DEATH AND DYING IN THE PERSPECTIVE OF CAREGIVERS OF ELDERLY DEPENDENT PATIENTS

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ABSTRACT
This study aimed to analyze the meaning of death and dying for caregivers of bedridden elderly treated and registered in a Family Health Strategy unit. Descriptive, cross-sectional and qualitative study conducted in Fortaleza-CE, Brazil. The sample consisted of 22 informal caregivers of bedridden elderly patients. Data collection occurred through semi-structured interview based on the following questions: “What do death and dying mean to you?” and “Do you think of the possibility of or closeness to death when caring for the elderly?”. For analysis, we used the Discourse of the Collective Subject. According to the result, dying is closely associated with human survival, and the body tends to dodge through any pain. Death is present in the transformations verified in old age and associated with each person’s lifestyle. For the group in study, death and dying reveal themselves as losses from the very process of senescence. Both represent the relief of suffering, where dependence and complications of this process lead to a negative projection of the future, closeness to death.

Keywords: Aged. Death. Caregivers. Nursing.

INTRODUCTION
The number of elderly people grows rapidly nationwide, changing the scenario and causing deep transformations in the age structure of countries. In 1930, there was little more than 6 million people aged 65 years old, and the average life expectancy stood at 59.7 years old; in 1965 the elderly population outnumbered the figure of 20 million with an average age of 70.2 years old, and in 2010 said population was 77.8 years old. Therefore, there are more than 34 million people aged over 65 years old.

With the change in the demographic and epidemiological profile of the population and consequent prevalence of chronic and degenerative diseases it is imperative that we comprehend the temporality of life and, in this way, the inevitability of human finitude.

Routinely the human being experiences countless losses, whether from a concrete or from a symbolic viewpoint and in several contexts: losses of friends, of family members, of jobs, separations. However, we notably have a big trouble approaching and discussing the death and dying matter. Such a fear is timeless and crosses a variety of cultures. This happens because death brings to our mind the idea of our own finitude. Thus, the detachment from the theme prevents us from discussing it, from better working concepts and researching about this process.

Dying happens to anybody and at every moment and, consonant with the way one lives, he or she has an intense fear of death; consequently, dealing with terminality (death) becomes a tough situation for all human beings.

A priori, death should happen in old age. Humans know they will die. This “knowledge”
represents one of the essential characteristics of humankind, beside language, thinking and laughing. The awareness of such a fact refers to the temporality of life and puts the latter before a course of collision with something ineluctable. Death is acknowledged by healthcare professionals as a stage of life, minimizing, therefore, the suffering it causes\(^2\)

The care provided to the elderly demands resources that go beyond the technical, pessimistic and limited view. Thus, the healthcare professional needs to aggregate skills inherent to his or her routine praxis concerning the health-illness-incapacity process in old age and the fears related to it, as well as to the loss itself\(^3\).

As the profession of caring, nursing acts in the different scenarios where the human being is found, whether in the joy for the birth of a child, whether in elderly care orientation to family members. In addition, it shares the distress of death, supporting people in moments of pain and seeking strategies aimed at comprehension before the loss of loved ones. It is a nurse’s duty to search for attention strategies in the household to instrument caregivers for the implementation of care actions. The term caregiver is understood as a person, family member or not, who, with or without compensation, provides assistance in order to make up for the temporary or definitive functional dependence of the elderly\(^4\). In order to experience the death and dying phenomenon, which is essential and inherent to the life cycle, family members in charge of caring need to possess knowledge, competences and skills to assist the elderly. They need, primarily, to adapt to and live with the changes caused by aging towards creating feasible habits within the family scenario\(^5\).

Thus, this is one of the roles of a nurse in the death and dying context, because despite the increase in the population’s life expectancy and all achievements in the healthcare field, living is still a finite process. Said finitude becomes more evident in the dynamic interaction of the health-illness-old age process, when the anticipated grief for the elderly subject reveals itself in the life with chronic and disabling illnesses and, consequently, with the awareness of one’s own finitude\(^6\).

