyle scrutinized. It was awful as it did not answer how my mother had the disease and if there was any hope.

Today, my mother is in Stage Three and Four. She was recently just rediagnosed in the last quarter of 2016. It meant that she had been managing over two decades with the illness and that in itself is quite a medical feat. But she after accepting the fact that she needed to use the aid of the walking stick, she is now freezing on her walking. What she hates most is people telling her to exercise as it is a daunting task even if she wanted to. The tremors are visible and embarrassing and she for a period of time, she was not able to leave the house as she was not confident that she will be able to walk without falling.

Challenges, aplenty.

Tier 1: Bottom of the Cliff

At this point, the treatment of Parkinson's is usually pharmacologic. The treatment can be divided into symptomatic and neuroprotective (disease modifying) therapy. At this time of writing, there is no proven neuroprotective or disease-modifying therapy.

Levodopa, coupled with carbidopa, a peripheral decarboxylase inhibitor (PDI), remains the gold standard of symptomatic treatment for Parkinson disease. Carbidopa inhibits the decarboxylation of levodopa to dopamine in the systemic circulation, allowing for greater levodopa distribution into the central nervous system. Levodopa provides the greatest antiparkinsonian benefit for motor signs and symptoms, with the fewest adverse effects in the short term; however, its long-term use is associated with the development of motor fluctuations ("wearing-off") and dyskinesias. Once fluctuations and dyskinesias become problematic, they are difficult to resolve.

Symptomatic anti-Parkinson disease medications usually provide good control of motor signs of Parkinson disease for 4-6 years. After this, disability often progresses despite best medical management many patients develop long-term motor complications, including fluctuations and dyskinesias. Additional causes of disability in late disease include postural instability (balance difficulty) and dementia. Thus, symptomatic therapy for late disease requires different strategies.

Dopamine agonists (ropinirole, pramipexole) provide moderate symptomatic benefit and delay the development of dyskinesia compared with levodopa. Proactively screen patients receiving oral dopamine agonists for adverse events. A review of the Cochrane and PubMed databases from 1990 to 2008 found that these agents caused a 15% increase in adverse events such as somnolence, sudden-onset sleep, hallucinations, edema, and impulse control disorders (e.g., pathologic gambling, shopping, and Internet use; hypersexuality; and hoarding). The side effects were not told to us during the treatments and it was quite worrying when my mother was telling us about the voices and “electric currents” that were running up and down her leg. Only much later the doctor decided to give her risperidone but the simple solution was to decrease her symptomatic medication.

The need for the medical personnel to be well versed with the disorder is vital and it was appalling that was not the case then. When the patient is hit with the news, he will need as much information as possible to ensure that he can recalibrate his life as soon as possible.

At the initial point, the physiotherapist was allocated to my mother. However, at that point, there was not real need for the physiotherapist but because it was the “procedure” she was encouraged to go. Instead, perhaps a lifestyle change was in order. Later in the years, it may be good to then refer her to the physiotherapist for more appropriate exercises at that time.

Tier 2: Safety Net

There is not half way point for Parkinson's and I reckon the safety net would not be recognizing the symptoms of shuffling or mask-like features but the rest of the associated symptoms that is brought about by the disease. There is a whole myriad of issues like, psychosis, anxiety, depression, sleep issues, anhedonia, apathy and even impulsive-obsessive disorder.

Nowadays, the patients are more informed to look out for these symptoms. It is vital that they are informed and as we look at the disorders that may co-morbid with Parkinson's, we can actually manage those disorders rather than Parkinson's itself. Lifestyle changes may be in order. An increase of exercise or activities can help to alleviate depression and anxiety. Decreasing stressors in the daily life can also improve the symptoms of the associated disorders and improve sleep.

Support groups and family support and activities are vital to keep the patient engage with the community and not be alienated. Teaching the family members what to expect, how to engage the patient, how to approach certain symptoms creates a conducive environment for the patient to be. For example, before, when my mother had some rigidity, the doctor did not bother to tell us what we can help her with. It was only during psychology class when we learnt about the disorder did I learn we can help her imagine "stepping over" things. Currently, as her dyskinesias is rather pronounced and we know that it is distressing for her, I have learnt to act nonchalant so as not to add to her stress. It worsens when she feel anxious or excited and will leave her rocking to and fro at a spot. By not reacting to it, she then does not feel even more stressed my "dramatics". These can be psychoeducation for the family members.

