

Non-pharmacological dimensions of end of life care

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Palliative care is a major focus in global health. There is a commitment to improve the quality of care at the end of life. The phrase ‘end of life’ can imply the terminal stages of any life-limiting illness; the last month, weeks or days. Generally it is used for the last days. The complexity of care at that time is well recognized. Integration of non-pharmacological and pharmacological management is required. Non-pharmacological management e.g., physical care, communication, family support, is the major part of routine clinical practice but is under-researched (1). Despite advances in knowledge and insights into the multidimensional experience of pain and other symptoms, there are deficits in assessment and pharmacological management of symptoms in the dying (2). Research about nurses’ perceptions and barriers to end of life care (3,4) has been done, but that which has involved patients and families is sparse. The difficulties include lack of resources and also the emotional and psychological barriers to research in a vulnerable population. Thus, clinical practice in this area is more anecdotal than evidence based.

The international qualitative study “Complexity in non-pharmacological caregiving activities at the end of life” (5) examined those provided to people with cancer. It showed that though difficult, such studies are possible. The researchers, units in different countries and the staff should be commended for the joint endeavor which captured the intricate details of care. This was a detailed, comprehensive database of non-pharmacological caregiving activities (NPCA).

It was conducted in sixteen units of nine countries. A preliminary list of NPCA was created after discussion about interventions with a single Hospice and Palliative Care home unit. This was given to all participating units. The data set comprised ‘free-listing’ statements of NPCA provided by unit staff. The documentation (collected over several weeks) illustrated the intricate and interwoven

nature of care at end of life. The participation by different countries provided a wider perspective.

Of the 985 statements, 71 were omitted from analysis (e.g., duplication, incomprehensibility). Computer assisted analyses were based on the nature/character of the NPCA and also the recipient i.e. patient, patient & family unit, staff and organization. Several forms of communication and care (either information or team member non-verbal presence) were recorded and analyzed. Most statements were from nurses (80%). The rest were physicians, occupational therapist, psychologist, social workers, chaplains etc. Statements were collected in English and other languages. Personal care and communication were identified as the two substantial components of NPCA.

Mundane activities like emptying a waste basket to avoid room odor, tea for families, or more complex work (wound care, assessment for an orthopedic bed) were all included. It is remarkable to see natural human empathic responses translated into practical daily care. NPCA can be integrated with two care skill areas. One requires education and experience (e.g., communication, bereavement support). The other is innate empathic responses (listening, touch). Education can enhance skills in both areas. Clinician empathy can improve patient satisfaction (6,7). The importance of teaching this early in both the medical and nursing curriculum has been acknowledged (8,9).

Though the report provides extensive insight into NPCA at the end of life, it did not address the cultural, ethnic or financial diversity amongst participating units. How the sixteen facilities were chosen from these nine countries is also unclear. It would have been helpful to know the criteria used. One questions whether a chosen facility could represent the care provided in the whole country? Could there have been selection bias? In addition whether the statements provided

differed in terms of number, content, care structure and process amongst units was not specified. The participating countries can be considered to be of similar economic status but the financial limitations, differences in health systems, family structures or ethnic diversity that could have impacted care between these countries was not discussed. This makes it difficult to assess whether clinical practices or structural variations influenced care.

Most statements were from nurses about their role in end of life care. Again, it is unclear if this differed from country to country, or unit to unit. Care at the end of life is based on social, cultural and diversity concepts (10-12). One of the intentions of this study was to investigate the diversity. From the analysis it is hard to appreciate the extent of this between units. Nevertheless, it appeared the ethos of care and level of empathy did not vary much between countries. As the authors suggested, acknowledgment of the complexity of care in the last days of life and integration with physical, psychological, spiritual and existential needs can be unanimously accepted everywhere.

Despite recognition of the multifaceted nature of end of life care, there is a national and international need to provide and improve the quality of this care. Along with integration of pharmacological and non-pharmacological methods, skills to enhance empathy in health professionals should be actively developed; it plays a major role in optimal patient and family satisfaction. These concepts should be incorporated with appropriate cultural and societal adaptations for the individual or the family unit.

One of the major inherent challenges in this work can be the terminology 'end of life'. It may be used to describe the palliative phase of life and not just the last days. This makes a standardized approach difficult. Research on aspects like the terminology of 'end of life', the environment of the dying patient, etc. can enhance care. Besides, it should not be forgotten that culture, belief, financial implication, clinical practice, and medical care structure vary between regions and countries. Insight into both the uniformity and diversity of how needs are met in different countries are key, especially when immigration is common. For this, a collaborative approach among nations should be encouraged to share, learn and research care at the end of life. Conversely, the generalizability of any research results should be carefully considered as the provision and norms of care do vary from country to country.

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