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THE ATTENTION OF END-OF-LIFE CONDITIONS FROM A SOCIAL WORK PERSPECTIVE

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ABSTRACT

The article takes a look at the evolution of the attention provided to end-of-life processes since its implementation throughout History. It starts with the development of palliative care programs and ends up at the present moment in which palliative care becomes a model of care, and more general attention is devoted to situations of advanced illness and, specially, the end of life. In this evolution, the figure of the social worker has also made a progress in the development of their tasks. Finally, proposals for improvement are made based on the evolution of the Social Work discipline.

Key words: end of life, social vulnerability and social work.

It is quite unique to the world of professionals of Social Work that one of the pioneering people in developing specific programs based on the relationship with the client and aimed at end-of-life care was a social worker, Cicely Saunders.

Attention to end-of-life situations is something that has been done throughout the whole history of humanity. Dr. Abt, A. (2017) exposes how death has occupied an important place in the evolution of humanity since it is something inevitable. The way in which each cultural environment has tackled death has been very diverse. Each society has approached the processes of death in many different ways that are determined by their beliefs, thus developing different myths and considerations about dying and the aspects of thanatology.

HISTORICAL APPROACH

It is in the middle of the last century that the matter of death begins to be a social concern and is recognized as a phenomenon that requires trained professionals to help people die with warmth and dignity.

Lies beneath this concern what has been called the "hospice" movement, which differs from the hospices that are usually charitable, dedicated to people in economic precariousness requiring clinical care. Previously, in different countries several hospices dedicated to caring in end-of-life moments have already been implemented. In France under Mme. Jeane Garnier's initiative in 1942, different hospices were created. In Dublin, Our Lady's Hospice is being carried out by the Sisters of Charity and in 1905 in London St. Joseph's Hospice was created. (Centeno, C. 1998)

St. Cristopher Hospice was inaugurated by Cicely M. Saunders in 1967. Cicely Saunders was a person who became interested in healthcare since his youth, undergoing nursing studies and later Social Work. It was in his development as a Social Work professional that assisting a person with an illness without the possibility of healing treatment, and listening to his needs, he developed an interest for care provided to sick people at the end of their days. Along with this same patient they initiated the first steps in order to create a place where professionals could treat the suffering of people with an incurable illness. Finally Cicely Saunders graduated as a doctor in 1957.

St. Christopher's Hospice is organized in different areas: hospitalization, external consultations, day centers and home care teams. It also has a clinical research program and other multidisciplinary training programs. Subsequently, in the United Kingdom other hospices with similar care philosophies than St. Christopher's were created.

The premise on which the health care model proposed by Saunders was based is that of the "total pain", which is based on the fact that end-of-life patients, especially those affected by an oncological illness, suffer from physical pain and other severe symptoms. Saunders considers that this physical pain is compounded by the impact of being in an advanced and threatening condition or with little life expectancy. That is to say, it considers that the total pain is conditioned by the different spheres, both physical and psychological, social and spiritual, and under this assumption appears the need to have professionals from different disciplines to develop palliative care. However, it is considered that people in the patient's surroundings also suffer a mourning due to the proximity of the death of their relative and it is considered that the family is also a subject in need of multidisciplinary attention to helps them understand the evolution of the illness by training them as caregivers and in the resolution of relational, organizational and practical problems (Saunders CM 1980).

At the same time, in the United States there are certain sensitivities regarding the need for comprehensive care of patients in advanced illness and Psychiatry Dr. Elisabeth Kübler Ros makes a great contribution in this regard by publishing her first book in 1969 "On Death and Dying." From here on, in the North American continent different types of palliative care services are created but in a more general sense, extending palliative attention to other non-cancer diseases and especially to people affected by HIV (Kübler Ros 1975).

Thus, the palliative care movement is being developed in different countries of the different continents under the philosophy of carrying out comprehensive care for the patients and their families with the intention of promoting dignity and autonomy with an active therapeutic commitment (Ministry of Health and Consumption 1999).

