Suffering As The Concept Of Modern Society

Suffering is an important concept in the end of life care which diminishes quality of life and it tends to be widespread in terminally ill patients. Dame Cecily Saunders coined the concept of ‘total pain’ and outlined some of the various physical, psychological, emotional, existential, social factors contributing to suffering. While these factors may contribute separately to suffering, a synergy often occurs among them. As a result, when one dimension of a person is threatened, this can provoke or add problems in another dimension which can lead to an overall increase in suffering for patients. This not only affects patients but also their families and the professional caregivers attending them.

Suffering is not coded or classified as a diagnosis in the ICD, rather it is a phenomenon of conscious human existence. Suffering is subjective, personal and unique to each individual as human beings perceive themselves as having a sense of self. Tate and Pearlman outlined three domains of a person’s sense of self: their relationships, their roles, and their self-narrative. A person is prone to suffering when one of these domains fade and experience negative affect. Although RL’s story is a typical example of the kind of stories about suffering, it is also completely unlike any of the others in the specific details. RL’s suffering was the result of his disease, response to treatment, his role in his family, his perception of the future and various aspects of everyday life that occurred in combination with his unique personal, social and cultural identity.

Although pain and suffering are closely linked and used interchangeably, current consensus shows that they are separate entities. Pain is rarely the only cause of suffering in cancer patients, but extreme pain alone is adequate to cause and sustain suffering. The International Association for the Study of Pain defines pain as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage'. Pain occurs in response to a noxious stimulus and poses a threat to the physical integrity which results in somatic expression. According to Krikorian and Limonero, when the threat is recognised as damaging to the integrity of the whole and regulatory processes and coping efforts are insufficient, the process results in exhaustion and suffering.

Whilst significant pain is present in approximately two-thirds of patients with advanced cancer, other physical symptoms have been reported which can equally diminish patients’ quality of life. According to literature, suffering is strongly correlated with physical symptoms such as pain, weakness, and dyspnoea and can be the dominant component despite the multidimensional nature of suffering. In a study conducted by Walsh D et al, the prevalence of physical symptoms ranged from 50%- 84% according to age, gender and performance status in cancer patients. Higher levels of symptom burden and higher levels of suffering were much more pervasive in younger patients likely due to added psychosocial distress. This was evident in the case of RL, where pain was a predominant and challenging symptom for him and further deterioration towards the end of his life contributed to further symptoms such as weakness and fatigue which compounded to his escalating suffering.

Advanced life threatening illness can often compel patients to face their mortality and this can trigger profound existential suffering as everyday life and the future are threatened for both

patients and their families. Although existential issues have been extensively analysed by philosophers, there is no widely agreed upon definition within their teachings. Strang et al. conducted a study involving hospital chaplains, palliative care physicians, and pain specialists, to define existential pain. The definitions ranged from those that stressed issues of guilt and religion (chaplains) to those that related to annihilation and impending separation (palliative care physicians) and those emphasised on “living is painful” (pain specialists). They concluded that existential pain is most often used as a metaphor for suffering and a clinically important factor that reinforce existing physical pain or even the primary cause of pain.

Existential suffering may point to past, present or future concerns. Distress from retrospection can often bring about remorse from unresolved guilt, disappointment related to unfulfilled wishes. Present concerns may involve disrupted personal integrity which includes changes in body image, changes in social and professional function, and perceived personal allure as a person and sexual partner. Anticipation of the future may trigger feelings of hopelessness, meaninglessness, futility, separation and death anxiety.

Death anxiety is an expression used to “conceptualise the anxiety caused by this unique concern of death awareness”, and have been well illustrated by studies using the Death and Dying Distress Scale (DADDS). Yalom described mortality as an existential domain in which awareness of the inevitability of death and a wish for life to continue. This then manifests as anxiety about dying and afterlife and concern about separating from loved ones. Several factors such as age, individual factors, culture, spiritual beliefs, family circumstances and physical suffering can influence the degree of death anxiety in an individual. Death anxiety is common among cancer patients and younger adults have shown to have greater death anxiety compared to older adults. In a Canadian study, death anxiety was positively correlated by fears about the effect of one’s death on others, physical symptom burden and having children under the age of 18 in the family. Only a small proportion of patients showed an untroubled acceptance of death.

