

Palliative care and primary health care: Ethical considerations

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Abstract

Palliative Care (PC) is presented as a public health problem, due to the substantial increase in the number of elderly and the prevalence of non-communicable chronic degenerative diseases. The importance of the reorganization of Primary Health Care Services (PHCS) to ensure the provision of this care has become evident. The objective was to identify cases of users, in order to inventory the ethical problems that the team experienced. This is a case study based on a Qualitative approach, using thematic analysis. Two cases were identified, that revealed, as ethical problems, the “responsibility of the PHCS towards the caregivers and families” and the “difficulty of frank and honest communication between the team and the family”. The results indicate that the training of human resources with technical competence and the continuity of assistance in the transition from curative to palliative treatment are factors favorable to the integrality and the obtention of more adequate responses to the ethical challenges that the teams experienced.

Keywords: Palliative care. Primary health care. Ethics, clinical.

Resumo

Cuidados paliativos na atenção primária à saúde: considerações éticas

Os cuidados paliativos (CP) apresentam-se como problema de saúde pública, devido ao substancial aumento do número de idosos e da prevalência de doenças crônico-degenerativas não transmissíveis. Evidencia-se a importância da reorganização dos serviços da atenção primária à saúde (APS) para assegurar a oferta desses cuidados. O objetivo foi identificar casos de usuários, a fim de inventariar os problemas éticos que a equipe vivencia. Estudo de caso de abordagem qualitativa, através da análise temática. Identificaram-se dois casos que revelaram, como problemas éticos, a “responsabilidade da APS para com os cuidadores e famílias” e a “dificuldade de comunicação franca e honesta entre a equipe e a família”. Os resultados indicam que a formação de recursos humanos com competência técnica e que a continuidade da assistência na transição do tratamento curativo para o paliativo são fatores propícios à integralidade e à obtenção de respostas mais adequadas aos desafios éticos que as equipes vivenciam.

Palavras-chave: Cuidados paliativos. Atenção primária à saúde. Ética clínica.

Resumen

Cuidados paliativos en atención primaria de salud: consideraciones éticas

Los cuidados paliativos (CP) se presentan como un problema de salud pública, debido al sustancial aumento del número de ancianos y de la prevalencia de enfermedades crónico-degenerativas no transmisibles. Se evidencia la importancia de la reorganización de los servicios de la atención primaria de la salud (APS) para asegurar la oferta de estos cuidados. El objetivo fue identificar casos de usuarios, a fin de enumerar los problemas éticos que el equipo vivencia. Estudio de caso con abordaje cualitativo, a través del análisis temático. Se identificaron dos casos que revelaron, como problemas éticos, la “responsabilidad de la APS para con los cuidadores y familias” y la “dificultad de comunicación franca y honesta entre el equipo y la familia”. Los resultados indican que la formación de recursos humanos con competencia técnica y que la continuidad de la asistencia en la transición del tratamiento curativo hacia el paliativo son factores propicios para la integralidad y la obtención de respuestas más adecuadas a los desafíos éticos que los equipos vivencian.

Palabras-clave: Cuidados paliativos. Atención primaria de salud. Ética clínica.

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Declararam não haver conflito de interesse.

Palliative care (PC) is an approach destined to improve the quality of life of the patient and family facing a disease that puts in risk the continuity of life. This involves the prevention and relief of suffering, the early detection, rigorous assessment and treatment of pain and of other problems of bio-psycho-social and spiritual natures¹. The demand for PC is currently a problem of public health, due to the progressive aging of the world population, resulting in a significant increase in the number of elders which, in turn, results in an increase of the incidence of chronic degenerative non-communicable diseases (CDNCD). In this context, the importance of PC becomes evident, as well as that of reorganizing health services in order to ensure its availability^{2,3}.

PC may be performed in an outpatient setting, in hospital and at the patient's own home. Most studies, however, focus on palliative care in hospitals. Therefore, studies to understand how this care model could be performed at home by the multidisciplinary team of primary health care services (PHCS) are relevant³.

