CONSIDERATIONS ON THE ROLE OF PALLIATIVE CARE IN THE MOURNING PERIOD

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Abstract

Death is a universal and inevitable phenomenon, with strong emotional loading for both the dying and those around them (family members or caregivers, of a medical or psychosocial, spiritual nature). The main response to the passing of someone dear is grief, which is usually reversible; however, in some cases, it may generate important general morbidity and mortality risks. Palliative care represents a complex approach meant to improve the quality of life of terminal patients and of their family members, by preventing and mitigating physical pain, as well as psychosocial and spiritual issues. In this field, responsibility toward the patient extends to his/her family after the patient's death. In this paper, the authors analyze the sources of mourning labour, as well as the intervention means suitable for the genuine existential crisis entailed by the passing of a loved one. The importance of the theme resides in the fine line between physiological grief and depression (with all the risks it involves) and in the need of identifying ways to familiarize the family with the idea of death, both before the passing of the dying and afterwards (to facilitate the mourning labour of those left behind and to avoid its complications).

Keywords: death, mourning labour, pathological grief, palliative care.

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Introduction

The loss of someone dear is a universal phenomenon, which all people have or will experience at a certain point. The main response to the death of a loved one is grief: a reversible process for most of those who experience it, surmountable by using one's mental resources. However, in some cases, grief generates increased risk of general morbidity and mortality and it may lead to the emergence of mental disturbances or to the worsening of pre-existing disturbances; persons who reach this stage require professional help (Roman *et al.*, 2013; Neimeyer, Prigerson, & Davies, 2002; American Psychiatric Association, 2013; Sadock & Sadock, 2000; Sadock & Sadock, 2001; Bowlby, 1973).

Palliative care represents a complex approach meant to improve the quality of life of terminal patients and of their family members, by preventing and mitigating physical pain, as well as psychosocial and spiritual issues (WHO, 2016). The medical responsibility of palliative care toward the patient and his/her family does not end with the passing of the patient, but it continues by supporting his/her relatives in getting used to the idea of death and especially of the death of someone close.

Grief – a clinical characterization

From a psychoanalytical perspective, grief is the state of losing a loved one, accompanied by helplessness and moral pain, which may entail a significant depressive response, surmountable through an intra-psychic process called "mourning labour" (Field, Gao, & Paderna, 2005).

From a psychiatric view, grief is pointed out when the focus of clinical attention is the response to the death of a loved one (American Psychiatric Association, 2013). As part of their reaction to bereavement, some persons experience symptoms characteristic to a major depressive episode (such as feelings of sadness, insomnia, lack of appetite, etc). These symptoms generate reactions that exceed the normal range of mourning, among which we mention guilt (concerning other things than the actions that the survivor took or failed to take at the moment of death), death thoughts (other than the survivor's idea that he/she should have died, too, or that it should have been him/her dead), the morbid preoccupation for uselessness. In the same sense, we also underline marked psychomotor slowness, marked and prolonged functional deterioration, hallucination experiences (other that the belief of hearing the voice and getting a glimpse of the deceased) (American Psychiatric Association, 2013).

The concept of mourning was outlined throughout several stages. Initially, loss was pinpointed as a human-specific experience, followed by a so-called

"Romantic era," where loss was associated with characteristic emotions and feelings. In the modern period, loss was characterized in psychological and medical terms, while the post-modern period posited that there is no universal pattern for experiencing and interpreting the loss of a loved one (Sadock & Sadock, 2001; Field, Gao, & Paderna, 2005).

Mourning is, on one hand, a natural event and, on the other, a veritable socio-cultural construct; the response to loss is actually the consequence of our evolution as biological and social beings. The death of a loved one leads to the interruption of attachment links, which are essential for our survival. To the death of a family or community member, we react both biologically (by releasing stress hormones) and symbolically (by the meaning ascribed to the symptoms of separation, of interruption of attachment links, and by the alterations occurring at the level of personal and collective identity) (Neimeyer, Prigerson, & Davies, 2002).

Three types of grief have been pinpointed: normal (simple) grief, complicated grief and pathological grief.

