

Palliative Medicine Doctors' Meeting

# Coping Strategies in the Face of Death

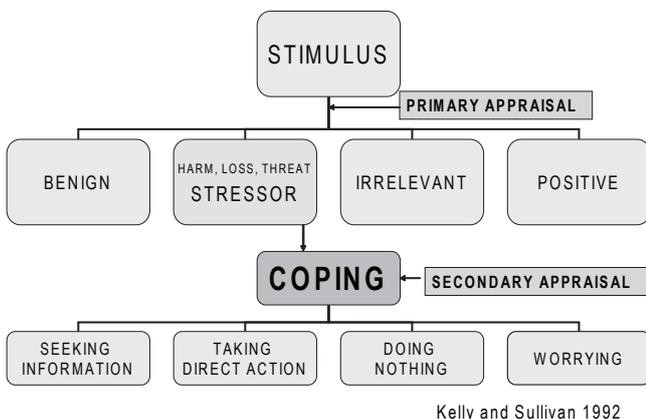
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Introduction: Theoretical background to stress, coping and death

Coping can be defined as 'a process by which a person deals with stress, solves problems or makes decisions.'<sup>1</sup> Stress has been defined as 'a particular relationship between a person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being.'<sup>2</sup> According to the stress-coping paradigm as developed by Lazarus, an individual will engage in two processes of appraisal when confronted by a stimulus that is potentially stressful – primary and secondary appraisal.<sup>3</sup>

Primary appraisal determines whether a stimulus is perceived to represent a harm, loss or threat (i.e. whether it is perceived to be a stressor) while secondary appraisal determines how the individual responds to and deals with the stressor (i.e. a process of coping). The stress-coping paradigm is represented in Figure 1.<sup>4</sup> Different individual appraises a stimulus and his/her own resources to cope with the stressor differently. Therefore, the same stimulus will lead to different coping responses in different individuals.

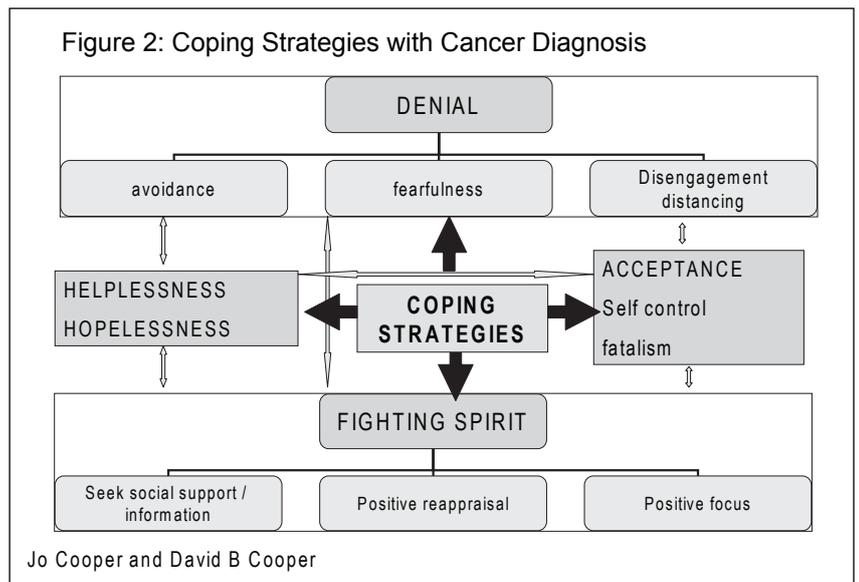
Figure 1: Stress - Coping Paradigm



Patients with advanced cancer and their families are often facing enormous stress and use many different and varied approaches to reduce emotional distress. However, each individual travels a unique life journey. Each person responds differently to difficulties and copes in his or her individual way.

For patients diagnosed with cancer, four primary psychological responses have been identified that can be grouped into four themes:

1. denial
2. fighting spirit
3. acceptance
4. hopelessness.<sup>5</sup> (Figure 2)



As shown in Figure 2<sup>6</sup>, coping is seen as a dynamic and fluctuating process and people use a range of coping strategies, depending on the situation. It is important not to permanently place an individual into any one coping strategy as each individual's coping may change over time.