Tier 3: At the Edge

Although there are no actual “causes” for Parkinson’s, there have been some groups that seem to be more susceptible than others.

1. Advanced age - Although there is the occasional case of the disease being developed as a young adult (like my mother), it generally manifests itself in the middle to late years of life. The risk continues to increase the older one gets. Some researchers assume that people with Parkinson's have neural damage from genetic or environmental factors that get worse as they age.

2. Being male - Males are more likely to get Parkinson's than females. Possible reasons for this may be that males have greater exposure to other risk factors such as toxin exposure or head trauma. It has been theorized that oestrogen may have neuro-protective effects. Or, in the case of genetic predisposition, a gene predisposing someone to Parkinson's may be linked to the X chromosome.

3. Family history - Having one or more close relatives with the disease increases the likelihood that you will get it, but to a minimal degree. This lends support to the idea that there is a genetic link in developing Parkinson’s. Hence my risk seems to be high!

4. Declining oestrogen levels - Post menopausal who do not use hormone replacement therapy are at greater risk, as are those who have had hysterectomies.

5. Toxic exposure - Exposure to an environmental toxin such as a pesticide or herbicide puts you at greater risk. Some of these toxins inhibit dopamine production and promote free radical damage. Those involved in farming and are therefore exposed to such toxins have a greater prevalence of Parkinson's symptoms.

6. Genetic factors - A Mayo Clinic led international study revealed that the gene alpha-synuclein may play a role in the likelihood of developing the disease. Studies showed that individuals with a more active gene had a 1.5 times greater risk of developing Parkinson's. These findings support the development of alpha-synuclein suppressing therapies, which may in the long run slow or even halt the disease.

7. Low levels of B vitamin folate - Researchers discovered that mice with a deficiency of this vitamin developed severe Parkinson's symptoms, while those with normal levels did not.

8. Head Trauma- Recent research points to a link between damage to the head, neck, or upper cervical spine and Parkinson's. A 2007 study of 60 patients showed that all of them showed evidence of trauma induced upper cervical damage. Some patients remembered a specific incident, others did not. In some cases Parkinson's symptoms took decades to appear.

Tier 4: Away from the Edge

There is no known way to prevent Parkinson's disease. Research has shown that people who eat more fruits and vegetables, high-fiber foods, fish, and omega-3 rich oils (sometimes known as the Mediterranean diet) and who eat less red meat and dairy may have some protection against Parkinson's. But the reason for this is still being studied. There have been other research that shows caffeine in coffee or green tea as being useful for the prevention of Parkinson's. However, all these are also not conclusive.

In conclusion, Parkinson's is a disorder that is rather mysterious. The causes are elusive and there are no actual treatment for the disorder despite advancement in medical technology. Yet, there are many areas that we can help the patient and the family. These methods are similar to how we manage our clinical issues. If there are more effort and care with the patients and their family, the quality of life for the patients and their family can still be rather rich.

References

Aarsland D, Karlsen K. Neuropsychiatric aspects of Parkinson's disease. *Curr Psychiatry Rep.* 1999;1:61–8.

Hauser, R. A. (2016) *Parkinson Disease Treatment & Management*. Medscape

<http://www.parkinsons.org/parkinsons-risk-factors.html>

Karlsen KH, Larsen JP, Tandberg E, Maeland JG. Influence of clinical and demographic variables on quality of life in patients with Parkinson's disease. *J Neurol Neurosurg Psychiatry.* 1999;66:431–5.

Meara J, Bhowmick BK, Hobson P. Accuracy of diagnosis in patients with presumed Parkinson's disease. *Age Ageing.* 1999;28:99–102.

Parkinson's Disease Foundation http://www.pdf.org/en/parkinson_statistics

Parkinson Society Singapore <http://parkinson.server281.com/Treatment.php>

Schrag A, Jahanshahi M, Quinn N. What contributes to quality of life in patients with Parkinson's disease? *J Neurol Neurosurg Psychiatry.* 2000;69:308–12.