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MEANINGS ATTRIBUTED TO PALLIATIVE CARE BY HEALTH PROFESSIONAL IN THE PRIMARY CARE CONTEXT¹

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ABSTRACT

Objective: to understand the meanings attributed by health professionals to palliative care assistance in primary health care.

Method: a qualitative research, guided by the social phenomenological dimension of Alfred Schütz. Twenty-five health professionals working in one of the three health units and a Family Health Support Center in the city of Natal / RN, Brazil, participated in this study. The fieldwork was carried out through an interview in the year 2015, and the information was analyzed according to the steps of social phenomenology researchers.

Results: it was understood that health professionals were able to recognize the need of the other in the practice of palliative care assistance in primary health care. The meanings attributed by health professionals involved the need for an organized system in a health care network that favored the social relationships involved in care. This involves redefining the social attitude of health professionals, in the confrontation of culture and the curative hospital-care model, in palliative care in primary health care, through the inclusion and awareness of the family.

Conclusion: the meanings attributed to palliative care in the primary health care context involve the intersubjective experience of health professionals. Based on continuous health practices in the process of interaction between professionals, health care network, patient and family, with the home context as a reality of care.

DESCRIPTORS: Palliative care. Primary health care. Health personnel. Quality of life. Health.

SIGNIFICADOS ATRIBUÍDOS POR PROFISSIONAIS DE SAÚDE AOS CUIDADOS PALIATIVOS NO CONTEXTO DA ATENÇÃO PRIMÁRIA

RESUMO

Objetivo: compreender os significados atribuídos por profissionais de saúde à assistência em cuidados paliativos na atenção primária à saúde.

Método: trata-se de uma pesquisa qualitativa, orientada pela vertente fenomenológica social de Alfred Schütz. Participaram 25 profissionais de saúde que trabalhavam em uma das três unidades de saúde e em um Núcleo de Apoio à Saúde da Família da cidade de Natal/RN, Brasil. O trabalho de campo ocorreu por meio de entrevista no ano de 2015, cujas informações foram analisadas conforme os passos de pesquisadores da fenomenologia social.

Resultados: compreendeu-se que os profissionais de saúde eram capazes de reconhecer a necessidade do outro, na prática da assistência em cuidados paliativos realizada na atenção primária de saúde. Os significados atribuídos pelos profissionais de saúde envolveram a necessidade de um sistema organizado em rede de atenção à saúde que favorecesse as relações sociais envolvidas na assistência. Isso envolve a resignificação da atitude social pelos profissionais de saúde, no enfrentamento da cultura e modelo da assistência hospitalocêntrica curativista, nos cuidados paliativos na atenção primária à saúde, através da inclusão e conscientização da família.

Conclusão: os significados atribuídos aos cuidados paliativos no contexto da atenção primária à saúde envolvem a experiência intersubjetiva dos profissionais de saúde. A partir de práticas de saúde continuadas no processo de interação entre profissionais, rede de atenção à saúde, paciente e família, tendo o contexto domiciliar como uma realidade de cuidado.

DESCRIPTORIOS: Cuidados paliativos. Atenção primária à saúde. Pessoal de saúde. Qualidade de vida. Saúde.

SIGNIFICADOS ATRIBUIDOS POR LOS PROFESIONALES DE LA SALUD PARA LOS CUIDADOS PALIATIVOS EN EL CONTEXTO DE LA ATENCIÓN PRIMARIA

RESUMEN

Objetivo: comprender los significados atribuidos por los profesionales de la salud para la asistencia en los cuidados paliativos en la atención primaria de la salud.

Método: se trata de una investigación cualitativa y orientada por la vertiente fenomenológica social de Alfred Schütz. Participaron 25 profesionales de la salud que trabajaban en una de las tres unidades de salud y en un Núcleo de Apoyo para la Salud de la Familia de la ciudad de Natal/RN, Brasil. El trabajo de campo se realizó por medio de entrevistas, en el año 2015, y cuyas informaciones fueron analizadas conforme a los pasos de los investigadores de la fenomenología social.

