

**UPDATE**

Family relationships in the context of palliative care

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Abstract

This paper aims to explore potential implications to family relationships in the end of life, throughout a narrative review of literature. Thus, it was perceived that increased longevity and the consequent increase in the prevalence of chronic-degenerative diseases have prolonged periods of treatment and care, which are usually physically, emotionally and financially expensive. It is understood that changes and loss involved in the process of illness harm patients and also their relatives, which justifies the need for assistance that provides care to these individuals and helps them to face the physical, psychosocial and spiritual suffering that they are exposed to.

Keywords: Palliative care. Family relations. Hospice care.

Resumo**Relações familiares no contexto dos cuidados paliativos**

Este artigo objetiva explorar possíveis implicações às relações familiares no fim da vida por meio de uma revisão narrativa de literatura. Assim, constatou-se que a maior longevidade e o consequente aumento na prevalência de doenças crônico-degenerativas têm prolongado períodos de tratamento e cuidados, os quais são por vezes dispendiosos em termos físicos, emocionais e financeiros. Entende-se que as mudanças e perdas no processo de adoecimento acometem o doente e também seus familiares, o que justifica a necessidade de assistência que ofereça cuidados a esses indivíduos e dê suporte aos sofrimentos físico, psicossocial e espiritual a que estão sujeitos.

Palavras-chave: Cuidados paliativos. Relações familiares. Cuidados a doentes terminais.

Resumen**Relaciones familiares en el contexto de los cuidados paliativos**

Ese artículo tiene como objetivo explorar posibles implicaciones en las relaciones familiares en el final de la vida, por medio de una revisión narrativa de literatura. Así, se constató que la mayor longevidad y el consecuente aumento de la prevalencia de enfermedades crónico-degenerativas, ha llevado a largos períodos de tratamiento y cuidados, los cuales son, muchas veces, física, emocional y financieramente costosos. Se entiende que los cambios y pérdidas en el proceso de la enfermedad afectan al enfermo y también a sus familiares, lo que justifica la necesidad de una asistencia que ofrezca cuidados a estos individuos y brinde soporte para enfrentar los sufrimientos físico, psicossocial y espiritual a que están expuestos.

Palabras clave: Cuidados paliativos. Relaciones familiares. Cuidados paliativos al final de la vida.

Declararam não haver conflito de interesse.

This study aims to analyse family relationships in the context of palliative and end-of-life care. It is understood that the theme is related to the increase in the number of people affected by chronic diseases, whose prevalence rates increase as there are more scientific and technical resources in the field of health. These resources, procedures and interventions allow for early diagnosis, effective treatment, rehabilitation programs and encouraging prognoses. On the other hand, they can extend life through technical mechanisms that are often incapable of promoting quality of life.

In this context, palliative care is a therapeutic modality that contrasts with futile procedures and interventions at the end of life (dysthanasia), through the search for the well-being of patients and their families, whose diagnoses indicate diseases potentially life-threatening¹. In addition, it understands suffering at the end of life as having a multidimensional (physical, psychosocial, spiritual) character, which implies the need for care that pays attention to all these aspects².

Thus, interventions in palliative care can be performed by a multi professional team composed of professionals such as nurse, psychologist, physician, social worker, pharmacist, nutritionist, physiotherapist, speech and language therapist, occupational therapist, dentist and spiritual assistant. The need for multi professional care originates from the complexity involved in palliative care³ and seeks to minimise the suffering of patients and their families, since it considers the relationships between them in the process of illness and end of life⁴.

It is understood that the end of life is a complex subject considering that, in addition to all symbolic losses related to the process of illness (bodily changes, suppression and replacement of social and family roles, impact on finances, restriction of autonomy), it includes the death of the patient, an issue that affects all those who surround him or her. Thus, the objective of this work was to explore this little discussed subject through a narrative review of the literature, that is, it is a non-systematic survey that does not specify keywords, descriptors, sources and period of publication⁵.

Family Institution

Research on family relationships at the end of life involves reflection on the conceptions about the family institution. In this sense, there are theories that report the constitution of the family nucleus to

the beginnings of the human species, such as the theory of Claude Owen Lovejoy^{6,7}, which considers among the advantages of bipedalism - how to better see predators in the savanna, for example - the possibility of using hands and walk upright, using only the feet. According to the author, this would have allowed males to carry food with their hands, bringing it to females and their offspring.