Simple grief – usually lasting 1 to 2 years – represents the normal reaction to the death of a loved one, expressed by the following: somatic symptoms, concerns related to the image of the deceased, feelings of guilt regarding the circumstances of his/her death, hostile reactions and the incapacity of coming back to being the person before the mourning period (Granek, 2010; Cosman, 2011; Larousse, 2006). Mourning labour comprises several stages – more or less numerous, depending on the view of various authors, such as Bowlby (1973) or Parkes (1998) – and it contains several reactions. These reactions include as follows: numbness or protest, which can last from a few moments to days or months (expressed by pain, fear and anger or emotional apathy); a feeling of surreal, of missing and looking for the lost one, which may take several months or years (expressed by atrocious separation pain, awareness of the irreversibility of loss, with somatic and psychic manifestations); disorganization and despair (anxiety and lack of goals, increase in somatic concerns, withdrawal, introversion and irritability, repeated reliving of memories related to the deceased) and, finally, reorganization, readjustment to life. This readjustment includes regaining the control of emotions and of behavioural responses, even during the last stage, emotional setbacks may occur, mostly at anniversaries or traditional religious occasions (Bowlby, 1973; Parkes, 1998).

Complicated grief is characterized by a blockage of the mourning labour; there is a persistence of the depressive phase, of stress reactions with severe somatic symptoms, which may degenerate in suicidal behaviour.

Pathological grief is represented by a delay in the emergence of deep pain, followed by a persistence of its evolution for longer than two years; this constitutes a real threat for mental health. The person who experiences pathological grief is unable to talk about the deceased without reliving the same intense pain for many

years, and minor events trigger the grief pain. This state can complicate by turning into clinical or sub-clinical depression, melancholic psychosis or grief mania accompanied by denial of loss or obsessive mourning, where the mourner behaves as if the deceased were still alive (Granek, 2010; Cosman, 2011).

Though currently, nosological operational classifications such as DSM-V and ICD 10 fail to define grief as a psychiatric disorder, (the first only provides the criteria differentiating major depression from grief with depressive elements) there has been a trend of including grief within pathology, considering the severe risks for the person who experiences it (Cosman, 2011).

Risk factors for the emergence of pathological grief

The way in which people experience and express grief is influenced by many internal and external factors, called "mediators of grief" or "determinants of grief." However, some of them may turn into risk factors for pathological grief, such as the following: background factors (very close relationship with the deceased – spouse or child, female gender, increased marital dependence prior to death, spiritual and religious beliefs and practices); factors related to the treatment received by the deceased (aggressive medical interventions, intra-family conflicts regarding the treatment, financial difficulties in procuring the treatment); or factors related to death (multiple and traumatizing losses within a short time frame, low acceptance of imminent death in the hospital) (Neimeyer & Burke, 2012) .

Many of the persons experiencing the mourning labour are aware of their state, but they do not usually get professional help for surpassing this existential crisis. Many times, silence is considered a sign of respect for the deceased, and mourning is assimilated to a pain that must be interiorized (Bowen, 1978). Certain factors such as burial or commemoration rituals can create the climate necessary for the individual to share his/her mourning labour with others. The manifestation forms of mourning labour differ by the person experiencing it, but they are also influenced by cultural and religious factors (Dima-Cozma *et al.*, 2014; Gao, & Paderna, 2005; Neimeyer & Burke, 2012; Stroebe *et al.*, 2002).

Approach to mourning within palliative care

Palliative care represents a complex approach meant to improve the quality of life of terminal patients and of their family members, by preventing and mitigating physical pain, as well as psychosocial and spiritual issues (WHO, 2016; Bowen, 1978). The support offered to the family during the patient's life in terms of preparing them for their imminent loss can continue in the mourning period, by

getting them used to the idea of death and especially of the death of someone close; hence, to the idea of mourning (WHO, 2016; Agnew *et al.*, 2010). This is a special type of assistance, also particularized depending on the spiritual, cultural and social values of the mourning family.

In the mourning period, the support offered to the family is the result of efforts made by a multidisciplinary team, comprising experienced professionals in the field of palliative care: psychiatrists, psychologists, social workers, nurses and palliative care volunteers.

There is no preset duration of palliative care in the mourning period; it is modulated by the needs of persons assisted, who get periodic evaluations (Altmaier, 2011; Department of Health, 2011; Doka, 2002). The support during the mourning period – provided by palliative services – is mainly destined for the close relatives of the deceased, but it can be extended (within the limits of material resources available) to other relatives or to caregivers.