In Catalonia in the mid 1980s, it is through the 'Vida als anys' programe of the Health and Social Services Councils that palliative care is developed in a very similar way than in the United Kingdom. Support teams are created within acute care hospitals (UFISS) that may be specific of geriatrics or palliative care sections. Also, home care teams that simultaneously address geriatric situations and oncological diseases in the advanced situation, and specific palliative care units whether in healthcare centers or in acute care hospitals.

It is in the deployment of the Program that the training of palliative care teams -following the Anglo-Saxon model- consists basically of doctors, nurses and social workers who develop their care tasks based on multidisciplinary proposals and work plans.

In the United Kingdom social workers carry out various tasks related to palliative care and several university programs of disciplinary specialization in palliative social care are deployed. The role of the social worker is very present in the different teams and assumes responsibilities in different dimensions such as socio-family care, mourning programs, education, volunteering coordination and joint work in teaching and implementing of research.

It is under this model that social workers begin to carry out their tasks in different teams throughout Catalonia.

EVOLUTION

More than 30 years have passed since the implementation of these programs and obviously these had progressed in accordance to the evolution of society. We will deal with some concepts that require consideration.

Care at the end of life

It is difficult to determine at what point we are talking about end-of-life situations, but in medical terms it is clear that these are situations in which the pathology does not only not allow care solutions but continues on progressing and producing more symptoms until death happens.

The Concepts on Medical Care at the End of Life by the Medical Organization and the Spanish Society of Palliative Care (SECPAL, 2002) among others, define the following concepts: advanced incurable Illness as a ‘gradual progressive disease with varying degree of autonomy affectation and quality of life affectation, with a variable response to the specific treatment, which will evolve towards death in the medium term; terminal illness as ‘advanced disease in an evolutionary and irreversible phase with multiple symptoms, emotional impact, loss of autonomy, very little or no capacity to respond to specific treatment and with a life expectancy limited to weeks or months, in a context of progressive fragility’.

Increase of the attendance

Palliative care programs have been giving way to the denomination of Care Programs to Situations of Advanced Disease or of End of Life. Palliative care is now more seen as a care model than as a care program.

It is true that the loss processes are a constant in the evolution of mankind and that it is something that no one can discard, but it is also true that these can be a source of experience and personal enrichment or can be a generator of involution or regressive stages. This philosophy is what drives to carry out comprehensive care that favors human growth despite suffering a crisis situation.

Areas are expanded and it is considered necessary and effective to carry out a comprehensive care approach in any health situation where the threat of end of life is present. That is, interdisciplinary care must be carried out not only in situations of advanced oncological disease, but also to the various pathological situations that evolve towards death.

New categorizations

Over the years, new classifications have appeared in relation to end-of-life situations such as the Advanced Chronic Disease (MACA) and the Chronic Complex Patient (PCC), and around these different programs have been implemented from primary care and other areas of health, aimed at the specific attention of this type of patient that includes the palliative care model.

Therefore, the range of attention to situations that are approaching end-of-life processes is becoming increasingly broad and the need for interdisciplinary approaches is fundamental, although a deployment of professionals has not yet been demonstrated to be sufficient to be able to develop the integral required care to the detected needs.

Also during this year, the implementation of the Advance Will Document in different medical devices has been developed and work is being done to implement an "Advance Decision Planning Model." (Las Marias, C. et. By 2015).

From my point of view, there is still a serious work to be done and I do not think it will take long to be addressed. It will be necessary to create ethic teams or groups that consider different approaches to Euthanasia.

Caring environment

In relation to socio-family care, some terms or concepts such as "main caregiver" are no longer a priority, given that the structures of family compositions are increasingly diverse and there is more heterogeneity in the distribution of responsibilities when taking care of the sick person. The incorporation of women into the labor market, divorces or reconstituted families, the current geographical dispersion of families, the fight for equality rights and the philosophy of care itself to include all involved members in the process as a therapeutic benefit make us talk about a caring environment. This includes all those people, relatives or not, who are present in some way in the care of the sick person. When talking about a caregiver's environment, it is necessary to have a broader view of the potential, capacities and needs of people close to the patient. Having a caretaker environment as an objective to deal with, within the care processes in situations of advanced illness, expands the care possibilities of the members involved, facilitates overload prevention and at the same time provides facilitating elements for the good evolution of the mourning processes.