PHCS includes a mode of care made up of essential health care based on methods, technologies, practices and socially acceptable scientific evidence that are universally accessible to individuals, families and communities, by encouraging popular participation. This assumption, originated at the *Declaration of Alma-Ata*, of 1978⁴, has in sight a new form of health system organization, characterized by multidisciplinary individual and collective actions on the first level of attention in these systems⁵. It is noteworthy that the PC involve an interpersonal relationship between those who care and those who are cared depending thus on a multidisciplinary approach to produce harmonic assistance, focused on the individuals with no possibility of healing as well as on their families⁶.

Given the growing demand for PC, it becomes difficult have a sufficient number of specialists for the assistance. Also, this perspective of health care is not just about the specialists, as the concern about the PC must also involve general health professionals, caregivers and family members, who provide primary care to these patients⁷.

However, a Brazilian study⁸ pointed out that there are still many barriers to the incorporation of PC in PHCS, especially with regard to the inability of professionals to deal with families and the non-availability of technological resources. The same study, however, highlighted the ability of these professionals to link to patients receiving such care, both for its proximity to these people as per their qualification

and distinctive profile, emphasizing the inter-relationship between staff, community and family.

For the protection of persons in terminal stage of life, the European Council calls for the identification of PC cases in PHCS, quantifying and describing the situation of patients and their conditions². However, in the European context, the need is also stressed for greater investment in PHCS in order to allow health systems to realize their full potential for the benefit of patients⁹.

It is worth noting that attention on PC in PHCS should not be understood as home care of the "home hospitalization" type. Home care programs of this type are arranged to suit patients suffering from advanced chronic diseases, with high dependence on traditional interventionist modes. In the case of PC in PHCS, on the contrary, it is meant to introduce a specific type of care that can be organized and offered on all reference levels without discontinuity. In the Brazilian context, the Program of Community Health Agents ("Programa de Agentes Comunitários de Saúde" - PACS) and the Family Health Program ("Programa Saúde da Família" - PSF), with wide national distribution, predict health professionals team of home visits, so that, even if not originally developed for palliative care actions can be structured to incorporate such a model, assuming important responsibilities in this care model¹⁰.

It should be noted that the issue of PC in PHCS is not just technical, but also includes ethical challenges such as: the decision on where the patient will die, how the health team workers take the experience of watching the death and mourning, as well as identification and management of the conditions of the family and patient for such mode of care at home.

The objective of this study was to identify cases of patients under PC that were being attended in some way in the PHCS and thereby, inventory ethical problems faced by staff in this experience. In this study, a contribution was intended to improve the quality and effectiveness of comprehensive care, since the inclusion of PC in PHCS favors the construction of an integrated system of actions that can enable the care of these patients, especially in areas that lack centers specialize in PC and hospital support is deficient.

Methods

A qualitative approach to case studies was developed through semi-structured interviews with

the discourse going through thematic analysis. Case studies rely on qualitative research strategies to map, describe and analyze the context, relationships and perceptions regarding the situation, phenomenon or episode under study. To verify the qualitative material, we used content analysis in the form thematic analysis. Content analysis is a set of communication analysis techniques aimed at obtaining, by systematic procedures and description of goals of message content, indicators that allow the inference of knowledge concerning the conditions of production or reception of these messages. The thematic analysis mode consists in discovering the units of meaning that make up a communication, of which the presence or frequency mean something to the targeted analytical object. Thus, for verification, in this study the three steps proposed by the thematic analysis were adopted: 1) pre-analysis (floating reading, *corpus* constitution, formulation of hypotheses); 2) exploration of the material; 3) processing and interpretation of results ¹¹.

The study site was a basic health unit (“unidade básica de saúde” - UBS) located in the south region of São Paulo, Brazil. First, there were semi-structured interviews with workers in order to identify who among them had accompanied or taken care of patients out of healing possibilities, for whom only the PC, aimed at improving or maintaining quality of life, was left. For the purposes of identifying cases of patients under PC, these individuals were classified as “patients out of therapeutic possibilities”. We used this classification, although its vagueness is well known, since the term “palliative care” - derived from the term “hospice” and used here as a synonym for “out of therapeutic possibilities” - may refer to both a philosophy care as a service place for that type of patient ¹².

