

## Opinion

# The Role of Emotions in Palliative Care

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Emotions are inherent to human condition and color all the activities we do every single day. They are the most important engine in our lives and facilitate the adaptation to environmental demands: they influence the cognitive superior processes, for example, perception, thinking, decision-making, language, beliefs, motivation, learning, memory and our behavior and intentions.<sup>1</sup>

People coping with advanced illness or life-threatening diseases, such as cancer, experience many symptoms, emotions, and feelings during their illness trajectory that can contribute to their suffering. These emotions may result from a variety of different factors and the intensity usually varies considerably from day-to-day, hour to hour and patient to patient.<sup>2</sup>

Using a metaphor to illustrate this point, the patient may experience a kind of emotional salad, where different emotions appear as different types of lettuce leaf (most negative than positive) with different degree of intensity (depending on leaf size) as a result of the coping process and the proximity of impending death. The most common negative emotions are loneliness, anxiety, anger, fear, guilt, hopelessness, sadness, but the patient can also experience positive emotions (e.g., happiness, hope, peace, security, love, meaning or gratitude). These emotions are experienced by the patient but also by the different members of their family, especially by the caregiver; they are dynamic and contribute to the well-being or emotional distress of the patient/caregiver. Many of these emotional reactions of the patient/caregiver during the illness trajectory are “normal” (e.g., anxiety, sadness, and preoccupation) and are related to the adaptation process and with the significance of the impending loss. In some cases, if the illness evolution is long and the patient does not have adequate resources to face it may ap-

pear clinically significant states characterized by symptoms of anxiety or depressive disorders.<sup>3</sup> Both the patient's normal emotional reactions and their emotional disorders can increase the emotional distress of the family/caregiver.

According to the integrative model of the suffering stated by Krikorian and Limonero<sup>4</sup> suffering occurs when the dynamic balance between perceived threats and regulatory processes (which include coping resources and strategies) is lost. A series of physical, psychological, social, and spiritual responses are employed, in order to adapt and regain well-being, where the emotional reactions are the cornerstone. Patient/caregivers experience a perception of threat as damaging the integrity of the whole, while available resources seem to be insufficient, which leads to exhaustion.

In this emotional context, the relief of suffering or emotional distress and the improvement of well-being are the two priority goals of the Palliative Care.<sup>5</sup> A first step to meet the patient's needs or help patients and caregivers to deal with negative emotions is to detect them. It means that there is a need to have adequate tools to assess emotional distress or suffering and the specific emotional reactions that occur in this complex situation.<sup>6-8</sup> In a previous study, we found that there were few assessment tools with good psychometric properties.<sup>9</sup> Keeping this fact in mind, we have recently developed two brief screening tools to detect emotionally distress, one addressed to the patient with an advanced illness or at end-of-life and another to their caregiver.<sup>10,11</sup> The detection of emotional distress scales (patient and caregiver) were developed in Spanish. Both scales consist of two questions that examine emotionally distress and coping efforts in a 0-to-10 visual analogue scale format. These scales show a good sensibility and

specificity and are very easy to administer. And, most importantly, help teams to make decisions.

To make a good assessment of emotional reactions of both patients and caregivers, it is necessary not only to ask them about their emotional reactions, worries or what is the most important for them but also to observe their reactions through their open behavior. In this sense, it is important to analyze the external signs of emotional distress, an assessment that can provide clues to team members to do a global emotional appraisal. These signs are very relevant, particularly in those caregivers who do not express openly their feelings or when communication is difficult.<sup>12</sup>

Emotional assessment is essential to the effective palliative care because of unmet patient's emotions (or caregiver emotions) and suffering may be underdiagnosed, minimized or underestimated. Without understanding these emotional aspects we cannot help patient or caregiver effectively. Specific interventions will be addressed to deal with emotional aspects, but these psychological interventions or psychotherapies will be evidence-based. For example, cognitive behavior therapy,<sup>13</sup> meaning-centered therapy,<sup>14,15</sup> dignity therapy<sup>16</sup> or specific psychosocial interventions have showed to be effective<sup>17</sup> in different studies on palliative care. For example, thanks to the analyses of the effectiveness of psychosocial interventions in the complex palliative care patients, we have observed that, after successive psychosocial interventions, the level of suffering in complex patients decreased until close to parity with non-complex patients, suggesting that patients with major complexity could benefit most from specific psychosocial treatment.<sup>17</sup> In the same way, a study conducted by Gil and collaborators showed that new issues relevant to patient well-being (classified as "emergent themes" example "threat, sadness, uncertainty") appeared when adapted meaning-centered group psychotherapy (MCGP) was applied to Spanish-speaking advanced cancer patients. It did not happen in the foundational work on MCGP by Breitbart and collaborators.<sup>15</sup>

Due to space limitations, we do not talk about mourning, where people experience many emotions during their grief. However, the survey of European Association for Palliative Care (EAPC) showed that the use of formal bereaved risk assessment was limited, occurring in only a quarter of bereavement services.<sup>18</sup>

However, from a psychological research point of view and from effective palliative care perspective<sup>6</sup> it is advisable to design specific psychological therapies identifying the most important elements or the underlying mechanisms, the number of sessions, the duration of the session, the type of patient, the clinical setting—home, nursing home, palliative care unit, inpatient- and as well as the follow-up of patients in comparison with other psychological support therapies. In this case, well designed randomized studies will be necessary. These specific tasks will surely provide a more comprehensive and coherent evidence base and will improve the development of psychological evidence in palliative care.

#### CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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