Resultados: se entendió que los profesionales de la salud eran capaces de reconocer la necesidad del otro en la práctica de la asistencia para los cuidados paliativos realizada en la atención primaria de la salud. Los significados atribuidos por los profesionales de la salud incluyeron la necesidad de un sistema organizado en red de atención de la salud que favorezca las relaciones sociales que participan de la asistencia. Esto incluye la resignificación de la actitud social por parte de los profesionales de la salud en el enfrentamiento de la cultura y el modelo de la asistencia hospitalaria-céntrica curadora en los cuidados paliativos para la atención primaria de la salud, a través de la inclusión y concientización de la familia.

Conclusión: los significados atribuidos a los cuidados paliativos en el contexto de la atención primaria de la salud incluyen la experiencia intersubjetiva de los profesionales de la salud a partir de las prácticas de salud continuas en el proceso de interacción entre profesionales, la red de atención de la salud, paciente y familia, teniendo al contexto domiciliario como una realidad del cuidado.

DESCRIPTORES: Cuidados paliativos. Atención primaria para la salud. Personal de la salud. Calidad de vida. Salud.

INTRODUCTION

Palliative care corresponds to a type of multiprofessional therapeutic approach, based on the principles of considering the individual as a whole, in order to improve the quality of life of the patient, his or her family members or caregivers, through coping with life-threatening illness and prioritizes early diagnosis in order to minimize physical, psychological, social and spiritual suffering.¹⁻²

Often, this term is defined as a multiprofessional care intended for people outside therapeutic possibilities, that is to say, in the dying process.²⁻⁵ For this reason it is difficult to differentiate the people who need palliative care and terminal care, as in both cases, it includes people with cancer, organ failure, infirmities and dementia.⁶

One worrying fact is that, although more than 100 million people benefit from palliative care annually, less than 8% of people who need this care actually have access to such health care.⁷ Thus, in order to provide integral assistance to these individuals in Brazil, the integration of palliative care actions within the Health Care Network (RAS) is sought after.

In order to do this, Brazil has about 40 specialized hospital services which provide palliative care.⁹ As well as Primary Health Care (PHC) and Home Care Services (SAD) networks, all of which belong to RAS, which also carry out these health services.⁸ In addition, it has the *Better off at Home Program* which regulates and guides its implementation in the context of the Brazilian Unified Health System (SUS) in an articulated way, in the different RAS services.¹⁰⁻¹¹

From this perspective, it should be noted that within this care network, PHC is considered to be the initiator of care and territorial action.¹⁰ It is considered the best level of care for the provision and coordination of palliative care,¹¹ as it has the potential to develop a set of interventions that favor the quality of life and continuity of palliative care, both inside and outside the home.⁵ In addition, it provides the patient with care close to their family, avoiding unnecessary hospitalizations and reduces the risk of infections.¹¹

However, it is difficult to include palliative care in the PHC context.⁵ This problem involves the lack of understanding of PHC professionals regarding this care,⁴ and the difficulty of establishing a frank and honest communication with the family.¹² In addition, there is little concern among managers to provide palliative care training, as well as the lack of inclusion of disciplines in the training of health professionals on this subject, predisposing that experience in palliative develops from practice.⁴

Thus, SUS has perceived the need to improve palliative care health services and, therefore, has encouraged new studies that include the training of healthcare professionals and continuous care.⁸ Therefore, the need to investigate the meanings attributed to palliative care in PHC by health professionals is evidenced, based on the philosophical contribution related to social phenomenology.

Thus, the objective was to understand the meanings attributed to palliative care assistance by health professionals in Primary Health Care.

METHOD

A study that aims to investigate the understanding and meanings attributed to the experiences that occur in the everyday world of health professionals, endowed with subjectivity, and experienced in interpersonal relationships. For this purpose, the need for a theoretical-methodological framework that supported the research in question was perceived. Thus, we opted for a qualitative research, guided by the social phenomenological approach of Alfred Schutz.

This referential is consistent with the palliative care assistance phenomenon, as it involves social experiences in communities and between individuals. Spontaneous behaviors experienced by subjects when establishing relationships directed through an intentional action are characterized in Social Action. This involves innumerable feelings experienced in the world, in which they perform their actions and share their feelings.¹³

When performing the practice of palliative care, health professionals incorporate actions and interactions with the individual, either by the assistance given due to the incapacity caused by the disease, or psychological support to the family. Thus, the social action of caring considers actions and reactions of other individuals, with care directed to the person and not the illness and relief from suffering being the focus as this gives value to intersubjective exchanges between caregivers and caregivers.

