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Grief on the agenda of multiprofessional oncology and palliative care teams: a family assistance program at the Federal University of São Paulo

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Abstract

Over recent years attention has been paid to the need to broaden the concept of palliative care and to include the grief reactions of patients' family members as a focus of multiprofessional teams. In hospitals, grief affects not just the patient who receives the news of a reserved prognosis, but also the patient's family and the technical teams who come into contact with the patient. Due to its potential to become complicated and cause physical, psychological and community problems, grief has already been identified as a public health problem, capable of silently placing a burden on care networks. This article aims to locate the problem of grief in hospital palliative care and oncology teams and give an overview of a group assistance program for grieving family members which has contributed to an improvement in the quality of communication and the dissemination of information in a teaching hospital in São Paulo.

Keywords

Grief, palliative care, oncology, multiprofessional care, terminality

The year 2002 may come to be remembered as a watershed in the history of the development of palliative care worldwide. That year, a document published by the World Health Organization (WHO) coined a new understanding of Palliative Care, which substituted the earlier understanding dating from 1990. The new, and broader, concept, can be summed up by emphasizing its core elements: palliative care came to be understood as an approach that seeks to improve the quality of life of patients and their families who are facing the problems associated with chronic, progressively debilitating and life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems (SEPULVEDA et al., 2002; WORLD HEALTH ORGANIZATION, 2002; 2004).

The WHO documents indicate that the concept of Palliative Care became broader on four levels. Firstly, it is not only terminal patients who are eligible for palliative care, but rather all patients with chronic degenerative illness, progressively debilitating illness and life-threatening illness. This means that patients with untreatable neoplasms, as well as those with acquired immune deficiency syndrome (AIDS), coronary failure, chronic obstructive pulmonary disease, chronic renal failure, neurodegenerative diseases, sequelae from cranioencephalic trauma and strokes and cystic fibrosis, amongst others, come to be targets of palliative care – and *from diagnosis onwards*. Secondly, it was determined that as well as patients' physical and symptomatological needs, their *psychological, social and spiritual* needs should also be addressed. In third place, both patients and their *families* come to be the focus of the planning and delivery of care. And fourthly, the families' grief comes to be a focus of attention and care, both before and after the death of the patient.

Grief can be defined as a set of emotional, physical, behavioral and social reactions resulting from a loss – whether a real loss or a fantasy loss (a “fear of losing”), whether death or the loss of a function, a possibility or an opportunity (PARKES, 1998a).

Work carried out in the more developed countries has positioned interventions with the bereaved as an important public health problem, due to the implications for the overall health of the survivors (YOUNG et al., 1963; STROEBE et al., 1993; PARKES, 1998b; KATO, 1999). Negative consequences for physical health include temporary drops in immunity levels, an increase in visits to the doctor, hospitalizations and surgery, and an increase in the mortality rate for bereaved groups, when compared to the general population (YOUNG et al., 1963; STROEBE et al., 1993; PARKES, 1998b). Consequences for mental health have been described in terms of varying levels of depression, anxiety, despair, disbelief and/or “emotional paralysis” (BOWLBY, 1961; PARKES, 1998b).

There seems currently to be a consensus that between the extremes of an adjusted, self-limiting grief reaction, which does not require therapeutic

intervention, on the one hand, and psychiatric syndromes on the other, there is an intermediary population made up of individuals who will present complicated grief syndrome – individuals who will require treatment to provide relief from the intense and damaging emotional symptoms of grief (PRIGERSON 1997; PRIGERSON 1999; SHEAR, 2001).

In the health area, observation of the various ways in which people are affected by grief could enable a great deal to be done to improve communication between patients, family members and staff. In general hospitals, we must note the grief that occurs in at least four situations (SOLANO, 2006):

1. The grief of the patient upon receiving the news that he or she is suffering from an incurable disease, or becoming aware of the unrelenting progression of his or her limitations and realizing that death is drawing near;
2. The grief of the family on following the functional decline of one of its members;
3. The grief of the survivors (family members and friends) after the death of the patient;
4. The grief of the medical team which looks after the patient.

In this article, as well as positioning ourselves alongside the WHO by arguing that bereavement care should be included in the activities of palliative care staff and oncologists, we will present an overview of a bereavement support program which originated from contact with the relatives of patients we have treated in the Palliative Care Division of the Federal University of São Paulo (UNIFESP).