The dynamic nature of an individual's coping with one's own impending death from cancer is also demonstrated in a qualitative study in 20 Swedish patients on how they reflected and acted when they tried to create

helpful strategies in the presence of their own impending deaths and how the strategies had served their purposes.<sup>7</sup> Their coping efforts could be visualized as a cognitive and emotional pendulum, swinging between the extremes of life and death. (Figure 3) During the swings of the pendulum, the individuals used every means available: their own resources, other people, animals, nature, a transcendent power, hope, imagination and magical thinking. They strove to find factors that fitted their conceptual system and supported their inner balance and structure, all to keep death at a discreet distance and preserve their links to life. These links were togetherness, involvement, hope and continuance, and they served as a shield against hurtful feelings connected to their impending death.

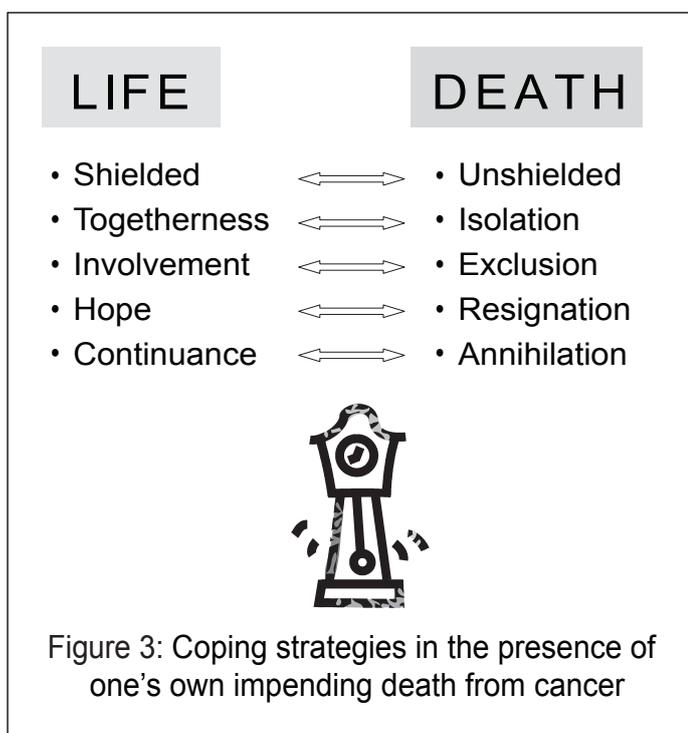
### Patient 1

Miss Chu, a 39-year-old office lady, single but lived with a constant boyfriend for years, and a newly converted Christian, had been diagnosed to have ovarian cancer with intraperitoneal metastases. Palliative surgery was done and chemotherapy was suggested. However she declined chemotherapy and sought help from a herbalist. One year later, she presented again with large pelvic recurrence. One course of chemotherapy was given but she developed complete small bowel obstruction which did not resolve with medical treatment. She was then referred to our palliative care unit.

On arrival to the palliative care ward, she looked dehydrated and cachexic and was very weak physically. Palliative Performance Score was only 30%. She was aware of the diagnosis and prognosis but she avoided to touch on death and dying issues. 'I do not think about life and death issues at this moment,' she said, 'and I do not know how to face the future or even today.' She could not make decisions regarding Cardiopulmonary Resuscitation (CPR) and delegated treatment decision making to her boyfriend.

A family meeting was held involving her boyfriend, mother and two brothers. All were shocked to hear about the poor prognosis and they thought that the patient was transferred to our unit for rehabilitation. They found it hard to accept her impending death and asked for active treatment. After an explanation on the poor condition and the palliative approach that our team would offer, the patient's boyfriend cried intensely while her brother agreed to our approach for comfort care. 'Do-Not-Resuscitate' (DNR) was reluctantly accepted.

Sepsis due to urinary tract infection developed and she became semiconscious. Her boyfriend asked for various types of active interventions such as albumin infusion, parenteral nutrition, blood transfusion, and herbal medicine. He did not want to miss any possibility of making her survive longer. Intravenous antibiotics were given and her conscious state improved. Hoping to know the patient's view, the doctor had a talk with her about her physical condition, poor prognosis, her goals and the risks and benefits of various life-sustaining interventions. She expressed a wish to prolong life as long as she remained alert, but preferred comfort care if she became



### The Stories

The following three real patient stories illustrated how different individuals were coping with their terminal illnesses. By reflecting on these encounters, we might gain a deeper understanding on the needs of patients and their families, and how we as palliative care workers could fulfill our mandate of improving their quality of life during this highly stressful period in their lives. The patients' names were changed to ensure anonymity.

unconscious. She preferred not to make decisions on life-sustaining treatment then.

The clinical psychologist and the chaplain were involved in psycho-spiritual support of Miss Chu and her boyfriend. She was baptized according to her request. From their observation and assessment, her mood remained stable and good, and she expressed no worry or other negative emotions. However, her boyfriend was observed to have intense emotions and stress, and he was physically and emotionally exhausted.