Thus, the social relationship occurs in a determinative redefining process of palliative care among health professionals, patients, family and the health care network. In the perspective of the sociologist Alfred Schutz, the understanding of the meaning of human action is based on existential motives, related to the knowledge constructed in the experiences, through a set of motives that is constituted in the social action of the subjects in the world in which the relationships take place.¹⁴⁻¹⁵

Thus, when interviewing health professionals who deal with palliative patient care in the primary health care context, it is possible to understand each experience from what has been experienced, seeking reasons to justify each action performed or not performed by health professionals.

The reflection on the attributed meanings emphasizes the understanding of the motives in order to make assumptions possible regarding the experience which occurs in primary health care in the palliative care context, as well as the reasons for

planning possibilities that will come after the experience of continuing care.¹³ The guiding question for the interview was: what meaning do you assign to palliative patient care?

The research location is not a physical space, but a conceptual context, in which experiences are experienced and the phenomenon occurs.¹⁵ Thus, the location of this research was where the researchers knew that the phenomenon occurred, considering the everyday life of health professionals who performed some type of palliative care at one of the Family Health Units (FHU) I, II or III and at a Family Health Support Center (FHSC), in the City of Natal-RN, Brazil.

Health professionals with more than one year of PHC and higher education were included in the research, as it was believed that these professionals, both those who worked in the health units and especially those who worked in the FHSC, received professional training and experienced this theme, as well as the capacity to act with this clientele. Therefore, it was understood that they had a foundation regarding performing palliative care.

Twenty-five health professionals participated in the study, these included five physicians, seven nurses, six dentists, a social worker, a nutritionist, a physical educator, two physiotherapists and a pharmacist participated. The convenience sampling technique was used.

The investigation of the study was initially done through two meetings with the researchers in the field of study. The first interview was performed in order to present the research to the professionals, and the second to bring them closer to the ethical precepts necessary for the effective participation in the research and to invite them to participate in the study. After accepting to participate, a date and place were set for the researcher to meet with each participant, for the purpose of individual interviews. Before starting the recording, the participant signed the Informed Consent Form (ICF) and the Consent form for voice recording, given by the researcher.

The collection took place between July and September 2015, based on recorded interviews in the participants' work place, and ended when the researcher's concerns were answered and the research objective was achieved.¹⁵

The information was analyzed according to the steps of social phenomenology researchers,¹³⁻¹⁶ reading and re-reading of each testimony, aiming to identify relevant aspects regarding the context of the experience of health professionals; identification and subsequent grouping of the significant aspects

of the testimonies into units of meaning; synthesis of units with the intention to compose categories.¹⁴⁻¹⁶

The discussion of the data was based on the theoretical reference of Alfred Schutz's social phenomenology and on literature related to the theme of the study.¹⁴⁻¹⁶ This is a segment from a master's thesis presented to the Post-Graduate Nursing Program. The study was performed in accordance with Resolution N. 466 of December 12, 2012, which deals with research with humans, and was approved according to Opinion N. 43895815.4.0000.5537.

To preserve the anonymity of the participants, pseudonyms were used, using names of flowers, as like flowers, which need to be cared for and watered, health professionals must be perceived in a human reality, in which they need to be stimulated to flourish.

RESULTS

The results showed that the meaning of palliative care assistance identified in the narrative of health professionals is influenced by factors that interfere with their care, such as: discoordination of the health care network, lack of resources for the provision of safe care, absence of professional training and influences of culture and the hospital-care centered model in palliative care in primary health care.

The meanings attributed to them by the work process in relation to palliative care in the PHC context are described below.

