The Psychological Journey of SARS:
observations and reflections of a physician

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SARS, as a new disease, brings most of us to a journey that is totally new to us. One may try to understand it from a perspective of a disaster; from that of a battle; or an event with multiple losses and yet with gratification from valuable life lessons. A lot is still unknown about SARS, and so is its psychological impact. The following discussion is based on the experiences and observations in the SARS ward, and hopefully will shed light on how to help those who are still profoundly disturbed or distressed by this event.

Tension in facing the paradox

One striking observation is the constant tension that occupied one’s mind while facing the paradox. The paradox, as observed, include the effect of disease and that of treatment; the boredom of the disease in contrast to its volatility; the will and need to maintain hope on one hand and to face the constant threat of death on the other; and the struggle of the identity as a caregiver, a victim, and a spreader.

The disease and the treatment

The disease, as defined by the term SARS, though primarily one of the respiratory system, can affect the mental state in various ways. High fever, hypoxia, electrolyte imbalance can cause mental dullness or even delirium. Not much is known about infection of coronavirus on human nervous system now, but as more is known about the science of the disease, this will be unraveled.

The treatment of SARS was empirical to start with. Patients and relatives were informed that, with this new disease, treatment offered was not proven in trials, but believed to be useful. This information giving, which used to be an important part of informed consent, was overwhelmed by the perceived urgency of treatment and the despair of contracting such a disease. Having something to do and to give was perceived as pivotal to preserve hope. Refusal of any drugs offered was rarely encountered, however, regrets, queries and anger were not uncommon afterwards. Doctors faced the same stress. The desperation to kill the virus was manifested as the urge to give a puzzling high dose of drugs with the slightest suspicion of its trace. The wisdom of treatment,
instead of giving all you had in your hands, was more that of resisting this temptation.

Drug treatment, notably with steroid, could cause mood changes and even psychosis. It was probably easier to diagnosis one with “steroid psychosis” then to elucidate all the possible underlying causes of the mental changes. Keeping an open mind by considering all other psychosocial impacts on the mental state was important. An understanding and empathetic attitude, instead of juggling with the dose of steroid, might give the difference.

**Boredom and volatility**

Despite the overwhelming fear, both patients and health care workers complained of boredom. The boredom of patients was more than the isolation from families and friends. The daily routine was fixed and reduced a minimal provided there was no drastic change in condition. Three meals a day were provided in disposable boxes. Blood were taken in the morning and chest radiograph before lunch. The only activity away from bed was to follow his/her own familiar route to the washroom, and to sit on the chair for radiograph to be taken. Health care workers who approached them were featureless and indistinguishable from one another. “I could only recognize one nurse with confidence, for she was extremely short”, one patient said.

Patients soon learned how their disease was monitored; the body temperature, the lymphocyte count, and the chest X ray changes. Dialogue with doctor could be as simple as a weather report. People were at least 3 feet away – safe from the droplets, but also beyond reach of arms and touch of hands.

For health care workers, meticulous repetition and slow motion were rules to obey. They lost count of how many times they washed their hands, or changed their gloves, or putting on all the gadgets before performing a trivial task. They too follow a highly regulated work pattern, following certain directions as they moved in the ward, only take in food and eliminate wastes at preset times of the day.

On the other hand, the disease was dramatically volatile. Body temperature rose up to 40C within a day, and could plunge down like a waterfall with steroid. Difficulty in breathing appeared overnight, and brushing teeth in the following morning became a heavy task for a previously fit adult. Chest radiographs progressed with alarming speed, with nerve-racking changes.

**Will to live and threat of death**

“I am too young to die,” was a thought that was common to many of the patients. “ I am not prepared”, was probably the other. Whether you were patients or health care workers, there were your beloved ones waiting for you at the doorsteps. This was perhaps the greatest source of strength in maintaining the will to live, and the will to remain vigilant in the midst of fear. Gratefulness, appraisals, encouragement, gifts were generously sent to all who were under the threat of virus and hence death.

