Mr. Chan was a construction site worker before the diagnosis of his gastric cancer in the late 2005. Despite surgery, his tumour relapsed locally and spread to distant lymph nodes few months later. Both the 1st and the 2nd line chemotherapeutic agents did not help, and further imaging indicated a large subdiaphragmatic mass and metastasis to liver, pancreas, adrenals and cervical spine. He had received radiotherapy to his cervical spine before referral to our palliative care service in June 2007.

Mr. Chan lived with his wife and 2 children. Both his wife and his elder son worked as a salesman, while his younger daughter had just graduated from university. Mr. Chan was left at home when everyone went to work, and in the past few months his mother, in her 70s, visited him day by day and became his main caregiver. He was admitted to our in-patient unit in July 2007 with distressing symptoms of tumour pain, progressive dyspnoea, nausea and vomiting. He was in very poor condition with severe cachexia.

His wife accompanied him on admission, and the team heard he told his wife, “Now you can leave…… Take care of yourself!” During the initial assessment, he was asked about his most distressing issue. “Doc, I agree for euthanasia…… I don’t want to be a burden to them! It has been lingering on for so long. They all suffered.” He sobbed out, “My wife still needs to toil and moil every day. All money has been used up for chemotherapy.” “Even my friends were bothered! They quietly gave some money to my children after visiting my home……”

Rapid symptom control was achieved in the following two days with continuous subcutaneous infusion of opioid and antiemetics. Tangible financial support was arranged by the medical social worker. The clinical team explored Mr. Chan’s concerns and facilitated communication and mutual support within his family. Mr. Chan was more at ease after admission. He passed away peacefully few days later.

Self-Perceived Burden in Palliative Care

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Self-Perceived Burden (SPB) in palliative care

The word burden comes from Old English byrthen, akin to beran, meaning to carry. For advanced cancer patients, loss of self-efficacy and independency due to physical deterioration result in the sense of having become a burden to others.

Self-perceived burden (SPB) has been defined as “a multi-dimensional construct arising from the care-recipients' feelings of dependence and the resulting frustration and worry, which then lead to negative feelings of guilt at being responsible for the caregiver’s hardship”.

Findings from a qualitative study exploring the perspectives of patients at the end of life suggested that the definition of SPB should be expanded to encapsulate the range of emotions aroused, and the effects to one’s sense of self, therefore it proposed SPB to be defined as “empathic concern engendered from the impact on others of one’s illness and care needs, resulting in guilt, distress, feelings of responsibility, and diminished sense of self”.

Prevalence of SPB

Sense of SPB is common among dying patients. A recent Canadian study examining sense of burden to others in 211 patients with end-stage cancer found that at least 60% of them reported certain degrees of burden-related distress, with 23% scoring within the most severe range. Similarly in another Canadian study of 52 advanced cancer patients, 19% experienced SPB at a moderate to extreme level, while 48% of respondents reported SPB as their single most distressing social concern. Such concern is also prevalent in other disabling advanced disease. The interviews with 100 patients with amyotrophic lateral sclerosis conducted in Oregon found that 91% felt that their medical condition was a cause of stress for family members, 65% felt they were a burden to their families, and 48% thought that their medical condition resulted in financial hardship.
Sense of SPB is a common concern for people with advanced diseases, but health-care providers may overlook this issue. In a study in United States looking at the factors considered important at the end of life by patients, their families, physicians and other care providers, 89% of the patients perceived “not be a burden to family” as a very important attribute at the end of life, and 81% rated “not be a burden to society” as very important as well. However, corresponding figures for a sample of 361 physicians in the same study were only at 58% and 44% only.

Dissecting SPB: from patients’ perspectives

McPherson et al. in a qualitative study has delineated SPB in details from patients’ own perspectives. In that interpretative phenomenological study, 15 patients with advanced cancer in a palliative care unit in Canada were interviewed upon their expressed concerns about being a burden on their family members. Participants’ experiences of SPB were reflected in two major interrelated categories: “Concern for Others” and “Implications for Self”. “Minimizing Burden” was identified as a third category describing coping strategies applied by participants.

Concern for Others: There are specific burdens that patients felt they are imposing on those around them because of their illness and its consequences.

1. Physical burdens: As most of the patients required considerable practical assistance, a major concern is the sheer physical load taken on by caregivers in attending to their physical needs, which involve a range of household tasks, and assistance with personal activities of daily living. Beyond routine tasks, further assumed duties to their care-givers which are both physically demanding and time-consuming include taking the patients to appointments, preparing special diets and managing complex medication routines.