Although the theory is not a consensus among scholars of paleoanthropology, it points to the possibility that the idea of family is quite old among humans. Thus, the nuclear family model goes back to the first hominids⁸. For Ariès⁹, the emergence of childhood coincides with the origin of the concept of family in the modern era. According to the author, individuals attributed immense value to their professions until the Middle Ages, which explains artistic works portraying men (alone) practicing their crafts. However, through iconographic analysis, the author identifies that as of the sixteenth century two other figures appeared in these works: the woman and the child.

It is important to note that, although the observation of Ariès⁹ refers to the period of the Middle Ages, even today one of the first questions asked when two people present themselves refers to their profession. The individual indicates their social position when informing that he or she is a nurse, lawyer, businessman, etc. The difference between that historical period and this one is that, in contemporary times, professions are also related to the social and identity roles of women¹⁰.

Despite recognising that families have always existed, the author points to these changes in iconography from the perception that, at that time, people began to value family life more than life in community, as it had previously occurred. The need for intimate life between close relatives - instead of a life that had been previously shared with friends and other members of the community - gradually led to the modern feeling of the nuclear family which is present in contemporary societies.

In addition, the author also highlights the relationship between the feeling of family (and affection) and changes in funeral ceremonies, indicating that the dying recorded in testament their wishes, testimonies of faith and forgiveness until the eighteenth century. After this period, wills began to be restricted to the transfer of inheritance, for it was at this historic moment that the feeling of affection for the family began to lead to the trust and belief that the desires of those who died would be fulfilled without the necessity of legal devices. From the nineteenth century onwards, the individual

would fear the death of the other, not his or her own death, as it was in previous times¹¹.

It is important to emphasise that the consolidation of the family as a core of value is concomitant with the institutionalisation of the medical power, both of which proceeded from the sixteenth century and were strengthened in the nineteenth century, when hospitals became the maximum representatives in health care (no more religious hostels aimed at the socially marginalised) and when the family, aware of the status of this institution, starts to relegate the care of the dying to hospitals as an act of love¹².

Thus, it is understood that the value to family bond superimposed on other attachments and affections is something recent in the history of the humanity. In this context, given the value attributed to family relationships in modern and contemporary societies, Bernal¹³ affirms the importance of this institution in the constitution of individuals and in the maintenance of health, since it is a founding element of societies, linked to the reproduction and continuity of the human species.

In addition, it is the first space of formation, development and socialisation of the individual, being responsible for the transmission of cultural, ethical, moral and spiritual values. It is, therefore, an institution of high value and personal and social significance, constituting a source of feelings such as love, satisfaction, well-being and support and, on the other hand, generating dissatisfaction, stress and illness.

Families are the first network of social support of an individual and spaces of protection in the face of the irregularities and tensions of everyday life. Thus, it is understood that the adequate support of this nucleus generates feelings of belonging, care, esteem, besides providing emotional resources to deal with stressful situations¹⁴.

In view of the importance of adequate family support in situations of stress such as illness and end of life, we find in the systemic theory contributions to the study of this theme. The sharing of life with others is something innate to the human condition, which would justify the existence of groups such as the family¹⁵. However, contemporary families differ from families from previous historical periods because they are not composed of a specific nuclei - they are diverse, more dynamic and diverge of the traditional mother-father-child model. That said, these different constitutions continue to be characterised by a group of individuals who are still part of a particular family nucleus; and if this nucleus was governed by

the factor of consanguinity, it is currently related to factors such as cohabitation and affinity¹⁶.

The type of composition leads us to think about how these families are organised, that is, how they are structured today. Thus, we identify that this structure consists of an implicit set of rules and norms that orders the relations between the members. Such norms will govern patterns of interaction (or transactional patterns) between family members, determining the roles of each member, and establishing the boundaries, limits, and alliances of the family nucleus. On this point, it is worth remembering the hierarchy in these family nuclei - parents and children have different levels of authority, while couples recognise their interdependence and act as a team¹⁵.

It is considered that these nuclei make up family systems, that is, grouping of individuals that interact by affective, consanguineous or political bonds, establishing a network of communication and mutual influence. Family systems are composed of subsystems: the conjugal subsystem, the parental subsystem, and the fraternal subsystem. In turn, these subsystems are regroupings of the general family system, in which interactions and communication dynamics are different from the main system - they are organised by variables such as age, gender, function, common interests, etc¹⁴.

While the main function of the system is to provide psychosocial protection to its members (internal objective) and to transmit and accommodate them in a particular culture (external objective)¹⁴, the subsystems have other specific goals and demands: the conjugal subsystem consists of the union of individuals in search of their own family system; the parental represents the roles of father and mother from the first child; the fraternal one refers to the relations between equals (brothers and sisters) and can prepare these members for other interpersonal relations with equals that do not participate of the same system. From the functions of each subsystem, arise roles that are based on the relationships and attributions delegated by the family to each member¹⁶.