The study justifies itself for attempting to integrate and think over the guidelines established by the National Policy for the Health of the Elderly, which stimulates discussions and researches about aging with dependence. From this viewpoint, the caregiver’s eyes should be turned to the comprehension of the death and dying process in the elderly, establishing a partnership with the healthcare professional in order to cooperate during this tough process of loss. In face of the exposed, the aim was to analyze the meaning of death and of dying for caregivers of bedridden elderly registered in and assisted by an *Estratégia de Saúde da Família* [Family Health Strategy program] (ESF) unit.

**METHOD**

This is a descriptive and cross-sectional study of qualitative nature. The research was conducted at two ESF units of the municipality of Fortaleza, Ceará, during August and September 2011.

It counted with the participation of 22 caregivers that met the following inclusion criterion: to be an informal caregiver of bedridden elderly, to be eighteen years old or over, to be taking care of the elderly for at least six months, to be a relative of the assisted elderly, and to be able to communicate verbally.

Prior to data collection, a pilot test was carried out in order to check if the instrument used for surveying data met the objective specified for the research. The semi-structured interview contained data for the characterization of the subjects, such as age, sex, marital status, degree of kinship, number of family members, household income, religion and schooling; in addition to the following guiding questions: What do death and dying mean to you? and Do you think of the possibility of or the closeness to death when you are taking care of an elderly person?

The interviews were conducted in the houses, according to the caregiver’s availability. After each interview the caregiver was requested to listen to it in order to confirm the answer, to deny or to add any data of interest.

The Collective Subject Discourse (CSD) technique of analysis was adopted, which is a proposal for the organization and tabulation of qualitative data of verbal nature. Such
methodology associates similar opinions from different discourses, forming a synthesis testimony, that is, as if there was a group of people speaking on behalf of an individual. In this way, the researcher analyzes the discourses and turn them into scientific products by means of abstraction and conceptualization operations, maintaining, however, the characteristics of the ordinary speech\(^{(7)}\).

The testimonies were organized through an enumeration system for the study participants (CSD1, CSD2, ..., CSD22), without using names. For the analysis of each testimony regarding the questions of the semi-structured interview, key expressions are extracted and then their respective central, equal or equivalent ideas are identified.

Finally, after the key expressions were aggregated according to the similarities of the contents in the discourses through the grouping of the equal or equivalent central ideas, the CSDs were composed, which served as a basis to the actual analysis and discussion of the results obtained.

The research was approved by the Research Ethics Committee of the Universidade Estadual do Ceará [State University of Ceará] (UECE), under legal opinion No. 433543 of July 25\(^{th}\), 2011, complying with all ethical and legal precepts for scientific researches involving humans.

**RESULTS AND DISCUSSION**

The age of the participants ranged from 19 to 72 years old, being on average 51 years old. Ten of them were within the 41 to 59 years old age group; five were less than 40 years old and seven were 60 years old or over.

As for sex, most of them were females (n=21); regarding degree of kinship, most of the caregivers were the daughters of the bedridden elderly (n=13), followed by wives (n=4), sisters (n=2) and granddaughter, great-granddaughter and daughter-in-law. About marital status, there was a majority of married individuals (n=11); and regarding religious orientation, they were mostly Catholic (n=14) and Protestants (n=6).

Considering the age of caregivers, as it is known, middle-aged and elderly caregivers are more prone to the negative impact of the care due to changes linked to the aging itself and the chance they have to present a health state similar to that evidenced by the receptor of care. These impacts include a greater awareness of the closeness to death itself.

Personal satisfaction, feeling of retribution, and improvement in the relationship with the elderly are some of the positive factors that the act of caring can promote for an elderly person’s caregiver. However, overload, emotional stress, physical exhaustion, limitation for leisure, and the imminent possibility of the death of the assisted elderly generate a negative image for the occupation of caregiver\(^{(8)}\).