Miss Chu's condition deteriorated fast and died after two weeks. Cardiopulmonary resuscitation (CPR) was not performed. Her boyfriend was still ambivalent about the DNR decision and even requested our team to do CPR after Miss Chu's deceased body had been transferred to the mortuary.

#### Reflections on Patient 1

Miss Chu was aware of the prognosis and accepted comfort care in case she became terminally ill and unconscious. However, apparently she avoided to think and talk about death and dying with the medical team and with her family. She found discussion about life-sustaining treatment difficult and delegated such decision making to her boyfriend. It seemed that such coping strategy served her in maintaining a calm and positive mood while she was still lucid, but at the expense of the high stress level in her boyfriend and family. She was shielded from the hurtful feelings of impending death by a protective family.

The rapid deterioration of Miss Chu's condition and the transfer to a palliative care setting rendered the family, especially the boyfriend, unprepared in facing her death. They coped by fighting – seeking information about and asking for various life-sustaining interventions and alternative therapies. They cherished any means that might offer them a glimpse of hope, no matter how small it was. With Miss Chu's rapid downhill course, there was not enough time for them to change from fighting for prolongation of life to acknowledging the reality of death and grieving. As the boyfriend still could not accept the patient's death after death had been certified, a higher risk for complicated grief was anticipated.

Although there is a trend to provide palliative care to cancer patients earlier in the

course of their illness, the transition from an acute setting to a hospice setting is still sometimes difficult as the shield from dying and death is often perceived by patients and families to have been taken away. The differences in practice in provision of life-sustaining treatment including CPR and policy about DNR between acute setting and palliative care units sometimes act as triggers to the distress in patients and families. There is no easy solution. On the referring end, integration of palliative care principles with focus on alleviation of suffering and enhancing quality of life into the service, timely referral to specialist palliative care service, as well as a truthful and sensitive preparation of patients and families before their transfer to a palliative care unit are important in smoothing out the transition. On the receiving end, sensitive exploration of patients' and families' needs, goals and expectations on admission, flexibility in clinical management based on sound ethical principles especially during the transition period, and ongoing communication with the patients and families and within the team are essential. On a more global level, raising public awareness on death education and palliative care, increased collaboration between palliative care and other clinical units, and integration of palliative care principles into medical and nursing school curriculum will reap their fruits in the long run.

#### **Patient 2**

Mr Lee was a 45-year old shop-owner with four children. The family relationship was good and close. He was suffering from recurrent colon cancer with peritoneal metastases not responding to two different courses of chemotherapy. He developed persistent intestinal obstruction and was then transferred to our palliative care ward.

On admission, his main goals were to be comfortable and mobile. He was fully aware of the poor prognosis, claimed that there was no unfinished business and could accept death naturally. His wife grieved that she could not share with her husband the fruits of their years of efforts in setting up their own business.

The intestinal obstruction progressively deteriorated and the couple coped differently. Mr Lee tried to seek active treatment. He asked for surgery despite a clear surgical opinion that surgical treatment was not feasible and for continuation of dexamethasone despite knowing

that it was not effective. He bought alternative medicine from Japan and was reading a book about some case studies of its effectiveness. He wanted to 'maintain some hope and live for a few more months'. He remained quiet and seldom talked about his emotions and grief anymore. Mrs Lee started to handle her own grief by reading books about death and bereavement, made a photo album sharing family stories of their dating and marriage, the birth and growth of each child, and their successful business. The family wanted to cheer up the patient by arranging family gathering, taking family photo and sharing the album. However, Mr Lee remained quiet and Mrs Lee was upset.

He deteriorated gradually and died. Mrs Lee and their children were able to cry and express grief at the deathbed.

#### Reflections on Patient 2

Mr Lee used different coping strategies at different time. On initial assessment, he apparently understood and accepted the poor prognosis well. As his condition deteriorated, he tried to fight by asking for treatment for his intestinal obstruction and seeking information about complementary medicine. He sought to maintain linkage with life and hope instead of focusing on dying and grief.