A differential feature between the mourning of a sudden death to that of an announced death is that the latter offers the possibility of doing a good, affective and restorative procedure of farewell.

Complexity

Fortunately, society is less often conditioned by the value judgments or stereotyped prejudices and classifications of the patient and their relatives, such as talking about “sick person and problematic family" or "family breakdown", etc. We also more often tend to identify what are the protective factors and what are the characteristics or phenomena that can impede the good evolution of the process.

The term complexity appears as an indicator that refers to the need for a specific type of intervention carried out by one or several specific professionals in order to address specific situations that could be hampering the proper procedure of care.

To speak about complex situations invites to understand, analyze and it stimulates professionals to seek ways of improvement that simplify and facilitate a favorable progression.

There is a lot of work to be done from the position of the social worker to prevent punitive, disadvantaging classifications that generate feelings of guilty in health settings.

A classic example of end-of-life care is the topic of family conspiracy. Given the multiplicity of adverse situations and the difficulty in defining, analyzing and treating them, often these go to a kind of container called "conspiracy of silence" that refers to the fact that things do not go well because the family prevents the patient from having the appropriate information regarding the diagnosis of the illness or prognosis.

It is naïve in the XXI century and with the amount of means to access the information, to believe that the sick person is not informed of the evolution of his/her illness due to the expressed impediment of the family. Under the stigma of the silent conspiracy, the professional inability to deal with adverse situations is hidden.

From different focuses of palliative care, complexity indicators are being developed to allow enriching the vocabulary and the conciseness of the diagnostic frameworks.

IDENTITY AND COMPETENCES OF SOCIAL WORK

As mentioned in the description of the development of services devoted to end-of-life care, it is clear that from the beginning it has always been considered a type of interdisciplinary care that responds to the needs panel that sick and caring environment requires.

Social Work is one of the disciplines that are part of global healthcare to deal with those family and social phenomena that are not strictly healthcare but which are due to illness or its evolution. However, there is no specialty in Social Work in Palliative care or in the end-of-life situation in our country and there is little literature that supports it.

At the European level there has been an Association of Social Workers since 1987, "The Association of Palliative Care Social Workers", with the following mission:

- Increase the profile of Social Work in palliative care
- Support and advise social workers who carry out their work in end-of-life care
- Reinforce excellence by sharing the best practical experiences
- Promote high quality research and evaluations in order to improve the continuity of end-of-life care and mourning (APCSW 2017)

Professional responsibility

The interdisciplinar approach of healthcare work -in this case the one of attention to situations of end of life- generates an allocation and distribution of responsibilities within the specific teams in order to work the proposed goals in each therapeutic plan. It is in this context that a social worker first provides the group with its diagnostic approaches and frames the application of a methodology and techniques of its own profession, in order to meet the needs set by the healthcare team to whom it belongs.

Nowadays it is unthinkable that a discipline develops itself alone without the collaboration of other disciplines that help complete the suggested task. This represents a plus for professional responsibility but ensures the wealth of the actions of the proposed tasks.

Commitment and ethics

Commitment becomes essential to an interdisciplinary intervention because the set objectives are the ones of the healthcare team and may not always coincide with those proposed by the social worker. This is one of the great handicaps that must be overcome in the application of the profession. Often it is difficult for the social worker to ethically solve proposals for intervention in the face of opposing interests.

There are several determining factors that make the social worker feel helpless to achieve the objectives set by the teams, since they often are in contradiction with those aimed at defending the rights of the people, that is, to respond to the needs raised by the patient and / or their caring environment.

In fact there is great evidence that health care needs are bigger among people in an unfavorable social situation than those of people who require general health care. There are several studies that show the relationship between the presence of social support and the reduction of morbidity and mortality (Seeman, TE. Et alt 1987-1999).

