「苦與樂」研討會

「在痛苦中成長：社會服務的啓示」圓桌會議

Living with Suffering

Ms. Catherine Tsang (Medical Social Work Service, Bradbury Hospice)

曾玉珍女士（白普理寧養中心沙田慈氏護養院）

When cure is not possible, the relief of suffering is the cardinal goal of medicine. In facing death and dying, suffering is common to terminal patients. The terms “suffering” and “pain” are often used interchangeably within the medical literature since pain and symptoms are prevalent to terminal patients. However, this will easily lead to an incompleted understanding of the fullest sense of suffering. Regarding pain as suffering is a profound misunderstanding of human suffering. Indeed, suffering extends beyond the physical.

What is suffering? Frankl believes that physical discomfort and deprivation are not sufficient to cause suffering as suffering depends on an experienced loss of meaning and purpose. Cassell understands suffering through the construct of personhood and described suffering as arising from a threat to the integrity or intactness of the person, and explained multiple factors or conditions contributing to that threat. Cicely Saunders has described suffering as “total pain” caused by physical, psychological, emotional, existential and social factors. For Cherny and Coyle, they describe suffering as aversive emotional experience characterized by the perception of personal distress generated by factors undermining the quality of life. Furthermore, taken from a family perspective, development of terminal cancer in a family member has great impact upon the entire family. Hence, not only does suffering occur among terminal patients, it also exists among the families of patients. The suffering of patient and family is interrelated and their distress may amplify the distress of the others.

Suffering occurs when the destruction of the person is sufficient. There are various aspects of personhood, including the lived past, the family’s lived past, culture and society, roles, associations and relationships, the body, the unconscious mind, the secret life, the perceived future, and the transcendent dimension, etc. and these aspects are susceptible to damage and loss. Injuries to the integrity of the person may be expressed by sadness, anger, loneliness, depression, grief, unhappiness, rage, withdrawal or yearning. However, the affect is only the outward expression of the injury, not the injury itself. We have to enter the patient’s inner world to understand what damage or injuries have caused his/her suffering since the

individual experience of each patient is very unique.

Persons are able to enlarge themselves in response to damage and grow in suffering. To some degree, and in some persons, this may be true. However, in the context of incurable disease, when patients are never able to return to the normal function and when dying and loss of ourselves are inevitable, chronic suffering frequently follows and the ring of suffering will not stop ringing. As persistent suffering will undermine the value of life and pain and suffering are closely related in medical sphere, many efforts have been dedicated to pain and symptom control. While controlling pain and other symptoms can offer consolation to some patients who suffer, it does not necessarily ease the whole suffering experienced by the patient. Actually, when dying patients are free from physical symptoms, they may have more space to contemplate their situation, fate and result in more suffering. As suffering involves psychosocial and existential factors, medicine definitely is not the sufficient answer to human suffering.

How can we help a patient tolerate and live with suffering? When confronted with persistence of suffering, our task as social workers is not to provide ultimate answer, but to manifest ultimate commitment to act for the good of our patient even when it's hard to see the success. We need to acknowledge our unknowing in facing suffering, to empty oneself and to listen since there's no algorithms. Instead of aim at controlling suffering, a different perspective is required. It is a perspective that embraces the suffering of another. During the interaction with terminal patients, "compassion" which means "to suffer with" is the soul of care for patients who suffer. With our heart and mind prepared, we could try to use "receptive and generative imagination" as a tool to respond to suffering in a deeper way.

When dealing with terminal patients', the complexity of the person and the personal meaning of the suffering should be emphasized. Attempts should be made to understand all the known dimensions of personhood and their relations to illness and suffering. Since the worst aspect of suffering is the endlessness, helplessness and absolute loss of control embodied in suffering, our interventions should aim at helping patients retain, regain and to realize a sense of intactness and integration, uncover an enhanced sense of hope, meaning and purpose within his/her personal experience of dying and discomfort. For families, supportive care to address family's stress caused by empathic suffering with the distress of the patient, grief and bereavement, role changes, and the physical, financial and psychological consequence of the burdens of care is also essential.

Yet, no matter how hard we try, we don't have the right or power to claim mastery over human suffering and we must not assume our goal is to extinguish all suffering. Expectation of control of suffering precipitates false expectation. Patients, their families, and clinicians become victims of these false promises and may impel clinicians away from the sufferers they care for.