In a qualitative study on how US-Resident Chinese immigrants with advanced cancer searched for meaning at the end of their lives, hope and faith was one of the 6 major themes revealed. Participants built hope and faith by continuing to live, believing in a possible cure, having religious beliefs, and receiving encouragement from family and others.<sup>8</sup> Participants described how they had mentally prepared themselves for the possibility of dying at any time after they were diagnosed with metastatic cancer, yet they found hope and faith when they believed that a cure for their cancer was possible. They acted on this belief by continuing to receive treatment. In Mr Lee's case, the team adopted a supportive and non-judgmental stance in dealing with the issues of using herbal medicine and seeking treatment for intestinal obstruction by exploring with him the potential benefits and harms of the treatment while keeping the communication accurate, realistic and honest. 'Being with and meeting the patient and the family at the point where they are' helps in fostering an open and

holding environment where they can explore and develop what they really want in the remaining time.<sup>6</sup>

Mrs Lee coped in a different way. She had more readily accepted her husband's impending death and prepared herself by reading, reflecting and life review through album making. The couple's different coping strategies were not in tune with each other as reflected by the distress experienced by Mrs Lee when she could not cheer her husband up by various means. Our team members including a nurse and a social worker once attempted to facilitate communication between the couple but such attempts apparently did not lead to much change.

Coping is unique to each individual. Even a couple with longstanding and close relationship may cope in very different ways. Whether, when and how palliative care workers should intervene when such a discrepancy is observed is more of an art than a science. The principles of respect, openness, support, honesty, and being with should be observed in handling such discrepancies.

#### **Patient 3**

Mr Luk was a 51-year old surveyor with Buddhist faith. He was married and had no children. He suffered from small cell carcinoma of lung with mediastinal lymph node metastases and radiotherapy and chemotherapy were completed. He developed adrenal metastases and one dose of second line chemotherapy was given but it was later stopped due to deranged liver function. Subsequently an enlarging lymph node in the retroperitoneal region developed leading to biliary obstruction and a biliary stent was inserted. He and his wife actively asked for palliative care and he was hospitalized for symptom control and psychological support.

The couple acknowledged the diagnosis and poor prognosis. Mr Luk had a naturalistic view on death and his main goal was comfort. He still wanted some anti-cancer treatment and herbal medicine with the aim to prolong his life, but requested comfort care if such treatment failed. He was also concerned about his wife's grief.

Multiple complications developed during his hospital stay including left sided pneumothorax requiring chest drainage, herpes zoster, upper gastrointestinal bleeding, urinary tract infection, urinary retention, and upper

intestinal obstruction. Further chemotherapy and surgical treatment were not feasible.

Experiencing these complications, Mr Luk accepted that no further life-prolonging treatment was possible. His main goal changed from life prolongation to comfort and symptom control. He adopted a 'let nature take its course' and 'here and now' attitude. From then on, the staff observed that he stayed in the room all of the time without much activities although he was physically able to do so. He was assessed not to be depressed. Symptoms were satisfactorily controlled by subcutaneous medications. Psychological support was given to Mrs Luk. On exploring his goals, he said he was ready and waiting to die.

On one occasion, one of our staff invited him to our garden with different types of flowers. He responded positively to this invitation. According to our staff's report, he smiled brightly, picked some flowers to his wife, sang a love song and took photos with his wife and the team. After this, he gradually deteriorated and succumbed a few days later.

### Reflections on Patient 3

We witnessed a change in coping during Mr Luk's hospital stay, from fighting and hope to accepting, yielding and readiness to die. There are questions on why our staff should invite him out to the garden. Apparently, his goals of symptom control, dying naturally and psychological support to his wife had been achieved. So why should we not stop at that point while continuing to provide the physical and psychological care he needed?

Our staff invited him to the garden out of a sincere hope that he might experience some connections with Nature, with its inherent life and beauty. It was a spontaneous, intuitive, and human act rather than a result of careful considerations of evidence-based practice and ethical principles. Learning to diagnose suffering is never a purely scientific endeavor. 'Knowing patients as individuals well enough to understand the origin of their suffering and ultimately its best treatment requires methods of empathetic attentiveness and non-discursive thinking that can be learned and taught.'<sup>9</sup> Such non-discursive thinking sometimes involves intuitive thinking that takes place below awareness.

The spontaneous joy in the patient while he was in the garden illustrated that change in coping was still possible near the very end of life. Palliative care workers' presence, empathic attentiveness and intuition might sometimes act as resources from which patients obtain strength in coping with this stressful time of their lives.

### Conclusion

In the face of death, each individual copes in his or her unique way. People in the same family may cope with the same stressor in very different ways. Coping is a fluid and dynamic process and individuals will change from one coping strategy to another. Moreover, it is also an interactive process – there are interactions among patients, their families and health care professionals. As palliative care workers, we should try to understand these processes in order to serve the needs of our patients and their families with respect, honesty, flexibility and empathy.

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