Challenges in the palliative care network

In this unit of meaning, it was possible to evidence the reality of a fragile health context, characterized by the discontinuity of care, represented by discoordination and lack of continuity in care in the health care network focused on palliative care, expressed as follows:

so, there is no standardization, we never organize a continuous care scheme (Palma);

there is a limit for us. Because it is still necessary to have a connection/articulation with CREAS [Centro de Referência Especializado de Assistência Social], CRAS [Centro de Referência de Assistência Social], with hospitals. This lack of articulation hinders the continuity of network care, which is often disorganized. What blocks us is when we go to a degree of assistance, and we cannot go forward. Because there is no way to continue the flow of the patient in the network (Carnation);

[...] the whole team would have to be coordinated in order to provide primary care together with the NASF. This has been strengthened with the arrival of the NASF (Celosia).

Therefore, continuity of care in the healthcare network is a challenge that involves the need for management to favor actions that meet the principle of integrality. The study reveals that there is a need to understand social relationships, which does not only involve professionals, but involves a whole health system, which is capable of providing fundamental resources for the continuity of health care assistance actions of healthcare professionals.

I provide assistance with the materials that I have. Sometimes the family even buys the material. Some patients in the community turn to the public defender, through denunciation, and get medication and material; unfortunately, the team is distressed by the lack of materials and work conditions faced with the lack of quality at work (Astromelia).

I have already given care in several situations: patients with heart disease, patients with diabetes, patients with deep pressure ulcers, the lack of material, medications in the network and the lack of specialist referrals in the network makes the work process difficult (Calla Lilly).

[...] the fact of feeling alone, not having a support and an adequate team makes it difficult. (Iris).

In a Congress that I attended, the need for infrastructure and logistics was shown so that this care can be offered. We need to talk more about it, redefine and organize (Lilly).

Some aspects highlighted the desire to assist users who need palliative care, but the lack of continuity of care, lack of resources and the need for programmed and coordinated actions go beyond the organization of the team alone. However, this concerns the need for an organized health network, to ensure continuity of care and to promote quality of life in palliative care. To do so, one participant highlighted the need for team building.

I believe that they should promote training so that the Strategy health team could provide support in carrying out this type of care (Cherry blossom).

In the primary healthcare unit, I admit that there is no basic or advanced preparation for this type of care. There is a home hospitalization team, who could assist us in following up these patients. I also see the need for a better dissemination of this team, which I think is better able to work together, in primary care and with the health unit [...] when requesting such attention, we did not free ourselves from caring, but it would be a sum of force for this continuity (Tulip).

[...] the guarantee of the right of people to have a better quality of life. There would have to be a local team, a support team and a more specialized team in

the health care network, because one team alone is not enough (Narcissus).

My role is very new in primary care. Unfortunately we are still in a learning process. The training is still very flawed (Hydrangea).

Thus, the nature of a comprehensive sociology is perceived from the analysis of interpretation against the phenomenon expressed in the discourses of the health professionals. The primary care context requires that health professionals establish social relationships that can recognize the subjective characteristics.¹³ This favors the continuity of care through the functioning of the health care network and teamwork assigned in the Home Care context

It is suggested that professionals need to be improved through training and the recognition of responsibilities by managers as in order to establish relationships, health professionals need to be organized in the health care network. The practice of actions which are agreed in a coherent manner is consistent with universality, equity and integrality of care proposed by SUS.

Influences of culture and the curative hospital-centered care model in palliative care in primary health care

The fact that health professionals and families often do not understand palliative care at home is due to the historical and cultural context of society that has kept people from living with their loved ones in the dying process, and seen as something that demands complex assistance which is provided exclusively in the hospital environment and performed by a specific team.

It is cultural, the family feels more comfortable in taking the user to the hospital, because he thinks he will have more assistance in that environment (Chrysanthemum).

Our culture rejects it, like our profession, and our administrative political system is within that logic (Sunflower).

The issue of this partnership with the family is what often makes it impossible to continue care. He goes to the hospital to get stabilized, and when he returns, and because he can't receive that care at home, this patient returns from the hospital with other comorbidities and ends up dying (China Pinks).

In the present context, people are afraid to approach the dying process, therefore the family plays a fundamental role in the palliative care context. The preference for the hospital reflects the

predominance of the hospital-centered and curative model associated with the hospital environment. This attitude, on the part of the relatives, which does not consider the primary health care context this contributes to discontinuity of care, and makes performing palliative care at home difficult.