Part of the crises and needs that are presented in this context of evolutionary illness are often related to social deficits (eg, the lack of caretakers or the lack of health of the persons identified as caregivers, situations of negligence or deficiencies in the needs covering, etc. that may lead to an inappropriate demand of a sanitary intervention. Murray SA, 2005. This demand, in the majority of the occasions usually is due to the fact that there is an asymmetry between the health and social services "in terms of the provision of resources (White Paper of dependence 2014) (O'Mahony S, et alt. 2008) (Chochinov , HM, et alt. 1998). In other words, the lack of social resources to deal with these situations means that more attention is demanded from the healthcare side since it has more resources and more immediate given access.

If one of our objectives is to protect the rights and interests of users and their carers, as the General Social Care Council (2002) says, these are not always easy to defend, since social workers generally carries out their work under the "commitment" of the service to whom it belongs and often, although it seems paradoxical, the interests of some are not the interests of others.

It is in this context that the social worker is often at a disadvantage and, for this reason, it can not always respond to the needs of the caregiver environment to face this situation of paranormal crisis caused by the disease.

Diagnostic amplitude

Nevertheless it is the social worker who can observe each case or situation from a holistic, wide and flexible perspective, allowing the professional to identify all those material elements and human potentialities that can help in improving the evolution of the different stages by which each case goes through.

Unlike other clinical diagnoses in the diagnostic framework, the social worker makes a prior description of the phenomenon, immediately identifying the causes that raised it and what are the genuine facilitating elements that, well channeled, enable a favorable evolution of the process. These protective factors may be present and be explicitly detectable or may be latent and / or blocked. In more modern terms, we are talking about the available social and family capital. (Woolcock, M. 2000)

Skills

In 2008, a group of social workers from Canada carried out a joint work to identify what were the necessary competencies that a social worker must have in order to be able to develop a service dedicated to palliative care or end-of-life situations. Subsequently the group of social workers of the European Association of Palliative Care EAPCSW published a very similar document since they used the previous work done by the colleagues from Canada.

In defining these competences, the areas identified were those requiring a specific training for the social worker to intervene.

12 competencies were defined and also the necessary attitudes and values that have to be internalized by the professionals of social work and at the same time they described the knowledge that must be acquired and what needed skills to develop it.

These competences are the following:

- Advocacy: Given that the social Worker is fundamentally committed to justice and social change, and therefore must defend the rights of the sick and their families.
- Assessment: Evaluate the circumstances of the patient and their families, including the degree of information they have. This competence is considered crucial for teamwork and joint decision making.
- Care delivery: Understanding that both the patient and their family will require at one time or another the intervention of the social worker to work on all those phenomena that require an improvement which is possible to achieve, whether during the disease as in the mourning process. This competence includes the ability of the social worker to evaluate their own work in order to modify it if necessary.
- Care Planning: The social worker must know how to plan and prioritize their interventions according to their relevance and viability. This planning must be agreed with both the team and the sick person and the family.
- Maintain a committed and constructive relationship with the community in order to promote the creation of a program aimed at the welfare of sick people and their families.
- Evaluation: To know how to periodically evaluate the processes and the clinical results and the programs. Ensure the identification of the patients' needs and their families and ensure that their resolution is being worked on.
- Decision Making: Helping to think about patients and their families so they can make the right decisions for themselves.
- Education and Research: To participate in interdisciplinary research by making contributions that are required from the psychosocial perspective. At the same time they must have initiatives and educational resources.
- Information sharing: To provide all the necessary information that allows to grow as human being and helps to solve the own problems.
- Interdisciplinary Team: The need to have the skills to be able to watch out for the sake of the team as well as caring for the sick and their families.

- Self-Reflective Practice: In the sense of having the ability to self-reflect on the individual practice and the healthcare team to which it belongs.

The main objectives set in end-of-life care are aimed at:

- Increase the communicative and expressive capacity as a way of allowing the expression of feelings, concerns, needs and the improvement of self-knowledgethrough reflection, information-guidance and education.
- Process the potential of the members involved in their ability to organize themselves in order to take care of both the sick person and the caregiver environment.
- Prevent possible adverse situations ensuring commitment and trust in care. To provide the necessary elements to normalize the mourning process.
- Apply the ethical and social commitment of transmission and communication, needs and proposals for the improvement of the attention in end-of-life situations, in the context of social policies.

