

## Opinion

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# Importance of Psychological Research in Palliative Care: Barriers in its Development

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Diseases in general, and particularly those that threaten the continuation of life, may affect the person in diverse manners causing suffering or emotional distress. At the end of life, suffering may be caused by different dimensions (physical, psychological, social & spiritual), and these dimensions can contribute separately or in an accumulative way to the experience of suffering. Consequently, the problems related to one dimension can cause or increase others leading to total suffering (in patients and their families).<sup>1</sup>

In palliative care the unit of care is the whole person, both the patient and significant others, with the well-being as the goal. To get this aim a multidisciplinary palliative health care team embraces the principles of holistic care with inclusion of psychosocial care as well as physical care.<sup>2</sup>

Taking in mind the interactive effects of the integrated dimensions of suffering, research on the psychosocial aspects in palliative care (emotional reactions, interactive emotions, coping strategies, spirituality...) is a basic task for later apply this knowledge in the care of the patient and his family to provide comfort or diminish suffering.<sup>3</sup>

The analysis of the psychosocial aspects in patients with advanced illness or at end of life has a number of characteristics that difficult the study. The barriers to psychological research are related to the following aspects: (1) psychological issues are subjective, variables or constructs are complex and difficult to operationalize, (2) psychological variables are difficult to measure, (3) the patients are fragile, their condition (both physical and psychological state) is mediated by the progress of the disease and the presence of impending death, (4) health professionals had limited time to conduct assessments or research, (5) and there was a lack of validated clinical tools.<sup>3-6</sup>

In psychological research, in many cases, the complexity of construct to study has been conceptualized in various ways, aspect that difficult research. It is particularly important to provide as clear a definition as possible for what is assessed. For example, the complexity of the meaning of life construct or the well-being construct reflects a lack of consensus among researchers as to what constitutes the essential dimensions of these constructs.<sup>7-9</sup>

One of the crucial aspects of psychological assessment is related to the instruments of assessment or screening used. In this sense, it is necessary to have adequate tools to assess emotional distress or suffering and the specific emotional reactions that occur in this difficult situation.<sup>10</sup>

These inherent aspects at the end of life situation difficult in many case the assessment of psychological aspects and the effectiveness of psychological intervention. The causes of emotional distress or suffering are multiple and changing in time and with the progress of disease, which implies the need to assess the patient's condition holistically and continuously.<sup>9</sup> These difficulties are evident, therefore, in the development of assessment instruments or screening measure.

Bearing in mind the specific characteristic of patient at end of life, the ideal assessment tool should meet the following criteria: 1) simplicity and ease of implementation; 2) language of questions adapted to patients; 3) avoid the iatrogenic with a excessive number of items; 4) to assess relevant aspects for the patient in their situation; 5) short implementation time; 6) that allows monitor the evolution of emotional patient' condition over time; and 7) to facilitate their derivation, if necessary, to a qualified professional for specific assessment and intervention.<sup>5,6,11</sup>

In addition to these characteristics, to facilitate clinical implementation, the assessment tools should be easy to use, without requiring extensive training.<sup>4</sup>

Given the above comments, we find that there are few tools developed to analyze psychological reactions of dying patient and his family, i.e, specific instruments to assess psychological aspects in palliative care.<sup>6</sup> However, this should not be an obstacle, but an opportunity to research and develop specific and validated clinical tools. For example, in the nineties we developed an easy screening tool to assess suffering in patients at the end of life based on the subjective patient perception of time. We asked the patients how long did yesterday (long, short or regular) and the reason of their answer. We obtained the subjective perception of time, as an indirect indicator of well-being or discomfort and the factors that positively or negatively may contribute to the same.<sup>12,13</sup>

In this field, is very important to take in consideration a theoretical framework of reference to understand the emotional reactions of dying patients or their caregivers as well to develop a screening tool.<sup>6</sup> For this, we have to take time to reflect, search psychological models to apply in this field or built a new model based in previous models or in research finding, as for example the Threat and Resources Model of Bayés et al<sup>14</sup> or the Integrated View Model of Suffering.<sup>3</sup> In this last model, for example, suffering is defined as a multidimensional and dynamic experience of severe stress that occurs when there's a significant threat to the person and coping efforts are insufficient, leading to perceived loss of control and loss of balance or homeostasis. In the case of end of life, threat occurs both at a mind and body level; therefore suffering entails cognitive, emotional, spiritual and physiological changes and responses oriented to recover homeostasis.

In this sense, at the beginning of palliative care, the focus on psychological aspects relied in the study of the phases of emotional reactions of dying patients, e.g. Kubler Ross,<sup>15</sup> currently, the research are diverse and are related for example to the following topics: discrete or complex emotions, emotional distress and suffering, coping strategies, resilience, spirituality, dignity, psychological interventions..., both the patient and his family. In this sense, we want to emphasize Dignity Therapy intervention developed by Chochinov<sup>16</sup> to enhance dignity and the sense of legacy in the terminally ill and the Meaning-Centered Psychotherapy developed by Breitbart<sup>17</sup> to help to the

patients with cancer to live with sense, of a full way, keeping and expanding the sense of his life, living in peace and with an aim in the life. These two models appointed the need to structure the intervention, giving the possibility to replicate the same models in different contexts, and with different therapists. Also, they guide us in the objectives, the process and therapeutic techniques and the future results expected with our intervention.<sup>18</sup>

Despite the achievements of the previous psychological interventions, a recent review of psychological intervention in cancer highlights the difficulty of comparing different psychological therapies, since the elements that compose or the mechanisms underlying them are not specified in many cases. This lack of clarity is a potential obstacle to the provision of a coherent evidence base if we compare with drug treatment that is more concrete.<sup>19</sup>

The legacy of psychological research is not very big, but is a great help to better understand the emotional reactions of dying people and help us to design the most effective psychological interventions. But isn't enough, the challenge of psychological research in palliative care is enormous,<sup>20</sup> further research is needed, despite the difficulties, since the psychological care is the cornerstone of palliative care.

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