

"CAN MORE BE DONE TO SAVE MY DAUGHTER?" – PRIMARY PALLIATIVE CARE FOR PATIENTS WITH UNEXPECTED, RAPID CANCER PROGRESSION

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ABSTRACT

This is a case study of a 58-year-old lady with metastatic nasopharyngeal carcinoma (NPC) who suffered a left neck of femur fracture. Unfortunately, there was an unexpected and rapid cancer progression, requiring her care goals to transit from rehabilitation after her fracture to palliation. The case brings to light the need for family physicians to be poised to manage cancer patients at the end of life in the community and work together with other stakeholders to deliver compassionate and supportive care.

Keywords: Primary palliative care, primary care, oncology care, family physician

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INTRODUCTION

Many patients with NPC often present at an advanced stage of the disease, resulting in a poor prognosis. Rapid deterioration results in the need to realign care goals and focus on palliation of symptoms to improve the quality of the last days of life. However, while this is what physicians know to be in the best interests of the patient, it is often difficult for the patient and family members to accept, as it can be misconstrued as withdrawal of care. Family physicians are well-positioned to serve as advocates for these patients and their families, by coordinating care and communicating with relevant stakeholders.

WHAT HAPPENED?

Presenting Complaint

Miss L was a 58-year-old lady who was pre-morbidly independent in her activities of daily living and community ambulant without aid. She found job fulfilment as a human resource assistant. She was single and lived with her 90-year-old mother and a domestic helper (her mother's primary caregiver). She had six siblings with whom she shared a cordial relationship. Notably, there was no family history of cancer.

She was diagnosed with metastatic NPC involving the liver and cervical lymph nodes in 2014 when she was treated with chemotherapy. There was good tumour response until December 2017, when she presented with left cranial nerve VI palsy due to progression of the locally advanced NPC into the brain, for which she declined surgical resection or palliative radiotherapy. A re-staging CT thorax-abdomen also showed new left supraclavicular and mediastinal lymph node involvement, with increasing size of the liver metastases. She was given a prognosis of more than six months and placed on palliative chemotherapy.

A month later in January 2018, Miss L was admitted to a tertiary hospital after sustaining a non-pathological left neck of femur fracture due to a mechanical fall. She had an uneventful hemiarthroplasty and was transferred to a community hospital for rehabilitation, with the goal of achieving pre-morbid functioning and resuming her job.

Unfortunately, during her second week at the community hospital, Miss L was noted to have aphasia, mild dysphagia, dysarthria and right hemiplegia. This decline in neurological and functional status was rapid and attributed to cancer progression. Owing to her left femur hemiarthroplasty and new right hemiplegia, both lower limbs had an impaired function, making independence in ambulation challenging despite optimisation of pain. Furthermore, her aphasia made communication and understanding of instructions difficult, limiting the effectiveness of physiotherapy. She required moderate to maximum assistance in her activities of daily living with progressive decline. Miss L's oncologist opined that the prognosis would be reduced to less than three months with her current situation. Palliative chemotherapy was stopped as it appeared to be ineffective, and she was also suffering side effects of nausea and vomiting. Symptom management became the goal of care.

Miss L's pain was managed holistically. On top of treating her somatic pain by adjusting analgesia along the WHO pain ladder, other aspects that contributed to her "total pain" were addressed. Chaplains offered pastoral counselling for emotional support, and her family members also lent unwavering support towards her care. Miss L could see that her condition was rapidly deteriorating and was accepting of her condition.

A family conference was held with Miss L's siblings and mother to update them on her condition. During the session, Miss L's mother was emotionally charged with a mix of grief and anger. She revealed that she was shocked to hear that Miss L had terminal stage cancer and questioned if "enough" had been done to save her daughter. Miss L's siblings admitted to only having told their mother that Miss L "was ill", rather than breaking the news of cancer specifically, so as not to shock their elderly mother. They had not expected this rapid trajectory of decline and hence did not see the need to tell their mother otherwise.

PATIENT'S (FAMILY'S) REVELATION

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“Has enough been done to save my daughter?”

GAINING INSIGHT: WHAT ARE THE ISSUES?

At this point, these issues were highlighted in the case:

1. What are the components of palliative care?
2. Who are the stakeholders in the palliative care of a patient?
3. What is the role of the family physician (FP) in palliative care?

COMPONENTS OF PALLIATIVE CARE

The goal of palliative care is to relieve patients and their families' suffering by comprehensive assessment and treatment of physical, psychosocial, and spiritual symptoms experienced. As death approaches, a patient's symptoms may require more aggressive palliation. As comfort measures intensify, so should the support provide to the dying patient's family. After the patient's death, palliative care focuses primarily on bereavement and the support of the family.^{1,2} Throughout this process, the patient should also be given the autonomy to make informed decisions for himself through the evaluation of his values, goals, and expectations of care. The authors of this article also recognise that palliative care extends beyond the population of cancer patients, however for the scope of this case, the focus is placed on the topic of primary palliative care in this specific population.

