Complexity in non-pharmacological caregiving activities at the end of life: an international qualitative study

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BACKGROUND
In late-stage palliative cancer care, relief of distress and optimized well-being become primary treatment goals. Great strides have been made in improving and researching pharmacological treatments for symptom relief; however, little systematic knowledge exists about the range of non-pharmacological caregiving activities (NPCAs) staff use in the last days of a patient's life.

METHODS AND FINDINGS
Within a European Commission Seventh Framework Programme project to optimize research and clinical care in the last days of life for patients with cancer, OPCARE9, we used a free-listing technique to identify the variety of NPCAs performed in the last days of life. Palliative care staff at 16 units in nine countries listed in detail NPCAs they performed over several weeks. In total, 914 statements were analyzed in relation to (a) the character of the statement and (b) the recipient of the NPCA. A substantial portion of NPCAs addressed bodily care and contact with patients and family members, with refraining from bodily care also described as a purposeful caregiving activity. Several forms for communication were described; information and advice was at one end of a continuum, and communicating through nonverbal presence and bodily contact at the other. Rituals surrounding death and dying included not only spiritual/religious issues, but also more subtle existential, legal, and professional rituals. An unexpected and hitherto under-researched area of focus was on creating an aesthetic, safe, and pleasing environment, both at home and in institutional care settings.

CONCLUSIONS
Based on these data, we argue that palliative care in the last days of life is multifaceted, with physical, psychological, social, spiritual, and existential care interwoven in caregiving activities. Providing for fundamental human needs close to death appears complex and sophisticated; it is necessary to better distinguish nuances in such caregiving to acknowledge, respect, and further
develop end-of-life care.

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