The use of the expression “patient out of therapeutic possibilities” led the respondent to question

and reflect on the patient’s situation, as expected. The guiding questions of the interview were: “As a health team member, have you lived the experience of watching a patient outside therapeutic possibilities?” Those who responded positively to this question there was a second one: “What were the ethical problems you have found in this experience?”

Each interview was identified by an alphanumeric code corresponding to the respondent, to the assistance team and to the research question. For example: E01ESF01P1 refers to the first interview (E01) performed in the team of Family Health Strategy 01 (“Estratégia de Saúde da Família 01” (ESF01) and to the first research question (P1).

After the interview, the records of the cases referred to by the respondents were consulted, with the due authorization of the patients or their families. Then, a home visit was payed to each patient and family, with the aim to check their clinical history, sex, age, pathology that led to the terminal stage, most frequent symptoms, who the caretaker is the socioeconomic conditions of the family to attend to the needs of the patient.

Results

Among the seven teams of the Family Health Strategy (ESF) of the UBS in the South Region of São Paulo, only two reported having the experience of caring for patients out of therapeutic possibilities, and each of them indicated only one patient in this condition. The cases reported by the teams were Mr. A. and Mrs. C., whose information described in the medical records and collected in the visit is displayed in the frame below.

Frame 1. Clinical data of the patients and the social conditions of the families in cases indicated by the teams as “out of therapeutic conditions” – UBS, South Region of São Paulo (2011-2012)

Patient	Mr. A.	Mrs. C.
Clinical history	Male, 65, brown skin, with sigmoid carcinoma unresponsive to chemotherapy. The patient underwent surgery (colectomy left for obstructive acute abdomen with colostomy bag placement). Started with chemotherapy (CT) neoadjuvant (before surgery QT) and then started adjuvant (after surgery); but despite the removal of the tumor, he had a relapse and started a “stronger” QT; however there was no response, and the tumor began to grow rapidly. Since then he started with palliative CT at home.	Female, 55, African-Brazilian, has cerebral encephalopathy along with ischemic injuries resulting from cardiac arrest. The patient is bedridden, unresponsive, supported by tracheostomy, indwelling urinary catheter (SVD) and nasogastric tube (SNE). Presence of sacral pressure ulcers, infected. Taking enalapril, valproic acid and Hidantal. She is attended by the Family Health Support Unit Team (“Núcleo de Apoio à Saúde da Família” - NASF): physical therapist, dietitian, speech therapist, physical educator.
Description of the PC performed	The health team has conducted several home visits, in the form of the Family Health Strategy (“Estratégia de Saúde da Família” - ESF) for low and medium complexity care, mainly related to the manipulation of the colostomy bag, blood pressure measurement, guidance on medications and dressings, and unspecified allergic reaction that the user presented with pruritus symptom. There were visits by the professional staff of the private health insurance service, which also follows the user in chemotherapy (medical staff, nursing, social work, occupational therapy). The patient has high blood pressure and makes use of hydrochlorothiazide. Also uses promethazine, Tamarine and dimethicone. EFA and health insurance teams operate separately, without reference nor counter reference between them.	The ESF team makes home visits provided for in this type of PHCS with care limited to guidance on how best to proceed with the change of position, the care of the SVD and the SNE, even if this requires more than three weekly visits home. The UBS team does not make the exchange of SVD or maintaining SNE; when this is necessary, the user has to either be taken to the ER by the family, or to pay a professional or resort to a neighbor who works in nursing, to do the procedure at home using materials provided by the health unit. The UBS also provides the material for the dressing, as well as exchange of SVD and maintenance of SNE. The patient requires constant care such as diaper changes, changing positions every 3 hours, control of SVD, administration of enteral nutrition; therefore the family was organized, with their own resources, so that the patient would not be helpless at any time of the day
Conditions of family	Own home, there is no information about family income in the chart; however, according to the community health agent (ACS), the family has no financial difficulties. The property has water, electricity, telephone and septic tank. Six people live in the house: the patient, his wife and four children. The wife, hypertensive, diabetic and dyslipidemic is the caregiver. One son, 34, has moderate to severe mental disabilities, is retired for disability and is under monitoring by the Center for Psychosocial Care (CAPS) and psychiatric service, given his history of seizures; according to information from medical records, he is “agitated, confused, disoriented in time and space”.	Own home with running water, electricity, garbage collection and septic tank. Four people live in the house: the patient, a daughter, a son in law and a grandson. The caregiver during the day is another daughter who does not reside in the house. At night the daughter who lives in the house is the caregiver. The family has consulted several neurologists, including private doctors, seeking a second opinion, but all of them said the situation is virtually irreversible. The patient makes treatment both at the UBS and through private health insurance. According to annotations in the medical record, the family still has hope that the patient will one day recover