In Singapore, the National Guidelines for Palliative Care³ serve as the guiding principles for healthcare providers to deliver optimal end-of-life care. These guidelines are divided into several domains, including patient care, family and caregiver support, staff and volunteer management and safe care. Broadly, all domains involve timely and ongoing communication, having adequate content or knowledge, and coordination of care between the stakeholders.

STAKEHOLDERS IN PALLIATIVE CARE

Apart from the patient, other stakeholders may be involved in end-of-life care. The patient's family members remain important stakeholders, especially in the Singaporean culture of collectivism, where close family ties are prevalent. In addition, the primary oncologist and inpatient healthcare team serve to establish pertinent medical issues and address them accordingly. Moreover, nursing staff help to follow-up on care in both inpatient and outpatient settings; medical social workers tackle other needs that may impact the care of the patient; and chaplains offer emotional and spiritual support. Finally, the FP has a role in the care of these patients in the community as well.

THE ROLE OF A FAMILY PHYSICIAN (FP) IN PALLIATIVE CARE

In recent years, there has been more awareness about integrating palliative care in the primary care setting. This is primarily due to the unique position of a FP. As the primary provider of longitudinal patient care, FPs can be said to have the best rapport with patients and are therefore equipped to elicit an individual's values, goals and priorities.⁴ This serves as an

important stepping stone in facilitating end-of-life discussions. Moreover, as FPs are often the first medical providers' patients seek out, they are primed to identify patients who need palliative care services.⁵

To better define a FP in the sphere of palliative medicine, a qualitative study⁶ identified three key roles that FPs can play in managing cancer patients using skills in the primary palliative care skillset (Figure 2).

i) Coordinating cancer care

This involves taking charge of the patient's care and facilitating early and active communication between the main stakeholders. It may seem counter-intuitive for FPs to take up this role, especially if they do not feel knowledgeable in cancer management. However, due to medical advances, an increasing number of cancer patients have a slower progression of the disease, and there will be more of these patients in the community. FPs must be ready to play critical roles in cancer care as the demands for palliative care services cannot be met by specialists alone.^{7,8}

FPs need to establish a communication channel with patients' primary oncologists early to continue to be a part of the care trajectory. Not only does this help the oncologists focus on curative treatments for the patients, but it also allows the patient to receive seamless care if both the FP and specialist are on the same page. This communication channel is ideally bi-directional, allowing the oncologist to update the FP about the patient's condition and simultaneously allowing the FP to flag up issues when they review patients in the community. Moreover, when FPs are readily accessible to the patients, trust and rapport are established, which has been shown to improve the quality of death of patients with advanced cancer.⁹ An example of how communication is carried out with stakeholders is shown in Table 1 below.

Gone are the days of paternalistic medicine, and this could not be truer in palliative medicine. Studies in the past have demonstrated that there may be major differences between what healthcare professionals and patients deem as a good death. Hence, communication channels are between members of the healthcare team and between patients and their care providers. Recurrent themes from patients' perspectives of a good death include decisions about treatment preferences, state of one's choice, avoiding inappropriate prolongation of dying, and preparation for death.¹⁰ These themes can be addressed when drawing up an Advance Care Plan (ACP), a tool that has increasingly gained traction over recent years.

While ACPs have been shown to reduce hospitalisations, increase use of hospice and palliative care services and decrease the use of life-sustaining treatment in concordance with patients' wishes⁸, the initiation of an ACP is still a difficult topic to broach. Guidelines do not suggest the right time to introduce it, although it is suggested to discuss patient preferences at the earliest opportunities.¹¹ It is routinely taught in our local context that the Preferred Plan of Care (PPC), a form of ACP, can be drawn up if the physician answers “no” to the question, “Would you be surprised if this patient passes on within the next 12 months?” Further signposts for reinitiating this discussion are

summarised in Figure 3. Early initiation of ACP discussions attempts to overcome the critical barrier of lack of patient capacity, which often results in more aggressive life-sustaining therapy chosen by surrogate decision-makers.⁸

ii) Managing comorbidities

As oncologists focus on the treatment of cancer, FPs continue to manage the other comorbidities. It is common for these patients to have other conditions that require longitudinal care, such as diabetes. Some conditions may even require heightened attention when patients are receiving curative cancer therapy (nausea and vomiting during chemotherapy, causing an increased risk of hypoglycaemia in diabetes treatment).

