Measuring non-pharmacological caregiving

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Recently, Lindquist et al. publish a prospective, descriptive study conducted in 16 palliative care programs in 9 countries (1).

The authors measured non-pharmacological related activities conducted near the end of life. They collected 914 statements, 80% of them from nurses, 15% from physicians, and approximately 5% from other members of the interdisciplinary team.

The majority of the reported activities related to bodily care, organizing, planning, and evaluating, and performing rituals surrounding death and dying.

Other important aspects included listening, talking, and understanding, as well as creating an aesthetical safe and pleasing environment.

The vast majority of these statements pertain to the delivery of nursing care near the end of life. It would have been useful to see the variation in different activities according to the setting of the teams since it is expected that some activities would be much prevalent at home while others will be more important in acute care units.

Future research should also attempt to describe the difference in activities reported by each of the different members of the interdisciplinary teams. While nonpharmacologic activities should be common to all disciplines, they are likely to be performed in quite different ways by physicians, chaplains, physical and occupational therapies, and counselors.

The structures and processes existing in different existing in different settings and in different countries should be measured in future studies. It is likely that in those settings where the teams are considerably smaller, the nonpharmacological activities of the remaining team members will be significantly more dense than in those settings where there are more disciplines.

The authors appropriately state that the delivery of palliative care includes very complex non-pharmacological interventions.

This study raises a number of important issues. One of them is the difficulty in evaluating the density of palliative interventions in the real world. Under each of these headings a member of the team could have described a task that could demand anything from a couple of minutes to more than an hour. In this regard it might be more useful to measure the activities using an outside independent observer rather than the simple reporting by the different healthcare professionals.

Another important issue is redundance. It would be very useful to see how many disciplines report similar activities on the same patient or family member on the same day.

Finally, perhaps the most important question is which activities are most conducive to enhancing physical and psychosocial distress in patients and family well-being.

In recent years most palliative care programs have adopted systematic evaluation of physical and psychosocial distress. This is a very positive step toward better evaluation of our programs. Systematic evaluations have clearly demonstrated that palliative care programs in the inpatient and outpatient settings are capable of reducing physical and psychological symptom burden (2-6). As Lindqvist et al. point out; the vast majority of interventions in palliative care are multidimensional and interdisciplinary. Therefore, research on what constitutes a basic palliative care package capable of optimal improvement in physical and emotional distress is of great importance for the planning of palliative care programs in times of increasing demand and diminishing resources.

Based on the authors data a better characterization of each of the different items, and perhaps comparison

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between groups where some elements are available and others unavailable, might help better delineate the very complex decisions we all need to make about the ideal size and scope of our palliative care programs in the future.

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