2. Social burdens: Care-givers usually have other roles and responsibilities within their own context. Patients witnessed the extra stress of caregivers who also have to contend with issues like childcare and work commitments. They may also need to restrict their own social activities or even to take leave from work, which imposed additional financial hardships. For patients with children, there is a sense of an unfulfilled parental role, which left others with the task.

3. Emotional burdens: This originates from the empathetic concern to the emotional strain of the caregivers. The emotional burdens laid on the caregivers include: anxiety related to uncertainty, strain of vigilance over patients’ well-being, frustration with their role as well as overwhelming due to competing demands.

4. Future concerns and aftermath: Patients frequently expect that the strain on the caregivers would increase due to anticipated decline in their own physical and mental function. Decision-making with regard to a possible transition from home to institutional care is often raised. A sub-theme of future concerns addresses worries about the anticipated effect of loss on survivors after patients’ eventual death.

Implications for Self: These are the themes that reflected patients’ own thoughts and feelings about burdening others.

1. Emotions: Guilt and regret at the hardships endured by others are frequently experienced. Sadness and mourning arise from the losses as a result of not being able to participate in the lives of their loved ones, or fulfill meaningful roles and expectations. Patients also express frustration and anger that they cannot do more to help themselves and others.

2. Self-blame and self-concept: Many patients struggle with the conflict around attributions of responsibility for having developed cancer, and for being limited functionally. They also struggle to come to terms with being dependent on others, which imply the loss of control. Such transition negatively affects their self-worth and lead to feeling of uselessness.

Minimizing Burden: A variety of strategies to cope with their sense of burden are reported. These include the problem-focused strategies aimed at alleviating burden to others, and emotion-focused strategies aimed at reducing perceptions of burden to self.

1. Alleviating burden to others: There is a general sense of responsibility on the part of patients to minimize the effects of their illness on others. By actively participating in their
care and being involved in problem solving around practical issues, patients retain their sense of control and counteract feelings of helplessness. Some patients positively move steps forward to manage the needs of others, by helping family prepare for their impending loss, by permission to move forward after their death, and by talking about future plans and arrangements. However, some patients may withdraw and try to minimize the burden to others by concealing their own need and distress. Not uncommonly, patients remark that burden may be reduced by hastening their own death.

2. Reducing perceptions of burden to self: These coping strategies are aimed at reducing patients’ own sense of burden. Some patients avoid thinking about the amount of burden presenting to others, while many express resigned acceptance that nothing could be done. On the other hand, some positively reappraise the situation that their illness and caregivers’ experiences actually strengthen their relationship and deepen feelings to one another. There are also patients coping with a sense of entitlement based on reciprocity for past care to their current caregivers.

Measuring SPB

Assessment of SPB is important in view of its clinical relevance. As SPB is multidimensional and highly subjective, it would be optimal to have detailed exploration of different perspectives of each individual patient. On the other hand, for an instrument to measure SPB suitable for use with chronically ill patients, it has to be brief enough to be used in clinical practice, and yet sufficiently detailed to distinguish various elements of the concept.

The Self-Perceived Burden Scale was developed and preliminarily validated by Cousineau et al. in 2003 1. This scale has been validated in a cross-sectional study of 106 cancer patients recently 7. In this brief and self-administered 10-item instrument, aspects of burden include the experience of guilt, indebtedness, loss of control, dependence, interference in caregiver’s lives, physical strain adversely affecting the caregiver’s health, anger, resentment, frustration and helplessness. Response options used a 5-point frequency scale. Convergent validity was demonstrated with global quality of life, physical well-being, emotional well-being, functional well-being, financial satisfaction and depression 7.

Understanding SPB: Equity Theory

The notion of SPB can be understood conceptually from Equity Theory. Equity Theory, also known as Adams’ Equity Theory 8, attempts to explain relational satisfaction in terms of perceptions of fair or unfair distributions of resources within interpersonal relationships. Equity theory proposes that individuals who perceive themselves as either under-rewarded or over-rewarded will experience distress, and that this distress leads to efforts to restore equity within the relationship. It focuses on determining whether the distribution of resources is fair to both relational partners.

When individuals find themselves participating in inequitable relationships, they become distressed. The more inequitable the relationship, the more distress individuals feel. While the person who gets too much may feel guilt or shame, the person who gets too little may feel angry or humiliated 9. In case of advanced cancer patients, since their opportunity to reciprocate and restore equity is reduced, they may consequently perceive themselves as having become a burden.