As for belonging, human beings seek to unite and establish bonds, which leads them to coexistence. Thus, the identities of the family members are derived from the interactions between them and refer to the sense of individuality and belonging to a group¹⁵. In view of the inter-relational context of families, it is possible to apprehend that attitudes and behaviours manifest by one member will have an impact on others.

Families, illness and end of life

Some periods of life are potentially stressful, as they require changes and negotiation of new family rules. This occurs, for example, with the birth of children, especially the firstborn, in the transition from childhood to adolescence, in financial crises, divorce, etc. These conflicting moments are opportune for the emotional strengthening of all members, and if there is no adaptation to the demands in those periods, this nucleus is likely to become dysfunctional¹⁵.

Changes in the structure and roles of family members are expected in times of crisis, as in the diagnosis of serious diseases or with the proximity of the finitude of one of its members^{17,18}. Because of this, it is necessary that palliative care teams also include the family in the care, aiming at the comfort of the patient and his or her family members, by means of attention based on adequate coping with death, acceptance of the finitude and minimisation of physical, psychological and spiritual suffering¹⁸.

In this way, families are included in palliative care in order to adapt them to situations related to illness and termination, so that they can also provide adequate support to ill family members. Palliative care also aims to provide emotional resources to deal with possible crises arising from illness and finitude and, finally, to face the period of mourning. Thus, the task of health teams would be to develop appropriate links with patients and their families through honest, effective and affective communication¹⁷.

Patients' relatives need to be supported since death is not the only loss related to the end of life. Even desired changes, such as marriage, divorce, or the birth of a child bring inherent losses, because one must inevitably give up roles and previous possibilities. In some cases, these losses are accompanied by a period of mourning, characterised by the recognition of change and by the acceptance of transformations¹⁹ which, in the case of poor health due to chronic illness, are linked to physical, financial, social and structural aspects, generating grief prior to death.

It is understood that illnesses potentially threatening to the continuity of life imply continuous adaptations and changes of roles, which causes situations of stress and tension in the caregivers, due to the exhaustion caused by the tasks involved in the care and the losses resulting from the treatment. As for the impact on parental relationships, the data

suggest that both the dying and their caregivers fear death; the former fears its own extinction, and the latter fear solitude, the lack of the deceased, and the finitude itself. Such fears can lead to sadness, separation, and ambivalent actions, in view of the desire to get closer at the end of life and the tendency to move away emotionally from the dying. It is even more evident, therefore, how much the possibility of loss is threatening and may hinder family balance at this stage²⁰.

The emotional and social resources of the family members can also predict whether they will perceive care as positive or negative, which will affect how the caregiver will perform his or her task. If they perceive the caregiver's action in a positive way, they tend to show love and satisfaction, but if they perceive it in a negative way, they tend to offer low-quality care¹⁸. Just as multiple sufferings are observed in patients facing potentially life-threatening illnesses, their families are also subject to physical, emotional, social and financial burnout, which affects their health and well-being²¹. Despite of this, some of them manage to keep company to the patient at the end of life with a positive attitude, describing the period as unique, rewarding, maturing and of personal and spiritual growth¹⁷.

The terminability process caused by chronic disease can be felt as a positive experience by those who face it (both the patient and those close to him), since it favours the resolution of emotional, legal, financial and social problems and pendencies, causing a change of attitude in people - through the approximation and strengthening of bonds between the family during the end-of-life period of their loved ones. In this sense, the adequate psychological support to these individuals is fundamental so they can face this moment in a more dignified and quiet way¹⁸.

According to the systemic perspective, death can be understood as a transactional process of life, whose dynamics involve the dead and the survivors on a common axis, since at the same time that the finitude is recognised, the continuity of life is also affirmed¹⁹. How family members will react to the loss of a loved one is associated with the level of emotional integration of the family nucleus and the relevance of the role previously occupied by the deceased. In addition, death causes rupture of the family balance, whose intensity is related to the ethnic and social context, the reactions to previous losses, the "moment", the nature of death, the function in the family system and the opening of this system to other systems²⁰.

It is pointed out to the perceived need, in those who are close to the patient, to attribute meaning to the suffering related to the end of life and to the task they perform, when, although impotent as to the progression of the disease, they perceive in the care something that can give dignity to their loved ones¹⁸. However, the experience of care as a burden, restriction of activities, fear, insecurity, loneliness, coping with death and inadequate support are factors that can increase the vulnerability of those who care²⁰. Consequently, it can be thought that this vulnerability compromises the quality of care offered to the patient and increases the emotional exhaustion of everybody, being potential generators of conflict between relatives.

