
GUEST EDITORIAL

Assessment measures in palliative care: The risk of inflation and the importance of listening to the patient's story

The present issue of *Palliative & Supportive Care* deals, once again, with assessment and outcome measures for the clinical practice in palliative care. This is indeed a “hot topic” in palliative care literature and has been for quite some time. A quick search in PubMed reveals more than 1,400 articles on these subjects in the past 5 years alone, with increasing tendency.

One of the reasons for this apparent inflation in outcome and assessment measures may be inherent to the very definition of palliative care by the World Health Organization: “an approach to improve *quality of life* of patients and their families” (Sepulveda et al., 2002). Thus, the whole discipline depends essentially on a single, highly subjective and rather ill-defined psychological construct. This has historically posed a serious problem for the field.

Looking at quality of life alone, assessment measures can be found by the dozens (a review in 2010 found 29 different measures specific for palliative care) (Albers et al., 2010). In a previous editorial (Borasio & Bernard, 2016), we discussed the basic difference between nomothetic (investigator-defined) and idiographic (respondent-defined) questionnaires, with the latter clearly being more attuned to the individualized approach that is typical of palliative care.

Here, we point out the increasing tendency to dissect the ultimate outcome of palliative care (quality of life) into smaller and smaller portions, each contributing its own bit to the overarching quality of life construct. This reductionist approach is understandable, given the urge to define, assess, document, compare, and evaluate that pervades our medical systems nowadays. But maybe we are beginning to overdo it?

The structure of the reductionist approach flows nicely from the World Health Organization definition itself, when it speaks of “physical, psychosocial, and spiritual” problems. This leads to a search for (hopefully) clinically meaningful and quantitatively evaluable parameters in each of these domains. We

have plenty of instruments at hand to evaluate pain and any other conceivable physical symptom. In the psychological domain, more and more constructs (positive and negative) are being explored for their relevance to palliative care: hope and hopelessness, dignity and its loss, personal values, meaning in life, gratitude...and so on. This has led to highly interesting scientific insights, but also to some degree of fragmentation and redundancy: a review published in 2012 on outcome and assessment measures for meaning in life reported no less than 59 different instruments (Brandstätter et al., 2012).

The same holds true for the social domain, in which more and more attention is now turned to the evaluation of the relatives and the family system, and the spiritual domain, with spiritual well-being being increasingly recognized as one of the foremost components of quality of life at the end of life (Bernard et al., 2017).

Although many of these instruments are valid, statistically robust, and clinically helpful, there is a real danger that we might be losing sight of the overall picture here. After all, one of the main components of palliative care practice is the skill of active listening. When we listen to patients' stories without trying to squeeze them into a predetermined frame of mind, we often find explications for their behavior that would escape even the most sophisticated of questionnaires.

For instance, we vividly remember one of our inpatients who showed a multitude of therapy-refractory symptoms going from pain to nausea to anxiety and more. No matter how hard we tried, she would not admit to any improvement of her well-being, and her morning tirades over her misery were quite impressive, indeed almost theatrical in nature. When this remark was made in the team meeting, the chaplain revealed to us that this lady had been a famous opera singer in younger years—and all of a sudden her behavior made sense. Her life had been a great theater piece, and she was not going to leave quietly. With

this in mind, the team could accompany her up to her last grand exit (and grand it was) with an inner smile of acceptance that greatly eased our relationship with the patient. After her death, the family told us that she had died “exactly the way she would have wanted.”

Of course, this is just a picturesque example of something we experience as clinicians on an everyday level: the power of narrative medicine. This field was pioneered in the 1990s by Rita Charon and colleagues at Columbia University. Defined as “the ability to acknowledge, absorb, interpret, and act on the stories and plights of others,” the practice of narrative medicine includes active listening as well as reflexive writing. It can be of invaluable help to clinical practice by “bridging the divides that separate physicians from patients, themselves, colleagues and society” (Charon, 2001).

Important attempts have already been made to link the fields of narrative medicine and palliative care (e.g., through the concept of life review) (Kwan et al., 2017). Perhaps the most concise version of this link is Harvey Chochinov’s improperly termed (to our minds), but highly useful Patient Dignity Question: “What do I need to know about you as a person to take the best care of you that I can?” This question has shown great potential for the improvement of patient care, not just at the end of life (Arantzamendi et al., 2016).

The link between narrative medicine and palliative care deserves further attention and progress. This is not to say that we should stop developing sensitive and specific assessment measures in palliative care. But only when we can truly comprehend each patient’s story in its uniqueness can we hope to be able to apply all the various outcome data to our clinical practice in a way that serves our patients well.

REFERENCES

- Albers, G., Echteld, M.A., de Vet, H.C., et al. (2010). Evaluation of quality-of-life measures for use in palliative care: A systematic review. *Palliative Medicine* 24, 17–37.
- Arantzamendi, M., Belar, A., Martínez, M. (2016). Promoting patient-centred palliative care: A scoping review of the patient dignity question. *Current Opinion in Supportive and Palliative Care* 10, 324–329.
- Bernard, M., Strasser, F., Gamondi, C., et al., and the SMILE consortium team. (2017). Relationship between spirituality, meaning in life, psychological distress, wish for hastened death, and their influence on the quality of life in palliative care patients. *Journal of Pain and Symptom Management* 54, 514–522.
- Borasio, G.D. and Bernard, M. (2016). Measure development and assessing outcomes in palliative care: Always look on the bright side of life. . . . *Palliative & Supportive Care* 14, 89–90.
- Brandstätter, M., Baumann, U., Borasio, G.D., et al. (2012). Systematic review of meaning in life assessment instruments. *Psycho-Oncology* 21, 1034–1052.
- Charon, R. (2001). Narrative medicine: A model for empathy, reflection, profession, and trust. *Journal of the American Medical Association* 286, 1897–1902.
- Kwan, C.W.M., Ng, M.S.N., and Chan, C.W.H. (2017). The use of life review to enhance spiritual well-being in patients with terminal illnesses: An integrative review. *Journal of Clinical Nursing* 26, 4201–4211.
- Sepulveda, C., Marlin, A., Yoshida, T., et al. (2002). Palliative care: The World Health Organization’s global perspective. *Journal of Pain and Symptom Management* 24, 91–96.

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