The experience of working in a multiprofessional Palliative Care team demonstrated at an early stage that there was an urgent need for a mental health support program for the family members and carers of the patients attended by the department. This program was set up in October 2003 and given the name PROLU – *Projeto de Proteção ao Luto* or Bereavement Support Project in English. The idea was supported by the University Dean's Office, which made available an amphitheater at the Center for Nursing Care and Teaching (CAENF), located 400 meters from the university. Carers, relatives and friends of all the patients referred to the Palliative Care Division (mainly in the advanced stages of cancer and from low-income families living on the outskirts of São Paulo) became eligible for an invitation to participate in PROLU's activities. They were offered two sequential activities: (a) participation in a group where they could meet other family members and carers of incurable patients (*carer group*); and (b) participation, after the death of their loved one, in a group with other bereaved people (*bereavement group*). The aims of activities (a) and (b) are set out in table 1.

A carer or family member who attended activity (a) was told that after the death of their patient or loved one, he or she would be invited to participate in the group made up of other bereaved people

(activity b). However, the bereavement group also welcomed clients who had never participated in activity (a), since two weeks after the death of a patient, a letter of condolence was sent out and at least one telephone call was made to the family. Table 2 shows the format of the condolence letter used by PROLU.

Table 1 - Aims of the activities carried out by PROLU – the Federal University of São Paulo’s Bereavement Support Project

<p>(a) Carer group</p> <p><input type="checkbox"/> Train non-specialist staff to provide home-based care to patients with a high level of dependency, family members or members of the community.</p> <p>(b) Bereavement group</p> <p><input type="checkbox"/> Help families of patients who died in the care of the university hospital (Hospital São Paulo) to meet each other and share their experiences of grief.</p> <p><input type="checkbox"/> Maintain a link between the families and the institution for several months.</p> <p><input type="checkbox"/> Accompany the families’ grief process, identifying the most serious cases and referring them for specific treatment.</p> <p><input type="checkbox"/> Train leaders of community self-help groups</p>
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Each of the groups met once every two weeks, used open verbal expression, lasted 90 minutes, had a maximum of 12 participants and was led by a principal therapist (a psychiatrist) and an observer (a psychologist or social worker). Attendance at the groups was spontaneous and there was no limitation on the number of people which each family could bring along; friends of the family were welcomed; young people under the age of 16 were not invited to attend the group but were not turned away if they turned up.

Different techniques were used to guide the two groups. The carer group (a) was run according to a psycho-pedagogical format, and offered practical information to those helping to care for an ill person at home. The bereavement group (b) sought to offer psychotherapeutic support, with active efforts made to study the process of bereavement and participants encouraged to invest in working through their grief; the cases of complicated grief were identified by the lead therapist and dealt with through additional measures (drug therapy or referral to the mental health

services, where individual therapy relationships could be established).

Table 2 - Template of the Letter of Condolence used by PROLU (*)

<p>São Paulo, [date]</p> <p>Dear family and friends of _____:</p> <p>The Palliative Care team at this institution hopes that this moment of sorrow which you are experiencing will pass as quickly as possible. We would like to say thank you for the trust you placed in us by allowing us to care for a loved family member, and by permitting us to enter the privacy of your home.</p> <p>In particular, we would like to salute you for having cared for _____ until the end of their days. We know that it was a struggle, and we saw your courage and dedication throughout.</p> <p>Now that the struggle is over, we hope that we can all rest. We know that even now that _____ is gone, his/her memory will stay alive. And we know that the strength that he/she showed will help us to face the battles still to come alongside our fellow creatures.</p> <p>So thank you, and please keep our contact details, because we remain at your disposal for anything you need.</p> <p>_____ (Signature) Palliative Care Division of the Medical Department Federal University of São Paulo</p>
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(*) The letter is only sent out two weeks after the death of the patient and is followed by (at least) one telephone call in which the family is invited to attend the bereavement group (activity b).

Activity (a) failed to establish itself because no cohesive group took shape over time. No meeting was attended by more than three people, and there were several where no participants at all turned up. The highly irregular attendance of a small number of participants made any attempt to measure the results impossible.

Activity (b) has taken place since the beginning of the project (October 2003), with one break between June and October 2004, due to travel by the principal therapist, and another between January and October 2006, while new premises were being renovated. As well as the meetings every two weeks, five “social events” were organized (four Christmas parties and a “send-off” for the therapist), with a large turnout of former participants. Up to now, 56 bereaved people have taken part in the groups. Six cases of complicated grief (11%) were identified and were or are being treated. Table 3 shows the diagnostic criteria used by

PROLU to identify cases of complicated (or pathological) grief, a nosographical category whose inclusion in the next (fifth) version of the Diagnostic and Statistical Manual for Mental Disorders (DSM-V) is being considered (PRIGERSON, 1999). From December 2004 onwards, the service was made available to any patients at Unifesp and the general public.