Terminal restlessness affects approximately 25% to 85% of all dying cancer patients during the hours or days before their death and it can be a terrorising experience not only for patients but also for family and caregivers. Terminal restlessness is a hyperactive variant of delirium in a dying patient, frequently associated with impaired consciousness. It is a phenomenon generally accepted to be multi-causal with coexisting multisystem failure, physical, emotional, existential/spiritual and psychological factors. Apart from poor pain control, patients with feelings of guilt, remorse, unresolved interpersonal conflicts, or unfinished business prior to death are at higher risk of terminal agitation. Existential/ spiritual causes are as equally weighted as physical and psychological causes in contributing to terminal restlessness. Existential issues including death anxiety can cause patients to become increasingly agitated and distressed as their clinical condition declines possibly as a result of loss of voluntary cerebral inhibition. Terminal restlessness in the home setting is particularly tragic for the family as the memory of this confused, agitated, distressed stage of dying is etched in their minds and hearts which can ultimately lead to complicated grief and bereavement.

The multidimensional components of suffering consisting of physical, emotional, social and spiritual distress not only affects the patients but also their family/ caregiver. The suffering and needs of the family escalate as the patient’s disease progresses with both patient and family facing significant changes in their roles, identity, daily functioning and quality of lives. The levels of patient and family distress and adjustment difficulties were interrelated and as a result, the suffering of one amplifies the distress of the other. This is described as reciprocal suffering.

Northouse and Peters-Golden described the three causes of spousal concerns: fear of cancer and its spread, helping the patient deal with emotional ramifications of the disease, and managing the disruptions caused by cancer. Beeney, Butow and Dunn reported conflicting emotions and adjustment tasks in the partner or spouse of a person with cancer, including conflict among feelings of loss, sadness and sometimes guilt; difficulty in knowing how to talk who is dying; worry about the possibility of death and difficulty in adjusting to bodily changes in the partner. Factors such as spousal age, gender, socioeconomic status, personality, social support, coping skills as well as the marital adjustment of the patient and caregiver may influence the degree of distress in spouses.

According to Compas et al, children whose parents are diagnosed with cancer experience psychological maladjustment. Children, adolescents, and young adults reported moderate to high levels of emotional distress when their parent was diagnosed and treated for cancer. Armsden and Lewis reported that young school-age children had difficulty comprehending the concept of cancer and their emotional responses were fear, loneliness, anger and uncertainty about the future.

Physicians work constantly with patients and family struggling through devastating illness and are constantly exposed to distressing events such as exposure to suffering, death and dying and this can challenge their clinical and emotional resources. Suffering of patient and family can cause an intense emotional reaction, it is therefore not surprising that healthcare workers, especially physicians, respond to them with emotions of their own. These may include a need to rescue the patient, feelings of disappointment and a sense of failure when the disease advances, feeling helpless and powerless against illness and its associated losses, grief, fear of becoming ill oneself and an intense feeling to separate from and avoid patients to get away from these emotions. Physician wellness experts agree that ‘the death of patients is an experience that almost all physicians must confront’ and they believe physicians’ psychological distress stem primarily from identification with suffering, the presence of death and the prospect of failure.

In a study involving general practitioners in France, 86% agreed that encounters with death were a cause of physician suffering. The specific elements contributing to physician suffering were the ending of doctor-patient relationship (58%), feelings of uselessness (55%), feeling like a failure (38%), increased awareness of the physician’s own mortality (49%) and the presence of ‘questions without answers’ (31%). The most commonly reported feelings experienced by the doctors during the patient’s terminal phase was sadness (94%), helplessness (89%), failure (82%).