NEW FORMS OF INTERVENTION

In the end-of-life care, mention should be made of the evolution of the Social Work practice. Some aspects to be taken into account are the following:

Consensus on diagnostic evaluation

The process of therapeutic dialogue or expressive education that is established between the social worker and the person or people attended is totally dynamic: data is collected, interpreted, reflected; links are strengthen and creative capital promoted, etc. This approach of the intervention allows the partners to make their own diagnostic impression and a plan of action is determined jointly with the social worker.

A key element of the diagnostic framework is that it is not static. On the one hand, it helps to plan the interventions depending on the priorities and the possibilities of success, and on the other, it is modified as the areas are improved or the achievement of the purposes is being evaluated.

Getting to a diagnosis consensus requires having sufficient terminology that allows the professional to define what must be treated without being subject to guilty feelings. In other words, labeling is often done and it brings difficulties to the successful development of the process. It is not the same to say "you do not want to take responsibility" than saying "it is becoming costly to carry out the distribution of responsibilities." The first is a statement that shuts down the possibility of dealing with the situation while the second extends the possibility of intervention and improvement.

To work from this position that eliminates value judgments and stereotypes helps securing the therapeutic bond by increasing the self-recognition of people and therefore self-confidence and self-confidence.

When it is said that the social worker must defend the rights of people this does not mean that he does not have to work with the people to learn to defend their own rights. Both need to be done together.

Health care prevention

The impact and symptoms of palliative illness often cause both physical and emotional difficulties to be taken care of and control of all aspects that surround their vital dynamics. Therefore, it is not enough that the patient and caregiver know that the welfare team has a social worker but it is the responsibility of the social worker to explore the current situation of each case and at the same time foresee possible future deficiencies or complications as the disease progresses.

Mediation

It is also possible that the interests of the patient and the family are in conflict, or those of a patient and family with the healthcare team, etc. and a mediation by a Social Work professional is required so that the parties can reach a consensus.

The indispensable factor to take into account in order to carry out the mediation is to take into account the limitation of time and the few possibilities of repair in the near future. The decisions that are made in a mediation process must evaluate the current state of mind but also a possible later state of mind, which may become a rush of decisions that are not matured. In this case, the figure of the social worker must help consolidate the ties and respect for the decisions taken.

Meetings with relatives / caregiver environment

In general terms it is understood that communication is one of the most necessary facts for information, understanding, and for reaching agreements. Meetings with the family group or the caregiver environment have the function of favoring a communicative space where sharing information and avoiding the misunderstandings, but also encouraging the active listening of the members and encouraging recognition and acceptance.

Meetings with the caregiver environment have a clear mission not just to allow but also to encourage people involved in caring for the sick person, regardless of the weight and time they may represent. In this way, value is given to the tasks carried out by each member according to their possibilities. On the other hand, the fact of giving value to something as important as caring is stimulating and allows approaches to alleviate the weight of the care of those members who have a more intense dedication.

In the family communication space, working with families in a group, as well as performing a comprehensive therapeutic act has a unique educational component, since the analogical communication provided by the social worker can become a model of communication for future meetings of the members of the family. In fact, the attitude of demonstrating to the family group that although they think differently they can reach agreements is a good example for new encounters between them.

Often social workers face complex environments that make them not feel confident enough to interview or share with the family group because of the fear of triggering more conflict, but if it is true that there are few researches on this topic, no experiences have been collected of failures so it is encouraged to use this practice.

Special attention

There are members in the family who need special attention because of their vulnerability. These are: elderly people, children and people with mental health problems and disabilities. Social Work professionals must perform a series of tasks so that the needs of these members are taken care of. These are:

- Detect situations that require practical support.
- Guide the healthy family members to convey the most appropriate information regarding changes in the family system caused by the disease.
- Help find ways to involve these members in caring for sick people to the extent of their abilities.
- Contact (if necessary) with the responsible institutions in order to transmit the information so that the appropriate measures can be taken to identify risk situations and reinforce support.
- Search for resources within the community network or create new ones (eg. groups, volunteering, etc.).