The criteria for the choice of the caregiver are consonant with the reviewed literature as the latter shows the predominance of kinship and has a direct relation with the existence of a sociocultural norm according to which it is the children’s role to take care of their elderly parents, and the spouses’ role to zeal for the care towards their partners as a matter of solidarity and respect\(^{(9)}\). The construction of this emotional bond between the elderly and caregivers is important for the establishment of a relationship of intimacy and trust\(^{(10)}\).

According to a study that assessed the level of a caregiver’s tension, married women as well as women who had their own family showed higher levels of tension since they had to balance the needs of the elderly with those of the rest of their families or with the demand of their jobs\(^{(11)}\).

Another decisive factor in relation to care is religiosity, for presenting itself as a vital and singular phenomenon in the life of a human being. Religion is a supporting element for one to face his or her problems, in addition to relieving or preventing negative emotional consequences. In this way, it is fundamental to understand the meaning of the death and dying process in dependent elderly subjects, because the humanization of this process encompasses the knowledge about and the deepening of the spiritual beliefs of the population to be handled.

Based on the analyses of the contents in the caregivers’ discourses, the meaning of death was built in consonance with four categories of discourses: a) discourse on the meaning of death as the certainty about the end of life and about the relief of suffering; b) discourse on the
meaning of dying as a process; c) discourse on the meaning of death as a transition to eternal life; d) discourse on the meaning of closeness to death as the problems that kill day by day.

The first category – Discourse on the meaning of death as the certainty about the end of life and about the relief of suffering – suggests that by dying the individual is set free from all suffering, and has as central idea: Death is the end of all things.

[I know that we were all born and will have to die one day. I will not be an exception, nobody does [...] death is the end of all things. It is the end, end of all things. It is the end of affection bonds, of partnership, of ties, of kinship. It is the separation from the loved person. It is the relief of suffering [...] death is the fulfillment of our mission on earth. A mission that [...] God prepares and takes away. Therefore, everyone has to die. Death is relief.] (CSD1)

The discourse evidences that, to the same extent that individuals see death as something bad they perceive it as a way out and the relief of all earthly suffering. Nobody knows for sure when they will die neither the conditions under which this reality will take place. For most people, the lack of knowledge regarding the temporality of life causes distress. In this way, the connotation of death as a conviction present in the discourse evidences the need to overcome this taboo that still reigns in our society. This is a warning for us to problematize it in the different contexts surrounding the human being. It is not enough that we acknowledge death as a fact in our lives and simultaneously see it with strangeness.

Once again nursing proves essential by enabling individuals to experience this phenomenon comprehensively, that is, seeking answers for questions, effecting communications with family members in order to unveil coping strategies, allowing themselves to apprehend the moment, to suffer with it and to reach means for acceptance. In this entanglement of relations every moment and sign are of extreme importance for both relatives and for the elderly, due to the possibility of mutual communication between family members and the ill elderly. It is thus an opportunity for us to remember about life and weakened emotional bonds.

The second category – Discourse on the meaning of dying as a process –, in which the individual defines that death happens little by little, brings as central idea: Dying is a process.

Dying to me is when the person languishes little by little, dies little by little, suffering, suffering, and suffering pain, just vegetating. For example, she was always running, used to eat everything, now she does not eat anymore. [...] She is dying little by little. It is easier to accept an announced and expected death than an unexpected event. (CSD2)

As pointed out, when death follows a long and painful dying process there is a greater acceptance by family members and by the individual/elderly person himself or herself. Such a process is seen as a psychological and spiritual preparation for the parties involved, allowing them to think over their human condition, their finitude, constituting a central problem of the human existence. Such moments are important as they mean a preparation for the reality that so far had been denied.

In the course of his or her existence, a person goes through stages that are substantially composed of multiple feelings, seeking to draw him or herself distant from finitude. However, regardless of denying or refusing to talk about the death and dying process, a person suffering from a serious illness lives moments that enable healthcare professionals to apprehend the stage at which he or she is(12).

