

“Palliative Care” – Not Just Simple Words

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Some years back, the author was referred a 60 year old lung cancer patient for at-home palliative care. The history was reviewed in detail and the patient was examined. He was of not cachectic, had no pallor or jaundice, no tachypnea, normal lung sounds and an essentially normal examination overall - aside from the fact he was virtually bedridden due to severe fatigue. The patient's reports from the regional cancer hospital confirmed he was stage 4, with bilateral lung metastases noted on a chest CT scan. There appeared to be a puzzling discordance between the nearly normal examination and the patient's self-reported poor functional status. By chance, the author was in the operating room with a thoracic surgeon the following week, and decided to ask for an informal second opinion. The patient's CT images were brought up on the computer monitor. The surgeon immediately diagnosed the patient with a rare fungal lung infection, which had a similar appearance to lung cancer metastases! An urgent PET scan was then ordered, which confirmed the diagnosis, and the patient was promptly informed. At that point, there was dramatic change in his functional status. Once he learned the lung spots were not metastases, and the cancer was potentially resectable, he regained hope and all fatigue rapidly vanished. He then explained that he was told by his previous specialist that his case was “palliative”. At the regional cancer center, this definition was officially associated with a less-than-3 month prognosis. Upon hearing this prognostic information, and

learning that a home “palliative care” team was being sent in to look after him, he began preparing for death and could think of nothing else. The severe fatigue leading to a bedridden state had been purely psychological. This true story highlights the potential impact of the word “palliative” on our patients.

The word palliative comes from the Latin *palliat* which means to cloak or cover up. Strict adherence to this definition means that palliative care is pure symptom control, with no attempt to slow or stop the disease process, whether it is cancer, end stage renal failure, end stage heart disease, or any other incurable illness. An example would be the use of analgesic drugs for cancer pain, to mask the tissue destruction from the tumours. Many health care organizations also add to definition: “less than 3 (or 6) month's prognosis”. Some organizations even formally state “no active treatment” will be given for patients designated as palliative. All of these meanings effectively deny any potential hope for survival beyond the time frame suggested by the palliative team.

However, an alternate definition is “affording relief but not cure” (Dorland's Illustrated Medical Dictionary 27th Ed, 1988). This definition does not specify a prognosis of lifespan. Use of this definition allows terminal diseases to be viewed more as chronic, life-threatening, but potentially controllable diseases. In other words, an illness such as cancer can be treated more like severe hypertension: serious but manageable with the right therapies. An example of this would be palliative radiotherapy for reduction of cancer pain, which partially treats the disease to control the pain.

In order to prevent the unintended negative consequences of using the word “palliative”, health care professionals should first attempt to grasp the patient's own understanding of the

term. One should appreciate what the patient has been told about palliative care, and how they would feel about receiving palliative care. This can be a very engaging and time-consuming discussion, which may not lead to a satisfactory resolution, if the patient has a preconceived negative notion of palliative care. After putting himself in the patients' shoes, the author has chosen a simpler approach: avoidance of the term "palliative", unless patients ask about it. In the author's practice, this terminology is essentially restricted to communication between members of the healthcare team. This novel approach does not require reviewing the patient's comprehension of the term "palliative care" and is not associated with the hope-robbing

connotations of these words, which are unfortunately all too common. Instead, more positive or neutral terms are used which are clearer to patients, such as "improvement in quality of life", "therapy to enhance comfort" or "pain and symptom management". It is the author's wish that nurses, physicians, healthcare administrators and other palliative care team members pay closer attention to the words they chose during discussions with patients about palliative care. Through careful reflection upon patient perceptions and improvement of our communication skills, perhaps we can revive some hope, where hope is desperately needed.