In addition, the curative model, focused on the disease and on the specificity of care, rather than the care centered on the individual needs of the patient and the family in their natural environment still prevails in the discourses of some professionals. Thus, training health professionals could favor their empowerment in the execution of health education and show the family that palliative care is a reality that can be implemented in PHC.

Finally, it reinforces the need, on the part of the management, to support the professional training regarding the person-centered care model; as well as making professionals aware of the paradigm ruptures and transformation of their care practice.

DISCUSSION

Despite the diversity in the proposed actions to improve the quality of life of people in a contemporary world permeated by technological advent, health reality is confronted with new health care demands. Among other things, due to the emergence of new diseases, new living conditions, and consequently new resources and therapeutic approaches, as is the case in palliative care in the PHC context. These new demands require that SUS provides a declaration of support and agreement for the integration of actions, even in an intersectorial nature.¹⁷

The perspective of integrated actions is the RAS differential. In Brazil, the RAS concept recently began to be disseminated along with the Sanitary Reform, which corroborated the construction of the current Health System. An organized network reflects decentralization and guarantees integral and continuous care to the population.¹⁸

The Home Care modality is one of the pillars within the RAS that supports the orientation of health services and professionals to the need for palliative care. Defined as a substitutive or complementary action to those already in existence, it is characterized by a set of actions which promote health, prevent and treat diseases, with rehabilitation provided at home that guarantees continuity of care and is integrated with the RAS.¹⁰

In Brazil, the recognition of the responsibility of the primary health care teams of the eligible users of the *Better off at Home Program* in the SAD, has

recently been applied. However, the coordination of home care programs with RAS has also been considered as a prime factor to guarantee successful experiences and to reduce the number of hospitalized people and prevent new hospitalizations.¹⁹

In a study which evaluated the integration of PAD, the discoordination of PAD with the other levels of care was verified, which, in the interpretation of the authors, generated the challenge of coordinating it with PHC. This study ratifies the meanings attributed to palliative care assistance in PHC, since some obstacles are related to the coordination with the municipal health network and have a direct relationship with the availability of equipment, supplies and professionals in order for continuity of care to occur.¹⁸

This study corroborated with the findings of the research in question, as there is a drop in the actions highlighted by the professionals that involves the discoordination in the network services, as well as the weaknesses that interfere in the structure of health units, impairment of the adequate supply of resources, as well as permanent education to guarantee professional training.

Therefore, it is necessary to move forward in the vertical integration of different levels of attention, in the formulation of health policies linked to management and intersectorial and interdisciplinary work, for the care of specific populations for the purpose of complementarity and continuity of health care.¹⁷

Thus, it is implicit that, even with the workers' concern regarding the resolution of the case, this discoordination corroborates the practice of a fragmented assistance, with little coordination between the reference services, which causes health professionals to feel disconnected in the health care network.²⁰

The construct of a comprehensive sociology also corroborates the need of health professionals to try to establish a process of interaction.¹⁶ Thus, when they cannot establish such social relationships, they attribute a disjointed meaning characterized by the distancing of actions that fragment care and lead to its discontinuity.²⁰

It is necessary to increase perceptions regarding the actions that will be developed in the scope of palliative care. This requires the social understanding involved in building a planned strategy that can change the organization of local work. One form of this is giving importance to critical-reflexive and systematic processes, in view of the renewal of traditional ways of understanding practice.²¹

Regarding the low availability of resources and inadequate structure, some studies²²⁻²³ highlight the difficulties that affect PHC. As a result of the decentralization of care, the majority of municipalities began to carry out the selection and distribution of materials and supplies for this level of attention. These activities depend on the technical and in particular financial support of the Health Secretaries and the Ministry of Health.²³

The professionals emphasize the need for a planned preparation of the health team in order to understand that the specialized work should not only be offered individually, but in a collective way, and that when it is done in an organized way there is a possibility of establishing a relationship of continuity .