The necessity of palliative support is assessed by the evaluation of bio-psychosocial factors likely to lead to complicated grief, as well as by applying standardized tools, which can predict or differentiate pathologic the grief. Such tools include Texas Revised Inventory of Grief – TRIG, Grief Experience Inventory – GEI, Core Bereavement Items – CBI, Inventory of Complicated Grief-R – ICG-R, etc. The evaluation must take into account the cultural factors (which may modulate the exteriorization of grief) and it must pay special attention to potential (self)-aggressive behaviours entailed by grief (Roman *et al*., 2013; Prigerson *et al.*, 2009; Faschingbauer, Zisook, & DeVaul, 1987).

Interventional strategies must be individualized by the gravity of symptoms and the risk of complicated grief. They may include universal strategies, such as an effective management of symptoms for the mitigation of traumatic impact, the provision of structured and support information in all moments preceding death per se and the mourning labour (upon the arrival to palliative care, when death is imminent, immediately after death, at regular intervals after death, for instance 3, 6 and 12 months, or whenever necessary). Other universal strategies include the information regarding support strategies by participating to informative sessions for reflecting upon the experience of losing someone dear and to group activities (meditation, art groups, etc). It may be possible to have to use specialized strategies, destined to persons prone to complicated grief. Such specialized strategies may include psychotherapy (cognitive-behavioural, family, etc), adhesion to support groups or the application of virtual therapy (Hall, Hudson, & Boughey, 2012; Bryant, 2010; Radbruch, L, & Payne, 2009). There are situation when – despite proper support provided – the situation remains or becomes of outmost gravity, which requires psychiatric assistance. The evolution of complicated grief is chronic-oscillating, comprising a sequence of periods when the separation and bereavement symptomatology is acute and a sequence of periods when it is

mitigated, but without the spontaneous tendency of disappearing, which induces ongoing stress. Persons affected by it are prone to drug abuse, suicidal acts (higher risk in women or adolescents) or depressive and anxious disorders (Prigerson *et al.*, 2009; Szanto *et al.*, 2006), which makes their safety the core element in all interventional strategies concerning the mourning period. Furthermore, palliative support is always based on the respect toward the autonomy and privacy of the person who receives help, manifested by ensuring confidentiality and setting boundaries of intervention, depending on the person's informed consent (Prigerson *et al.*, 1995; Szalontay *et al.*, 2015; Worden, 2002; Nanu *et al.*, 2011).

Conclusions

Though individuals are most of the times aware of the existential crisis valence of their mourning labour, which challenges the resources they need for leading a normal existence, they only rarely appeal to professional help. Henceforth, they expose themselves to the risk of getting beyond a physiological response, of getting to a state of irreplaceable bereavement, of a genuine psychiatric disorder. This reality underscores the necessity of determining detection and intervention strategies for preventing the pathological complications of mourning labour destined, on one hand, to getting the family members of terminal patients familiarized to the idea of death and of the death of a loved one, in particular, both before and after his/her passing. On the other, it is destined to assessing the mental state of family members throughout the entire mourning period.

References

Agnew, A., Manktelow, T., Taylor, B., & Jones, L. (2010). Bereavement needs assessment in specialist palliative care settings: a review of the literature. *Palliative Medicine*, *24*(1), 46-59.

Altmaier, E.M. (2011). Best practice in counseling grief and loss: Finding benefit from trauma. *Journal of Mental Health Counseling*, *33*(1), 33-45.

American Psychiatric Association (2013). DSM-5. *Diagnostic and statistical manual of mental disorders*. https://psicovalero.files.wordpress.com/2014/06/dsm-v-manual-diagnc3b3stico-y-estadc3adstico-de-los-trastornos-mentales.pdf

Bowen, M. (1978). Family therapy in clinical practice, London: Aronson.

Bowlby, J. (1973). *Attachment and Loss: Separation, Anxiety and Anger*, volume II. London: Hogarth Press.

Bryant, R.A. (2010). Grief as a psychiatric disorder. *British Journal of Psychiatry*, *201*, 9-10.

Cosman, D. (2011). *Psychologie et medecine*. Cluj Napoca: Casa Cartii de Stiinta.

Department of Health (2011). Strengthening palliative care: Policy and strategic directions 2011–2015, Melbourne: State Government of Victoria.

Dima-Cozma, Corina, Patacchioli, Francesca Romana, Ghiciuc, Cristina Mihaela, Szalontay Andreea, Mitu Florin, Azoicai Doina (2014) Current perspectives in Stress Research and Cardiometabolic Risk. *Revista de Cercetare si Interventie Sociala*, *45*, 175-188.