In addition, patients are likely to go to their FPs, whenever new symptoms arise, including dyspnoea and pain related to malignancy. Knowing how to manage common cancer-related symptoms is valuable in primary palliative care.

iii) Providing psychosocial care and support to patients and their families

Patients with terminal illnesses expressed that their quality of death is also dependent on being treated as a “whole person”.¹⁰ Other than palliative therapy for their illness and symptoms, consideration for the social and psychological needs is important in the face of imminent death.

It is also important not to overlook family members, who may serve as informal caregivers for patients. Caregivers suffer from a wide range of problems, including anxiety and depression, and are usually regarded as fellow sufferers alongside patients. Studies done involving caregivers of cancer patients reflect a range of unmet caregiver needs, including disease-related information and emotional support, and these are often ignored and excluded from healthcare planning.¹³

FPs, having established a strong rapport with the patient and family members, are thus poised to craft an individualised approach for each patient. This approach may be developed through a series of discussions, considering his/her values, beliefs, expectations, family dynamics, and spiritual needs, with their family members alongside.

MANAGEMENT: HOW DO WE APPLY THIS IN OUR CLINICAL PRACTICE?

PATIENT'S PROGRESS

The patient's PPC was discussed a few days after the family conference and she was transferred to the inpatient palliative ward. Her mother was given emotional support by the medical team and allowed the time and space to come to terms with Miss L's condition. Unfortunately, the patient became increasingly delirious, although terminal symptoms of headache and nausea were well managed. She passed away peacefully after one month. Her family, in particular her mother, were thankful for the support provided.

It was clear from her mother's revelation that she struggled with emotions of shock and denial when she received news about Miss L, especially in the context of her daughter passing on

earlier than her. She may not have been aware of the interventions undertaken or fully understood the cancer diagnosis's severity with further treatment futility. Furthermore, being included in the patient's care only at the tail end of the disease trajectory meant that Miss L's mother could have regarded symptom palliation as withdrawal of treatment instead, especially with limited awareness of palliative care's essence. Eventually, further details of Miss L's condition and the benefits of palliative care were explained to her, and she was accepting of the ways forward. Miss L spent her last days in the company of her family members. The inpatient healthcare team had acknowledged her mother's emotions and rendered her with the psychological, emotional and spiritual support by journeying and keeping pace with her needs and concerns at each phase. This included exploring any unresolved issues that her mother had concerning the patient and helping her express her love and gratitude towards her dying daughter. Interestingly, upon follow-up by the chaplain during the bereavement phase, her mother shared that she was appreciative that the team had done “more than enough” for the patient and family.

Certainly, it would have been ideal if Miss L was involved in the discussions regarding her care earlier in the disease process when she still had the mental capacity. This would have allowed her physicians to tailor her care to suit her wishes and relieved her family of the psychological burden of making decisions on her behalf, which may be discrepant with her preferences.¹⁴ It is therefore important for the FP to have the foresight to initiate such discussions, which could be improved with easily accessible guidelines and training of FPs, as well as encouraging the embedding of such discussions in an FP's routine practice.⁸

While multiple qualitative studies have attempted to describe a good death, this concept is still a personal and complex one for each patient. An FP should remember that patients yearn to be a whole person with attributes beyond the physical disease manifestations and that dying is a process that unravels over time. Figure 4 shows the main categories describing good end-of-life care, identified by a local qualitative study.¹⁵ These components are echoed in a separate study performed with caregivers of cancer patients. These caregivers also prioritised a fulfilling caregiving experience with their efforts recognised and allowance for proper grieving and closure as important parts of their loved ones' death.¹⁶ It truly is the FP's unique privilege to journey with a patient and their family through this process.

CONCLUSION

Palliative care has been given more importance in recent years and will continue to be an important component of primary care medicine in light of Singapore's ageing population. Physicians must aim to relieve patients of their distressing symptoms and afford quality over quantity of life. Palliative care has strong foundations in the principle of autonomy, and hence goals of care are highly individualised for each patient. Care for these patients has to be well-coordinated, and end-of-life discussions initiated early. The FP is arguably best primed to deliver this care and truly see patients from the cradle to the grave.

