Life & Times

How can we understand illness?

Phenomenology and the pillar of person-centred care

INTRODUCTION: A PHENOMENOLOGY OF ILLNESS

Understanding illness, defined as *'a feeling, an experience of unhealth which is entirely personal, interior to the person of the patient'*,[1] is a central task of a physician's life. McWhinney's principles of family medicine state, *'The family physician attaches importance to the subjective aspects of medicine'*,[2] which encompasses the understanding of illness and people. Although understanding illness is an essential task for family physicians, achieving it is challenging. The reason is that illness is a first-person experience, only available to the patient concerned.

The key to closely approaching a patient's illness is empathy. Edith Stein, a German philosopher, describes that empathy *'allows me to see or understand the inner life of another and the body of the other as both other and similar to my body'*.[3]

To understand illness with empathy, there is a helpful reflective mode, phenomenology. Phenomenology itself has been developed by various philosophers such as Husserl, Heidegger, Sartre, and Merleau-Ponty.[4] Among recent phenomenologists, Toombs and Carel have elaborated particularly on the phenomenology of illness. Havi Carel, a professor of philosophy at the University of Bristol, explores what patients experience when ill using phenomenological analysis in her book, *Phenomenology of Illness*. She introduces phenomenology as *'a method for examining pre-reflective, subjective human experience as it is lived prior to its theorisation by science'*, and it *'enables us to direct our attention towards others in thoughtful empathy'*.[5]

ONTOLOGY IS A STUDY OF BEING; PHENOMENOLOGY IS A STUDY OF EXPERIENCE

This idea is not familiar to us because we are deeply immersed in the world of ontology. Ontology is the study of 'being', and can be a way of thinking that there are invariants in reality.[6] Most evidence in medicine, especially quantitative, has been founded on ontological grounds. For example, in the view of the ontological thinker, the effect of a drug must be universal when all other conditions are the same. While ontology is a study of being, phenomenology is a study of experience.[4] Phenomenology, together with medical anthropology, sociology, psychology, and qualitative research, is vital to reaching a comprehensive understanding of the experience of illness.[5]

ILLNESS EXPERIENCE AND REFLECTIVE LEARNING

I experienced minor illness: calf pain. I reflected on this experience using Carel's book as a guide and gained meaningful insights that helped me better understand a patient's illness.

I enjoy a 5-km run in the morning. One day, I felt pain in my left calf when running. At first, it was vague and I continued to run. However, the pain gradually grew, and finally I had to quit running. After that, the pain hit me for several days even when I just walked, and I found that the commute to work seemed endless. Running had been my irreplaceable pleasure but the pain now disrupted my life and enjoyment; I feared that running pain-free was no longer guaranteed in the future. One week after the event, the pain had almost disappeared. I started running carefully at a gentle pace. I then felt subtle discomfort in my left calf. While I was running, I was nervous about this sensation in my left calf and felt profound fear every time I took the next step, anticipating a relapse of pain. I continued to doubt the competence and wholeness of my leg. Eventually, however, I could complete a 5-km run without pain. This accomplishment allowed me to regain some confidence. I ran slightly faster the next day, but didn't feel any pain. I felt that I was getting back to my usual self.

REFLECTIVE LEARNING: CALF PAIN

Bodily doubt. Phenomenology can shed light on our unaware embodied existence. Carel argued that we have a tacit certainty about our bodies, unrecognised in daily life except when we experience its breakdown in illness, called bodily doubt.[5] Bodily doubt disrupts our normal experience of bodily continuity, transparency, and trust. From the occurrence of the calf pain, the continuity of my body, which I had experienced implicitly, was interrupted. I needed to pay explicit

> *"... we have a tacit certainty about our bodies, unrecognised in daily life except when we experience its breakdown in illness ... understanding the general aspects of illness can cultivate our creative capacity of empathy towards patients."*

attention to my body and physical activities; my body was once transparent (that is, not the thematic object of experience), as Sartre described,[7] but was no longer. Even after continuity is restored, the possibility of doubt persists, contaminating future experience. It consistently reminds us of *'the contingency and fallibility of the original continuity'*.[5] It seems that a similar experience can be seen in cancer survivors.[8] Although cancer has gone, the possibility of doubt doesn't disappear, and patients live in fear of recurrence.