It is therefore necessary to invest in innovative strategies so that the fragmentation of health services does not occur and that they function in a coordinated and comprehensive way in order to fulfill the expected functions for resolute, equitable and integral community care.¹⁹

The need for health professionals to redefine the social attitude regarding the culture and the curative hospital-care model in palliative care in primary health care was evidenced in the study in question. This involves the inclusion and awareness of the family in accepting the continuity of palliative care assistance in order to make it a reality at home. In western culture it was common for a person to have the right to die at home with his family, in a close relationship rather than remoteness.²¹

However, the transition to modern medicine coupled with the prevalence of the hospital-centered, biomedical hegemonic model has distanced people from allowing themselves to experience the death process at home.²¹ On the other hand, in a paradigm shift where the focus is no longer only healing alone, caring emerges as the core of this new paradigm. Thus, the therapeutic approach to palliative care should aim at relieving symptoms that compromise quality of life, integrating actions of the multiprofessional team, such as physicians, nursing teams, psychologists, nutritionists, social workers, and factors that influence the type of life and death that the patient will have.¹⁸

In order to achieve integrality in actions, the health care provided requires the attention of a multiprofessional patient-centered team, which requires specific clinical skills that should not be restricted to care directed to pain and suffering, but extended to family members so that they may be more active in the process of providing palliative care.²⁴

This should be reinforced in view of the need for health care, especially with regard to home care services by adopting a model centered on the work of multiprofessional and interdisciplinary teams and to encourage the active participation of health professionals with the user, the family and the caregiver.¹⁰

Thus, the logic of rigid hierarchical organizations must be replaced by networks structured on flexible tessituras open to sharing and interdependences in objectives, information, commitments and results.

It is also understood that in the contemporary perspective of public administration, social dilemmas and paradoxes, which require administrative bodies to coordinate their difficulties with the management in order to minimize the impact of these difficulties faced by professionals.²² According to Schütz's understanding, this puts us at the forefront of the need for exchanges through actions that enable a common understanding in the context of a specific health context. Thus, the meaning of existence is understood through human action capable of assisting in the execution of care.¹⁶

Therefore, it is urgent for managers to strengthen the practice of health professionals by stimulating and potentializing the professionals' cognitive tools so that they are updated periodically, and consequently reinforcing the care provided.²⁵

Actions aimed at the adequate use of communication skills together with interpersonal relationship with the patient that facilitate interdisciplinary work, constitutes a third element in what they call a triad of foundations for palliative care.²⁵⁻²⁶

In order for health practices to be strengthened with the work of professionals and individuals, it is recommended to build accountability plans for greater primary health care and the exercise of the right to health.²⁷ They become fundamental within the home care, which includes palliative care assistance, multiprofessional team work and become integrated into the health care network.¹⁰

According to the data of the study, the meanings attributed to palliative care in the PHC context involve intersubjective experiences based on continued health practices in the process of interaction between health professionals, RAS, patient and family, and the home context as a reality of care.

The limitations of this study are related to the number of participants and to the study scenario as it is a local context, which prevents the generalization of the findings, but these are considered valid

as they reflect similar conditions verified in larger studies, highlighting the need for further studies on this theme. There is still a lack of studies on the practice of palliative care in the Home Care context, as it is generally more discussed and researched in the hospital environment.

CONCLUSION

The theoretical-methodological approach of social phenomenology made it possible to understand the experiences of health professionals, from a perspective that values the social dimension through everyday experiences. This study made it possible to understand that the everyday life of health professionals shows meanings attributed to the existence of discoordination in the health care network, through fragmented and discontinued actions, caused by the lack of hospital referrals and counter-referrals, together with services that promote home care. In the scenario investigated, scarcity of resources in the health units also makes it difficult to provide continuity of care in palliative care.

The contribution of this study is characterized by the expectations reported by health professionals, as they establish a way to solve the problem that includes the discontinuity of care in a health care network, which is the recognition of actions that go beyond the biomedical and hospital-centered model. It is believed that initiatives that promote communication between health professionals and lifelong education favor better preparedness for palliative care in the PHC context.

The implementation of systematized care in the PHC context for palliative care patients needs involves the submerged constraints on interpersonal relationships. These, in turn, involve the intersubjective experience of health professionals, based on continuous health practices in the process of interaction between professionals, health care network, patient and family, and the homecare context as a reality of care and redefine quality of life.

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