Nevertheless, according to what some authors(13) report, families in which one of the members has a prolonged illness are subject to a stress caused by permanent uncertainty.

Still in the second category, as it has been evidenced, pain is something tough for everyone, because for the family, to see a loved one in pain without being able to do anything, is distressing. Therefore, in face of this situation, it is not rare that the agonizing individual and his or her family long for death. One of them is the social death, in which the elderly deprived from a healthy body and unable to produce are excluded from society.

According to some authors(14) as well, when one experiences losses, such as loss of health, which kills off the fantasy of immortality and indestructability, and the loss of identity, of the reference he or she once was, he or she lives several grief processes. Grief for the healthy body,
grief for all restrictions and limitations imposed in terms of mundane activities, grief for the future. Thus, the ability to listen is essential for handling patients at this stage, because there are moments of fear, anguish and emotions to be shared.

The third category – Discourse on the meaning of death as a transition to eternal life – has as central idea: Death is a transition.

I think that is because I see death as a transition. [...] It is a transition to eternal life, but it depends on your behavior, on what you have been here. If you have been a good person, you will be beside God. They say that we do not die. We move from one life to another, an eternal one. (CSD3).

In the discourse the connotation attributed to death as a transition is the man’s attempt to prolong life and to find in it a meaning other than interruption, cessation or end. Then, transcendence emerges as a solution; life goes on and transcends, being eternal in another realm. The discourse points to the idea of death as a transition instead of an end, being possible to see death as an inner rupture of a life that continues on. Such image is strengthened by culture and belief.

Seen as rest, transition and natural fact, death constitutes a coping strategy since it allows dealing with it in a less painful and exhausting manner. In this way, this phenomenon could be accepted by the individual that experiences it(9). As it can be inferred, along with the dying process comes the fear for what might happen after death. From this perspective, the judgment for the acts committed on earth does not make death, regardless of how present it is, an experience free of suffering. Almost always the man seeks to find a way to deceive death and, then, to become immortal. That is, denying death works as a means to block one’s awareness of its eventuality and effects. This prevents the individual from seeing possibilities in death and from conceiving it as a fundamental part of his or her existence.

In the fourth category – Discourse on the meaning of the closeness to death with the problems that kill day by day – the central idea is: The problems that kill day by day.

[It is clear in daily care. I cry almost every day. I feel desperate because I am afraid of everything. I already have it in my mind every day due to the problems she has, she is getting weaker, [...] moments when she was very sick, I began to see her getting worse. I felt death approaching. [...] so decaying, so thin, you know, bleeding [...] so old already, very weakened. We do not know. Life has stopped. (CSD4)

As a process, aging can be understood through three different dimensions and needs to be identified and analyzed comprehensively by all individuals that assist it. They are: biological, social and biological dimensions (15). According to what can be perceived in the discourse, these three dimensions are strictly related to the closeness to death. In this scenario, the presence of the illness causes a biological imbalance. In the elderly this imbalance and the condition of being cared for by another person directly or indirectly affects his or her psychological and, consequently, social life.

Human aging starts from the moment the man is born until the end of his life. We are permanently aging, even when we do not realize that. Apparently, old age presents itself more clearly before the eyes of the other than of those of the aging subject himself or herself. However, only in the elderly such perception seems to be more evident due to innumerable changes derived from the senescence process.

The normal and the pathological are closely related, and the line dividing them can be barely seen. In senescence illnesses settle down in a more insidious way and bring deep impacts to the lives of these individuals and their families.

As the discourses show, caregivers identify the closeness to death in face of losses coming from the senescence process and, consequently, from the illness that led the elderly to lose their ability to perform their activities independently.

Old age is the last stage in the life cycle and, therefore, decay becomes more visible and pronounced; then the onset of illnesses becomes stronger as well(16). We observe, in this way, an intimate association between death and old age, because as the individual experiences losses death becomes increasingly present.