Socio-therapeutic groups

The realization of socio-therapeutic groups due to their characteristics helps individual and collective growth of individuals.

The most characteristic feature of group processes is the therapeutic effect that emerges from the horizontality of the relationships and contributions of the participating members.

However, contributions acquire a consistent weight and consolidate the importance of the group in itself. It involves providing the opportunity for people who are living similar situations to share and at the same time contribute is a very positive reinforcement for self-esteem and the recognition of the participating members. In care on end-of-life situations there are multiple experiences and research in the literature confirming the benefit.

Groups with different objectives and offers can be made, but the professional always has to make a design with a well structured proposal including the evaluation of the proposal indicators.

Creative proposals sharing

Creativity is a feature that is deeply rooted in the figure of the social worker, since it often has no opportunity to provide sufficient resources aimed at promoting the most possible welfare, despite the critical situation at the moment.

Sharing the initiatives with the healthcare group and proposing to carry them out together with some other member of the therapeutic team facilitates that the whole team feels the proposal as part of their own development and when they feel involved they will help carry it out. It is advisable not to carry out initiatives if there is no enthusiasm for the teams.

MOURNING AND THANATOLOGIC MOURNING

It is studied that one of the most stressful factors to which human beings often are confronted is the experiences of loss processes due to death.

Mourning is conceptually understood by most authors as the process of physical and emotional reactions that causes a loss or the possibility of it. Likewise the intensity of the affectation will depend on the expectations or the meaning deposited on the object, absent person or at risk of disappearance.

To face the losses is something that everything human beings do from the beginning of their lives. Throughout human development we acquire and lose personal incorporations relevant to us who are part of our evolution, growth, relationships, etc.

From the attention given to end-of-life situations, mourning is understood as the inevitable process from the loss of a significant person, but not only at the time of his/her death. The mourning process appears from the rush of consciousness of a loss or possible loss and therefore it is crucial to give attention to the end of life or palliative processes of mourning.

The loss of health is the beginning of a whole series of loss processes for the sick person but also for the people of their environment, and the ability to face it will depend on personal and collective maturity, personal own abilities, previous experiences and also the external support that may be provided.

It is at this point that the relationship between the patient and the professional can be crucial for the healthy development of the processes and will provide the patient and his environment with all achievable facilitator elements.

All the work done by the social worker in reference to end-of-life situations is addressed, therefore, at dealing with the processes of mourning (Hudson, P. Pain, S. 2009). In fact any task carried out by any professional who is dedicated to deal with end-of-life situations comes with the attention to the processes of mourning.

The Thanatologic mourning

The thanatologic mourning is that process undergone after the death of a close being or with whom an intimate bond has been maintained. The intensity and variability of reactions is very broad and some are socially accepted while occurring over a period of time more or less closely related.

In the world of health care there is a certain tendency to pathologize or semi-pathologize the processes of mourning. It is wrong, since it is sufficiently studied that mourning is a normal process and one should avoid taking advantage of psychic vulnerability of the moment to create therapeutic dependance.

The social worker is a suitable professional to carry out hygiene programs of mourning and normalization in which by means of the expressive education one helps the people to recover the own capacities to continue with life. However, mourning hygiene programs allow identifying those situations that will require special attention.

CONCLUSION

- End-of-life care requires the availability of Social Work professionals in order to take care of the patients’ social needs and the caring environment. That is why it is necessary to demonstrate its importance not with justifications but with evidences.
- In order to carry out Social Work tasks related to end-of-life situations it is necessary for the professional to have a series of specific competences, abilities and knowledge.
- In order to be able to evaluate the work, it is necessary to have well-defined and agreed concepts and indicators that allow us to describe the different social complexities that occur in each specific situation.
- It is essential to avoid professional immobility and to assume progressive work challenges for one's profession and in interdisciplinary teams.
- The social worker in the field of end-of-life care as well as in any other areas of care must fulfill the ethical-professional commitment to carry out the relevant contributions to achieve the improvement of the social policies directed in this case to the Integral Attention to end-of-life situations.

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