Doka, K. (ed.) (2002). Disenfranchised grief: New directions, challenges, and strategies for practice, Champaign, IL: Research Press.

Faschingbauer, T., Zisook, S., & DeVaul, R. (1987). The Texas Revised Inventory of Grief. In S. Zisook (Ed.), *Biopsychosocial aspects of bereavement*, Washington, DC: American Psychiatric Press.

Field, N., Gao, B., & Paderna, L. (2005). Continuing bonds in bereavement: An attachment theory perspective. *Death Studies*, *29,* 277-299.

Granek, L. (2010). Grief as pathology: The Evolution of Grief Theory in Psychology From Freud to the Present. *History of Psychology*, *13*(1), 46-73.

Hall, C., Hudson, P., & Boughey, A. (2012). *Bereavement support standards for specialist palliative care services*, Melbourne: Department of Health, State Government of Victoria.

Larousse (2006). *Marele dictionar al psihologiei*, Bucuresti: Trei.

Nanu, A., Georgescu, D., Voicu, V., Ioan, B. (2011). Place and relevance of legal provisions in the context of medical practice in Romania. *Revista Romana de Bioetica*, *9*(4), 90-101.

Neimeyer, R.A., & Burke, L. A (2012). Complicated grief and the end-of-life: risk factors and treatment considerations. In: JL Werth, *Counseling clients near the end of life*, New York: Springer.

Neimeyer, R.A., Prigerson, H.G., & Davies, B. (2002). Mourning and meaning. *American Behavioral Scientist*, *46*(2), 235-251.

Parkes, C.M. (1998). Bereavement in adult life. *British Medical Journal*, *316*(7134), 856-859.

Prigerson, H.G., Horowitz, M.J., Jacobs, S.C., Parkes, C.M., … & Paul K. Maciejewski, P.K. (2009): Prolonged grief disorder: psychometric validation of criteria proposed for DSM-V and ICD-11, PLoS Medicine, 6(9), DOI: https://doi.org/10.1371/journal.pmed.1000121.

Prigerson, H.G., Maciejewski, P.K., Reynolds, C.F., Bierhals, A.J., *et al*. (1995). Inventory of Complicated Grief: a scale to measure maladaptive symptoms of loss. *Psychiatry Research*, *59*, 65-79.

Radbruch, L, & Payne, S. (2009). White Paper on standards and norms for hospice and palliative care in Europe: part 1. *European Journal of Palliative Care*, *16*(6), 278-289.

Roman, G., Enache, A., Parvu, A., Gramma, R.,…& Ioan, B. (2013). Ethical issues in communication of diagnosis and end-of-life decision-making process in some of the Romanian Roma communities. *Medicine Health Care and Philosophy, 16*(3), 483-497.

Roman, G., Gramma, R., Enache, A., Parvu, A.,…& Ioan, B. (2013). The health mediators-qualified interpreters contributing to health care quality among Romanian Roma patients. *Medicine Health Care and Philosophy*, *16*(4), 843-856.

Sadock, B. J, & Sadock, V.A, (2001). *Manual de buzunar de psihiatrie clinică*, 3rd edition, Bucuresti: Editura Medicala.

Sadock, B. J., & Sadock, V. A (2000). *Kaplan & Sadock's Comprehensive Textbook of Psychiatry,* Lippincott Williams & Wilkins Publishers; 7th edition.

Stroebe, M., Stroebe, W., Schut, H., Zech W, van den Bout, J. (2002). Does disclosure of emotions facilitate recovery from bereavement? Evidence from two prospective studies, *Journal of Consulting and Clinical Psychology*, *70*, 169-178.

Szalontay, A., Burtea, V., Ifteni, P. (2015) Predictors of Institutionaization in Dementia. *Revista de Cercetare si Interventie Sociala*, *49*, 249-256.

Szanto, K., Shear, M. K., Houck, P. R., Reynolds, C.F. 3rd, Frank, E., Caroff, K., Silo-wash, R. *et al*. (2006). Indirect self-destructive behavior and overt suicidality in patients with complicated grief. *Journal of Clinical Psychiatry*, *67*, 233-239.

WHO (2016). Supporting countries to achieve health service resilience. http://apps.who.int/iris/bitstream/10665/205944/1/WHO_HIS_SDS_2016.2_eng.pdf?ua=1

Worden, J.W. (2002). *Grief Counseling and Grief Therapy* (3rd ed.), New York: Springer Publishing.