Professionals from the two teams agreed to participate in the interviews: two doctors, three nurses, six nursing technicians and four ACS. Each interview lasted for 10 to 15 minutes and took place in their own UBS during the work shift, having been previously scheduled in order not to interfere with the functioning of the care unit.

Based on the reports of health professionals of the PHCS, it was possible to identify two categories of analysis that reflect the ethical challenges faced by these professionals: 1) “*responsibility of the PHCS to the caregivers and families*”, in the physical, emotional, social and financial aspects, and 2) “*difficulty to keep open and honest communication between the team and the family*” as to the situation of the patient and palliative care. The first category reveals the problems of organization and access to PC in PHCS, through reports that show the lack of support for these PHCS caregivers and family members. The second deals with ethical issues related to respect for the autonomy of patients and families, as evidenced by these communication difficulties.

Category 1. Responsibility of the PHCS towards the caregivers and families

In the results of the interviews, it is evident how the PC of the patient can be straining on the caregivers:

“There is an overload on Ms. I [wife] because, since Mr. A developed the disease, she has become the most responsible, she really did” (E03ESF01P3 – community health agent);

“The caregiver, who is the daughter, she is beginning to show hypertension peaks; the son in law, who also cares a lot, already shows backbone problems and also shows hypertension peaks (...) besides caring for the bedridden, we also have to care for the family, care for the drama of the caregiver” (E06ESF02P3 – nurse).

Sometimes, this occurs because the other members of the family do not live nearby, which makes difficult their formal participation in caregiving:

“...sometimes, other children go, because she has other children that live elsewhere, but they just come to visit, they do not have a specific, direct care with Ms. C.; as far as I know, these other two sons do not help with money, they help mostly with some little visits, like once a week, just to say hi and go away” (E04ESF02P1 – community health agent).

The reports demonstrate the existence of an informal system organized by the family to care at home for the patient out of therapeutic possibilities. Such a system does not have the participation of PHCS. The main caregivers are family members or people hired by the family, when they are unable to care for the patient. Family arrangements for home care of these patients demonstrates, in every way, the burden on caregivers, due to the lack of adequate support from the health system to provide the PC.

Category 2. Difficulty to keep open, honest communication between the team and the family

Respondents claim the team and the family do not communicate in an effective way, because they cannot speak sincerely and openly about the patient’s real situation nor on the meaning of the PC:

“The whole team is acting with the most professionalism. We only comment among ourselves and not in front of the family, because we know what the family goes through. We never came in saying something, we know what is going on, that it is palliative care, we orient, we certainly give support. But we were never like: ‘You’re under palliative care, OK?’ No one ever told him [Mr. A.], I think even the team at the hospital where he gets treatment and gets his medication also have never said anything” (E01ES-F01P1 – nursing technician);