The threat of death was genuine, even though the physical body was not decaying as in other life threatening illnesses. The shortness of breath was approaching that of suffocation. Seek for early treatment, as the authority said so, would mean good outcome. However, very soon after admission, patients realized that this was not necessarily so. Even robust and kind-hearted staff was not exempted from the disease. One was never too young to die.

The death would be no ordinary one. The journey started totally unprepared at the point of departure at the front door of the hospital or at home. Instead of surrounded by your loved ones, the dying process was one of extreme loneliness;
at least so for the physical body as rigidly required by the public health care policy. This loneliness would accompany the living body, the corpse, and even the ashes.

What did this disease mean to those who were no longer young? Could SARS be another valuable life lesson for them, when in fact they had had so many already? Could recovery from SARS bring along revival, when in fact it only add another entry to their own accounts of chronic debilitating or life limiting illnesses? An advanced cancer patient put her thumb down and shook her head to express her boredom and helplessness when greeted by the health care team, despite a good recovery from SARS. It was not easy to refute. After all, finding positive meaning in this event for an old lady with life limiting cancer needed great faith.

For most of the elders, they might not be able to comprehend the complicated issues of being regarded as highly vulnerable to the disease, and yet alleged by some to be a silent spreader; not to say the energy to defend themselves.

**Identity as a caregiver, a victim, a spreader**

For those who survive, the struggles as mentioned above are not those confronting them now, though long lasting memories will remain. As they return to the community, or as things revert to their normality, there follows the hardship of returning to the reality.

Care providers gained the highest appraisal ever in this event. However, being a caregiver was seldom the one and only identity. Sacrifices were too many: pain or even bleeding with repeated hand washing; sweats from layers of protective clothing; a restrictive life style not very far from that of a patient; the threat of being infected; the threat of death; and in a few, that was a threat came true. How much to give away and how ready to give away were individualised. There would be a time or threshold when they recognized themselves as victims, with a hidden or overt notion that someone or something was culpable. It had been recognised in study that care providers, including health care workers and families, to patients with life threatening illness such as AIDS were hidden victims because of the psychological impact of the caring process. If unresolved, the emotional conflicts would jeopardize the patient-caregiver relationship and hence the delivery of care. The high demand for care from the providers was conflicting with the great urge to be cared for.

“Care” has now emerged in various forms: countable compensations; medals of glory; and a rose garden of appraisals. For many health care workers, who do not believe they should loss their life in order to provide care, and indeed who have not, dollars and gold are nothing worthy to them. The zest of calling health care workers heroes is nothing more than a hollow victory if we ourselves do not have intrinsic values incorporated. The emptiness after the event, as experienced by some of the workers, is more than the fatigue from this enervating event. They belong to a group who do not call themselves victims and heroes, which the society has conveniently dichotomised. They have the willingness to exhibit their professionalism, but not a willingness to die. They may not have the glamour to be the light, but they are more than happy to be the salt that dissolves to add flavour. Their spirituality has grown, but they have not found a suitable environment to discuss and link with others.

The issue is further complicated by the fact that one can also have the identity as a spreader in addition to the above. For those who have had all such identities at one time or another, the emotional conflicts may seem irresolvable. The basic instincts and values of health care workers are to achieve cure and care, and to bring good to the patients. Guilt, self-doubt, low self-esteem can
arise when these basic goals are not fulfilled or violated. This is also the struggle of many workers as they have to compromise the caring process because of risk of infection. Self evaluation journey may be too painful to begin, or too enmeshed in struggles to continue. Patients and workers feel nurtured as they learn how to love: themselves, families, friends and things around them. This is an unanimous response from all. However, they also need to learn to forgive, especially of themselves, in order to bring along peace in mind. This forgiveness has nothing to do with over coming judgment, punishment or compensation. This forgiveness is not a bypass route of letting go, forgetting, and condonation; and this is not self deception. This needs a safe and supportive environment so that they can address them honestly and have an objective verification of the difficult process.

Bravery or courage, so often mentioned in the event, is not something a merit on its own. Bravery will only bring good if humbleness is the foundation of it. In front of this new virus and fearful disease, one needs humbleness to bring good protection and then courage to move on. In going through the psychological journey, one needs the humbleness to face our own weaknesses, and hence courage to forgive.

References:
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