

Addressing Quality of Life in Palliative Care

Robin L. Fainsinger, M.D.

Director - Palliative Care Program, Royal Alexandra Hospital.

Associate Professor, Division of Palliative Medicine, Department of Oncology, University of Alberta.

The difficulty of addressing quality of life begins with the definition. We all use the same motherhood statements such as the physical, psychosocial, spiritual and existential domains. However quality of life is a complex mix of these elements, with many nuances within this broad framework. We attempt to address function and autonomy, advanced care planning, patient and family satisfaction, well-being, perception of care received, family burden, strengthen relationships among family members, bereavement, and the need to provide continuity and skilled care. However it has also been pointed out that we as health care professionals often use narrow interpretations that serve our administrative and financial purposes. However the patient and family definition of quality of life may not necessarily be the same (1, 2, 3, 4).

What we measure in numbers to report to the people to whom we justify the existence of a palliative care program is relatively simple, compared to what we need to measure to prove to ourselves that we really are providing quality of life to patients and families. A major factor is when we should measure quality of life? Should it be measured at the point of entry to the program; at some defined mid point; or toward the end of life? However patients with advanced disease may be unable to report on their quality of life, and we certainly cannot get any measurements from patients after death. Measurements of quality of life from families may be affected by their own physical and emotional exhaustion during the course of their relative's illness. If you attempt to overcome this by asking for family perceptions of their relative's quality of life in the bereavement period we will inevitably get different answers based on whether we ask weeks or months after the death has occurred.

The main quality of life assessment tool we use in our program is the Edmonton Symptom Assessment Scale (ESAS) (5). The ESAS has begun to gain popularity outside of Edmonton, however its strengths and weaknesses are beyond the scope of this editorial (6, 7).

There are clinical, teaching, research and administrative benefits for attempting to measure the concept of quality of life. We measure the clinical aspects to ensure we are providing the best quality of life possible to patients. There are also benefits both for teaching and research as we learn things to help us improve aspects of physical and psychosocial support for patients and families. For administrative uses we use quality of life data in a global way to prove that we are meeting our goals such as patient access to palliative care in a cost efficient manner.

We have to recognize that there is often a perspective gap in interpreting quality of life and the success of the palliative care that we deliver. This is due to the distress that families may experience when a loved one dies, no matter how good the palliative care provided. As an example, if we were to tell our families, "You have the good luck to be part of our palliative care program, and we are recognized to be one of the best palliative care programs in the world. We

are so good, let us begin by attempting to address the thing you would most like us to fix. What would that be?" Many people, if they honestly searched in their hearts would say, "If you are that good, my wish is you make my relative not die."

In summary addressing quality of life in palliative care is confusing, complicated and difficult. The global dimensions such as access to palliative care and the right location for the right patient are easier to measure. The micro day to day assessments of quality of life for patients who are dying are shifting sands. We will always have to be somewhat humble about our ability to accurately measure and represent them.

(This clinical note is a summary of comments in the on-line journal "Innovations in End-of-Life Care" and can be found at:
<http://www2.edc.org/lastacts/archives/archivesNov00/fifainsinger.asp>)

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