For the man death is lived in the losses experienced throughout aging, whether they are symbolic or real. The way that the individual experiences losses will allow him or her to give a real meaning to his or her finitude (17).

Thus, death is intensely present in the transformations that aging imposes to the man. This presence is made concrete in the real but
also in the symbolic sphere. The infantilization of the elderly just as the losses they suffer are examples of experienced losses capable of causing a change in their role and in their status in the family, triggering grief processes.

Thus, when the discourse evidences sadness, apathy, desire to die, the assisted individual/elderly person does not find motivation for life, because all that made him or her complete and whole no longer belongs to him or her. The healthy body, the social status, the position in the family, the love of the wife are examples of little deaths consciously lived and that cause a deep impact in the life of the elderly.

In this way, the failure to establish a frank dialogue between family members and patients is harmful to all involved parties. Without it there will be no place for the exchange of feelings not even for the resolution of previous conflicts. Consequently, doubts, worries and fear will abound.

Fear, as a consequence, is the most common psychological answer in face of death. The fear of dying is universal and affects every human being, regardless of age, sex, socioeconomic level and religious belief.

Therefore, nursing should help individuals in the search for adaptive strategies aiming at better preparing them to face this situation in the best way possible, allowing both the individuals and their families to experience death as a particular feeling inherent to humankind.

FURTHER CONSIDERATIONS

The meanings attributed to death in the discourses by caregivers allow us to infer this: the resignation before the certainty about the phenomenon warns us as to the need for discussions on the theme; perhaps this is the greatest difficulty given the nature of the death theme. It is our responsibility to seek strategies that make it more palatable and more human, since every individual will eventually go through it.

In the dying process, the elderly suffer several losses that work as an anticipation of their death. This process, for countless times, is experienced in a lonely way.

In this sense, the study was important as it allowed perceiving that the caregiver would be a great source of empiric knowledge, a bridge between practice and theory. The caregiver is the one who identifies the symptoms that affect the biological side of the elderly, which has an impact on the psychological and social life of the bedridden elderly. This study also enabled us to apprehend the imagery of caregivers of bedridden elderly, revealing the possibility of working on the theme in basic health attention, by means of proposals of health education aiming at death.

For the investigated group, the death and dying process is evidenced as losses resulting from senescence itself. It represents the relief of suffering, in which dependence and complications lead them to a negative projection of their future, announcing the closeness to death.

Thus, this study means to nursing changes in the process of health assistance concerning the preparation of professionals for elderly care, bringing communication strategies that allow the caregiver/family member/professional to see that the needs of those individuals are imperative in order to enable a humanized and comprehensive care.
MUERTE Y MORIR BAJO LA ÓPTICA DE CUIDADORES DE ANCIANOS DEPENDIENTES

RESUMEN
El objetivo fue analizar el significado de muerte y morir para los cuidadores de ancianos encamados, atendidos y registrados en una de las Estrategias de Salud de la Familia. Estudio descriptivo, transversal y cualitativo, realizado en Fortaleza-CE, Brasil. La muestra fue formada por 22 cuidadores informales de ancianos encamados. La recolección de los datos fue hecha mediante entrevista semiestructurada, basándose en las siguientes preguntas: ¿Cuándo se encarga de la atención al anciano, ¿piensa en la posibilidad o proximidad de la muerte? Para el análisis, se utilizó el Discuro del Sujeto Colectivo. Según el resultado: morir está íntimamente conectado a la supervivencia humana, y el organismo propende a retirarse frente a cualquier dolor. La muerte está intensamente presente en las transformaciones verificadas en la vejez y asociada con el estilo de vida de cada persona. Para el grupo estudiado, muerte y morir son pérdidas originadas únicamente del proceso de senescencia. Ambos representan el alivio del sufrimiento, en el cual la dependencia y las complicaciones de este proceso los encaminan a una proyección negativa del futuro, proximidad de la muerte.

Palabras clave: Anciano. Muerte. Cuidadores. Enfermería.

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