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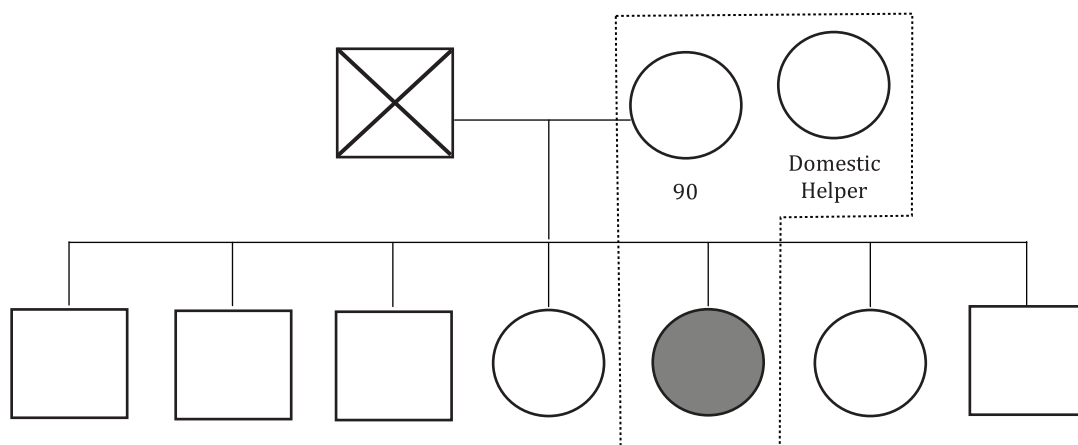
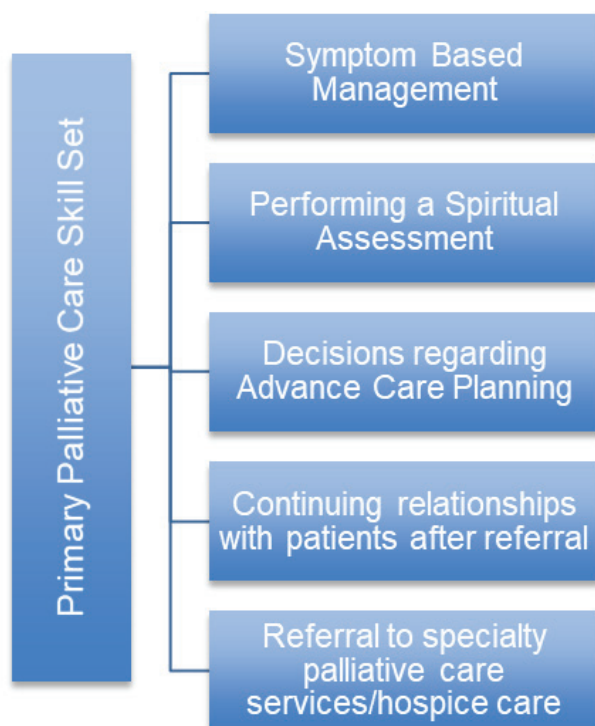
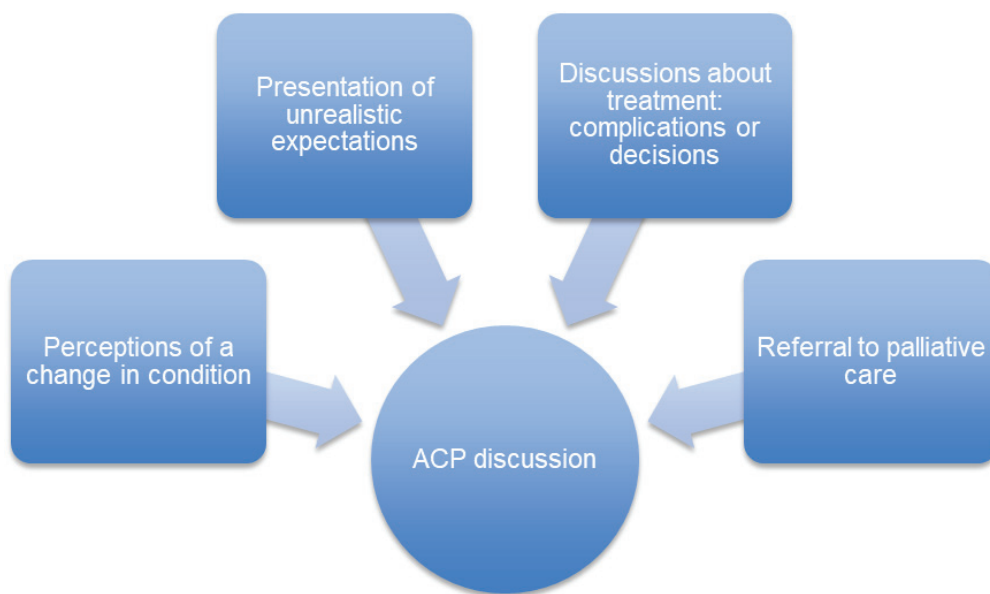
Figure 1: Genogram**Figure 2: Primary Palliative Care Skill Set⁵**

Figure 3. Timing of ACP discussion in disease trajectory¹²**Figure 4. Good End-of-Life Care¹⁴**