There are two ways that a person can restore equity to a relationship: by restoring actual equity or by restoring psychological equity (the perception that equity actually exists when it does not) 9. Such ways of coping inequity correspond well to some of the problem-focused and emotion-focused strategies.

Impact of SPB to patients

A recent systematic review article focusing on SPB in the end of life has clearly indicated its clinical significance 10. SPB impacts negatively on one’s quality of life (QOL), is correlated with physical, psychological and existential distress, and can influence the choices one makes, even to the extent of considering to end one’s life.

Quality of Life: Studies into the nature of QOL in patients with advanced disease have found that concern about burdening others is a commonly expressed theme.
The Quality Of Life Concerns in the End of life questionnaire (QOLC-E) is a locally developed and validated measure to capture the end of life experience of patients with advanced chronic diseases. In this questionnaire, sense of alienation is one of the eight domains emerged as central to participants’ QOL. “Sense of alienation” included being lonesome, being afraid to look into the future and, importantly, feeling of being a burden to others.

Cohen et al. in a study on what determines the QOL of advanced cancer patients also pointed out the significance of SPB. “Relationship” is one of the five core themes relevant to the QOL of palliative care patients, and it includes SPB, along with support, communication, change in role and closeness in crisis.

Distress and suffering: Studies of patients who are terminally ill consistently identify strong associations between SPB and marked end of life distress.

Wilson et al. found that in patients with advanced cancer, SPB was correlated with certain physical symptoms (pain, weakness and dyspnoea), psychological entities (depression and anxiety) and existential issues (loss of control, loss of dignity and hopelessness). Pain was found to be a significant predictor of SPB in regression analyses, while loss of dignity was the most important factor, followed by anxiety. Another study by Chochinov et al. involving 211 patients was aimed to clarify the relationship of SPB with various physical, psychosocial and existential issues. It found that depression and hopelessness are two of the most highly correlated variables with SPB, and they are also two of the variables emerged in a multiple regression analysis predicting SPB.

The existential concerns of advanced cancer patients commonly raise the theme of SPB. The construct of existential distress was explored by Morita et al. in 88 terminally ill cancer patients. The existential concerns of Japanese terminally ill cancer patients were categorized as relationship-related concerns (which included concerns about family preparation for the patient’s death and for the family’s life after the death), loss of control, burden on others, loss of continuity, uncompleted life task, hope / hopelessness and acceptance / preparation. In the model of dignity in the terminally ill suggested by Chochinov et al., social dignity inventory is one of the three major categories. Burden to others and aftermath concerns (on the wellbeing of surviving family members) are two themes under this category.

Decision-making: SPB is reported to affect the process of decision-making particularly in issues faced by individuals at the end of life. These include decisions around treatment, advanced directives, place to receive care as well as the issues of euthanasia and physician assisted suicide.

A qualitative survey with 40 Chinese seniors in Canada found that respondents based their end of life decision making on hope, suffering and burden, the future, emotional harmony, the life cycle, respect for doctors and the family. The authors interpreted that a person who decides to forego life-sustaining treatment because of the emotional or financial burdens that his illness incurs would be performing a compassionate act based on Buddhist thought.

Advance care planning to avoid placing undue responsibility for decision making on loved ones is a means to mitigate SPB. Perspectives of 140 patients with HIV / AIDS were explored by Martin et al. in 1999. Patients mentioned the burden of substitute decision-making and suggested that the process of advance care planning, with its psychosocial implication, was more important than the completion of a formal written advance directive.

SPB also affects the place of care preferred by terminally ill cancer patients. A descriptive study was conducted in Taiwan to explore the preferences of 180 advanced cancer patients of their preferred place of terminal care. Nearly 90% of the subjects preferred to die at home; however, concerns of being a burden to others and availability and ability of family caregivers were two major factors considered important by patients in choosing a place other than home for place of care. Other major considerations included QOL, long-standing relationships with healthcare providers and quality of healthcare.

Last but not least, the link is evident in various studies between SPB and desire for death and requests for euthanasia in individuals with
advanced illness. Morita et al. tried to clarify the reasons for desiring death and requests to hasten death by retrospective interviews of 290 family members of Japanese terminally ill cancer patients. 21% of families reported that patients expressed a desire for death, and 10% reported the request to hasten death. Being a major reason in 42% of cases, sense of burden to others was among the strongest factors in desire for death.

**Conclusion**

Sense of SPB is prevalent among patients with terminal illness. In order to pursue better QOL for our patients, it is imperative for palliative care workers to be aware of the multidimensional construct of SPB as well as its potentially destructive impacts to patients.

**References**