Table 3 - Proposal from PRIGERSON *et al* for the inclusion of the category of complicated grief in the DSM-V.

<p>Criteria A: loss of a loved one through death, followed by a reaction including at least three of the following:</p> <ul style="list-style-type: none"> - intrusive thoughts about the deceased; - anxiety to meet the loved one again; - behavior of searching for the deceased; - feeling of loneliness as a result of the death. <p>Criteria B: at least four of the following:</p> <ul style="list-style-type: none"> - feeling of aimlessness or futility associated with the future; - subjective feeling of emotional numbness, disconnection from the world or loss of emotional responsiveness; - difficulty in accepting the loss; - feeling that life is empty or meaningless; - feeling of having lost part of oneself ("I died with them"); - rupture in personal beliefs;- repetition of symptoms (or risky habits) of the deceased;- excessive irritability, bitterness or anger about what happened. <p>Criteria C: duration of at least two months.</p> <p>Criteria D: the disturbance has a significant negative effect on social and professional functioning and other important areas of the individual's life.</p>

Source: Adapted from SOLANO, 2006. Translated into Portuguese by João Paulo Consentino Solano.

Grieving families have often indicated that they were comforted by the letter of condolences they received. However, no objective measurement of the impact of this procedure has been carried out up to now.

The obvious question is why intervention (a) failed. One relevant hypothesis is that low-income families,

residents of far away areas on the outskirts of a large city who are trying to care for a sick family member at home (as the Palliative Care team requests) find it difficult to send a family member or carer to the hospital once every two weeks – since this might leave the ill person without a carer for half of the day and increase the emotional and financial burden which these families already suffer.

The bereavement group (activity b) was made up of people who had lost a loved one and who were invited to join the group by the same professional who had provided home-based assistance to the sick person, one of the authors of this article. They knew that it would be this professional leading the bereavement group. In all, 38 families were invited to join the group. Twenty-seven of them attended the group (a response rate of 70%), leading to an attendance of 56 bereaved people at the group.

Between June and September 2004, the group interrupted its activities due to force majeure and it was clear that from October 2004 onwards a second phase in the group's history had begun: most of the bereaved did not return to continue the work, despite being contacted by telephone and mail. After considerable reflection by the therapists, it was understood that they should not persist with the invitations, since this could send out ambiguous messages about the capacity of the ex-clients to deal with their own grief process – now without the help of the group. This second phase in the history of the group may purely and simply have meant the formation of a new group, since almost all of the most reliable members were replaced.

Group psychotherapy with the bereaved generally follows two main technical lines: one which places more emphasis on the *emotional expression* of members and another which prioritizes the *actions* through which participants should modify their internal and external reality so that their grief process consolidates itself. A third technical option for working with this kind of group stems from a mixture of the two approaches. This is the technique used by PROLU, based on a belief that its inherent flexibility may better suit the oscillating demands of open group therapy (CONGRESSO INTERNACIONAL DE TANATOLOGIA E BIOÉTICA, 2005).

The decision to work with a group of the bereaved in a house outside of the hospital – although this was informal at first – proved to be beneficial, since, as the specialist literature suggests, many families which had lost loved ones would hesitate, after months or years of visiting the hospital's various wards and outpatient clinics, to continue to spend time in the same spaces in the first weeks or months of bereavement (PARKES, 1998a; CONGRESSO INTERNACIONAL DE TANATOLOGIA E BIOÉTICA, 2005).

Since December 2004, people have been included in the group even when they are not from families supported by the Palliative Care Division. Up to April

2005, 56 people were attended by PROLU, of whom eight found out about the service through the media.

At the end of the first half of 2006, an attempt was made to measure the impact of the intervention through interviews with all the participants and former participants in the activity. The results of this evaluation will be presented in a separate article.

It has been estimated that for every person that dies, five relatives, close friends or lovers experience grief (ZISOOK, 2000). This means that any person involved in Oncology and Palliative Care must know that they will come across many more grief reactions around their patient than actual patients.

Work dealing with questions relating to death and grief is still something new in Brazil, especially in the hospital context (and, in particular, among doctors). However, there is no doubt that the recommendations made by the WHO about extending the care offered to terminal patients to their families and carers need to be implemented here.

Our next step will be to carry out high quality studies to measure the effectiveness of the intervention, using larger samples than that we have had access to this time. Nonetheless, even before measuring the impact of the intervention, we have been able to observe that it is in itself capable of improving the quality of communication between patients and the teams working in the hospital, as well as enabling the dissemination of information which is critical for the prevention of pathological grief reactions in the community.

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