“The family is not totally aware, they have not understood that he [Mr. A.] is under palliative care (...) from the moment chemotherapy stopped. For the family (...) he did not need (...) not because his condition had worsened but because it had improved; to the family, that is the way it was understood. For them, the cancer responded to chemotherapy and it was no longer necessary, that he only needs a treatment with pills at home” (E03ESF01P3 – community health agent);

“This thing about the team not telling the family and the patient [Ms. C.], if she were in conditions to understand that she is under palliative care, I think it’s even a matter of respect, by the family, not accepting, because not every family accepts; you get there and say that we are going to care for this person, but to get there and say that she is never go back to what she was or, then, that she is not going out of this situation alive (...) you start talking and the get it wrong, this may even harm her treatment” (E07ES-F02P4 – nursing technician).

Asked about the knowledge of the family of the real health situation of the patient, respondents say they notice that the family goes through the phases of the death process, especially bargain and denial¹³:

“Not in the case of ha family or Mr. A., they are not prepared to get the news that Mr. A is under palliative care, and when they find out that that, in fact, the tendency is to get worse, they will not be ready for this (...) For the family, he is getting better,, he is responding to the treatment, so much so that he had some allergic reactions and (...) these are better and, for the family, since these are better, then the whole disease is better” (E03ESF01P3 – community health agent);

“We notice the family has a sens that there is no longer a curer [for the disease], but they do not want to believe this. I notice that, when health professionals tell them there is no cure (...) they always say: ‘No, I know that, but I want to try something else’ (...) because they have hope. They know there is no cure, the situation has been explained to them, we have told them and other professionals have also said there is no cure; it was even difficult to talk to them, juts that they always try to find other ways” (E04ESF02P1 – community health agent).

As for the care, the respondents report difficulties in dealing with the autonomy of the patient and family in decisions relative to procedures. As it is home care, they also question the invasion of privacy:

“What happens is that we ask to remove a urinary catheter; the family does not want to remove it because you can not and there is no way out There are some things that you can not break into inside and do the procedure, right? Get out there and say that will pluck this, this and this, for I am not the one who will stay there overnight if there is problem, as in the case also of the nasogastric tube she [Ms. C.] is using, if it becomes obstructed, [the caretaker] says thus: ‘The problem is that we are the ones who stay with patient “; then you are left with your hands tied and can not do the procedure. I believe that the family is afraid” (E05ESF02P2 – physician).

Discussion

Among the patients treated in the PHCS, there are those who can be considered “out of therapeutic

possibilities”, i.e. eligible to PC. Therefore, it is necessary to identify the needs of these users and their families or caregivers, and serve them according to the particularities of this level of attention, which involves preparing professionals for this type of assistance.

In this context, we emphasize the importance of considering the ethics of the PC, which is concerned with identifying the underlying values of the specific end of life needs and requires a multidisciplinary approach, capable of encouraging and helping the patient to enjoy the best that life provides him every day, through the respectful treatment, meeting their needs and tolerance for their values, beliefs and habits¹⁴.

From the health professionals reports of the PHCS, they identified problems linked to the organization and access to PC in the PHCS, since the statements show the lack of support to caregivers and family. This lack of support was evidenced by the testimonies of the participants grouped in category 1, which shows that caregivers and family members are overwhelmed by the care provided to patients out of therapeutic possibilities.

Some studies¹⁵⁻¹⁷ recorded situations of pain and suffering related to family caregivers of patients with cancer. One of the papers¹⁴ highlighted that the continued participation of the family in the disease process is permeated with suffering and loneliness, with increasing dedication of the family and interruption of individual demands for the sake of exclusive nursing. In another study¹⁸, caregivers reported fatigue, health problems and insufficient time for themselves and other family members and friends.

The finding that caregivers wear out within the assisted families increases the sense of the ESF team responsibility, as shown by the testimonials. The professionals understand that they need to respond to the health of the family as a whole and also to that each of its members.