Pursuing our purpose. I lost trust in my body. For me, running has been an irreplaceable joy and one of my main motivations in everyday life. Cassell argues that people need to function well enough to pursue their goals in order to have a sense of wellbeing.[9] Furthermore, he states: *'The basic aim of healers must be the enabling or return of function so that patients may pursue or achieve their purposes and goals.'*[9] In response to these, many consultation models that focus on person-centredness explore function,[10] effect on life,[11] and aspirations and purpose in patients' lives.[10]

Loss of the familiar world. I experienced the loss of wholeness, bodily doubt, the inability to walk as normal, and the strain of the commute. Toombs describes the five essential features of illness: loss of wholeness, loss of certainty, loss of control, loss of freedom to act, and loss of the familiar world.[12] I realised that I indeed experienced all of those features. Of these, loss of the familiar world needs special mention. Illness prevents us from continuing our usual activities, including social participation. The loss of shareable experience with other people deepens an ill person's sense of loss. Furthermore, previously established plans according to the familiar world have to be adjusted in light of the ill person's new world. This kind of loss and these adjustments can occur in survivors of stroke.[13] They suffer the loss of the familiar world, adjustments of future plans, and participation restrictions.

ILLNESS: WRIST INJURY

Another illness that I recently experienced was a left wrist injury. I acquired this injury from climbing a chair and falling while trying to change a light bulb in the living room. Immediately after the injury, my left wrist started aching and became swollen. I received radiography of the wrist repeatedly but there was no evidence of fracture. So, I continued daily life without bandaging or immobilising the wrist. I felt pain, but nobody cared for me because I had not shown any outward sign of being ill. Furthermore, this injury prohibited me from pursuing my daily routine, a handstand push-up. My body suddenly changed to one unable to perform the training routine. I felt that the injury diminished my value as if I would never be able to do it again. Several weeks later, my wrist still hurts after strenuous exercise. However, I finally found a way to train myself. Push-up bars allow me to perform handstand push-ups without feeling too much pain in the wrist. My wrist is not fully repaired, but I can resume my routine. Although I have an illness, I feel a sense of wellbeing.

REFLECTIVE LEARNING: WRIST INJURY

Illness as first-person experience. We cannot understand whether a particular person has an illness from the outside. Thus, as many person-centred consultation models suggest,[10,11] we need to ask patients what they experience, even if they do not appear to have illnesses.

Wellbeing in illness. Although bodily continuity is disrupted, we can still pursue our goals through various adjustments. In that case, we can reorganise our wellbeing. Sometimes, this process occurs reactively without reflection, as in my case. However, illness instead can also be seen as changing the ways of being. For an ill person, the future is full of uncertainty. To overcome this fear of uncertainty, we need to re-evaluate time as something not to take for granted but to cherish. McWhinney quotes a long-term survivor of metastatic osteogenic sarcoma: *'Hope for the present moment is the capacity for living in the moment by developing the practice of mindfulness.'*[2] This kind of philosophical reflection could occur in patients receiving palliative care. I remember several patients who I cared for experiencing similar spiritual realisations.

CONCLUSION: PHENOMENOLOGY IN FAMILY MEDICINE

Although my ailments were transient and minor, the experience and the reflection provided me with a foundation for understanding patients' persistent and profound illnesses. Just as we cannot diagnose diseases without knowing about clinical reasoning and diseases, we cannot understand each patient's illness without knowing about person-centred care and general aspects of illness. Although illness is an entirely individual experience, phenomenology can facilitate our understanding of the shared aspects of the human experience of illness. Carel states: *'The purpose of abstraction is to understand that world and then return to it with new sensibilities.'*[5] Therefore, understanding the general aspects of illness can cultivate our creative capacity of empathy towards patients. It can further enhance the patient–clinician relationship, the most therapeutic aspect of family medicine.[10]

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