End of life relationships

Sometimes the responsibility for care lies with someone close to the patient, and the decision about who will care for the patient is usually arbitrary (either by the family organisation or by the expectations of the dying person). Therefore, the care of the patient is not always permeated by feelings of love and affection, and can be understood as a moral obligation, which hampers the performance of this function and requires a re-determination of the relations between both parties^{18,21}.

The death of a loved one can be felt in different ways by those who take care of the patient, or even as a double loss - the death of the loved one and the loss of their main role during the illness, besides the possibility of the death being understood as emptied of meaning. However, it is noted that most of the family members feel relieved by the death of the loved one, because they reassure themselves that he or she is no longer suffering²².

In addition, it turns out that the end-of-life care is usually attributed to women - wives, mothers, daughters and daughters-in-law. This care is delegated to women because of cultural conceptions that consider the issue as something related to the feminine, that is, the woman would be responsible to care for others from birth to death²³⁻²⁵.

Regarding this, Gutierrez and Minayo²⁶ question the maintenance of the uncritical relationship between "care" and "women" and point to the repetition of this idea in studies that address family and health care (besides indicating how the direct association between family and care fails). In times of discussion about gender identity, it is important to reflect on this naturalisation of care

as a feminine attribution, since it recognises that female and male roles are socio historical constructs and, therefore, "caring" would not be an intrinsic competence of women. It is also up to health professionals to question the reproduction of these conceptions in their work.

Regarding the care that health teams should provide to the families of patients undergoing palliative care, the relationship that allows open communication and helps to cope with death is considered important²⁷. Some professionals know that they should guide prescriptive practices related to optimal control of the patient's pain and other symptoms, the provision of existential support, good communication with the family and their preparation for death and mourning, and permission to participate in the final moment of the dying¹⁷.

On the other hand, the guidelines to psychologists on interventions for relatives of patients in palliative care are broad and differ from other professions by avoiding prescriptive formats. The end of life is understood as a moment when professionals are required to listen adequately and comfortably to those who face it, in order to offer understanding and respect¹⁸. In addition, communication must be direct and honest in order to break the silence between team, patient and family, in order to avoid the concealment and minimisation the severity of illness and prognosis, which happen quite often.

Systematically avoiding talking about what is happening can increase the patient's isolation and bring close relatives to more suffering as they tend to strive to preserve silence²⁸. In addition, some family members feel invisible during the illness of their loved ones, since the concerns of the health teams and other relatives and friends revolve around the dying person. Thus, it becomes even more necessary to support these individuals at this time to minimise potential stressful effects²¹.

Regarding changes in the relations, it is observed that the task of making decisions in the name of the patient is one of the attributions considered to be more distressed by the relatives, because they consider that the responsibility for the definition of the future of a close person is unfair²⁹. At this point the support of the team once again comes to the family, since these professionals have technical skills for care and should guide the parties on the prognosis and therapeutic possibilities so that decisions are taken jointly. In addition, one notices how much the conspiracies of silence can hinder and cause suffering to those involved.

There is also evidence that many family members feel that the care given to the dying end up submitting them to the exclusive family-sick relationship all the time, preventing them from caring for themselves²⁹. Many of them complain of major changes in this relationship: husbands and wives, for example, report suffering because they no longer identify their partners due to bodily and especially personality changes. Another issue raised concerns the renunciation of their bodies and desires during the end-of-life period of their family members, which further undermines the caregiver because they feel responsible for mitigating patient identity conflicts. Thus, illnesses that threaten the continuity of life can cause intense emotional suffering to those involved, thus justifying the presence of psychologists in the palliative care teams.

Final considerations

Families are the founding element of societies, being the first social network to support individuals and responsible for the formation, development and

socialisation of the individuals, which makes them an institution of significant value as well as personal and social meaning. Family nuclei are governed by a set of norms that guide the relations established among the members. From these norms patterns of interaction between the family are organised and the roles and attributions of each individual in the family nucleus are determined.

In crisis situations, such as in the case of illness and end of life, changes are expected in this family organisation and, consequently, in the roles played by relatives, which justifies the inclusion of these people in the care provided by the palliative care teams. These teams can help both the sick and the family to face and accept the end-of-life situation through care that minimizes physical, psychosocial, and spiritual distress. Palliative care for patients and their families is justified by the fact that they face, during the course of the illness, symbolic losses such as the loss of social roles, autonomy and identity, as well as the real loss, that is, the death of the patient. Care in this case should be guided by honest communication, avoiding conspiracies of silence and favouring the maintenance of the autonomy and dignity of patients and their families.

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