In the case of Mr. A., the caregiver is the wife, who performs on her own the task of taking care of her husband and also of a child with special needs. In the case of Mrs. C., which is absolutely dependent, the family has organized itself in order to share the care between her two daughters. During the day, the daughter who lives near his mother’s house is responsible for the care; at night, this task falls to the daughter who lives with the patient.

The burden on the family stems from the lack of formal support to the patient in home care.

It is worth noting that in neither case there were patients included in the Better at Home Program (Programa Melhor em Casa”), proposed by the Brazilian government with the aim of expanding home care in the public health system. However, Mrs. C. is in home care Mode 2 (AD2), which would be elective for the Better at Home Program. The formal support is the one provided by the state and / or private or philanthropic institutions. Informal support is afforded by family, friends or neighbors, motivated by feelings of affection or social and moral obligation¹⁹.

Another aspect to highlight is the role of women (wives and daughters) as caregivers, as shown in another study²⁰ which recognizes that in the case of a family in need of care, usually people from the family itself are chosen to perform certain roles, especially that of caregiver. However, the same study found that in the choice of this caregiver process, there is a hierarchy subject to factors linked to that person, such as: gender, age, relationship to the patient, location of residence, financial situation, available time, affection to the patient and type of personality. Moreover, it found that this hierarchy there is a predominance of wives performing the role of caregiver, followed by the predominance of daughters, sons and daughters-in-law. About the role of women in PC, although this research has not verified the frequency with which wives and daughters play the role of caregiver, both cases reported involved women in this role.

However, despite recognizing the impact of chronic disease on the family as a whole, health systems are not focused on meeting the needs of this clientele. For the development of family support systems, to improve and promote the health of all family members, it is necessary to seek knowledge about the nature of the intervention processes and, therefore, understanding the possible working arrangements. One study²¹ pointed out the great relevance of the “conversation on family health model” for the clinical and intervention practices in the PHCS.

This study²¹ proposes having three meetings. The first starts with the discussion of the objectives and expectations on to what extent conversation can help family members. In the second meeting, each family member is invited to tell their experience in relation to the situation of the family. Finally, family members and two health professionals (established as leaders in the proposed model) meet and, based on the reports, seek to obtain a consensus on what would be both desirable and possible changes within the family. The intention

in the second conversation is to advance towards minimizing the suffering of the family, reinforcing the beliefs that facilitate caring and modifying those which limit it. In the third meeting, in addition to advancing this goal, a reflection about the changes in the course of conversation is added.

Support for caregivers for home care becomes a reality in the PHCS context, as the home can be considered the preferred place of the dying process, besides the fact that it can encourage the organization of health services. Such preference is related to the fact that, in the Brazilian context, the “territoriality” as an important PHCS instrument, provides, among its work premises work, both the recognition of the “environment” of the population and existing social dynamics in these areas and the establishing horizontal relations with other adjacent and vertical services (such as reference centers), thereby contributing to the better organization of services²².

The identification of caregivers should be the first step in the structuring of a support network. Since April 2013, the PHCS of Scotland has enabled its employees to carry out a protocol to identify these caregivers as well as a mechanism to refer them to assessment by social services. However, in most countries there are no such support systems¹⁷. Particularly in Brazil, a national health policy towards PC has not been established, and even the National Health Policy for the Elderly (“Política Nacional de Saúde da Pessoa Idosa” - PNPI)²³, there is no similar program aimed at the elderly. Although the PNPI determines the family’s responsibility for elderly care in meeting their needs, in practice there is no support system to families or definition of responsibilities of instances of formal and informal care²⁴.

A study conducted in Belgium with general practitioners²⁵ showed that these professionals are not prepared to offer quality home PC nor understand the implications of this care model - factors that can reflect in their clinical practice. The lack of experience in palliative care in clinical practice during graduation was identified as a major cause of insufficient training of these doctors. Respondents also reported a fact that highlights the importance of seeking forms of organization of PC in PHCS, that training experiences in hospital can not be easily transferred to the home environment, which requires specific care practices.

Another study from the Basque country²⁶, reveals the importance of establishing a network of social support to patients under PC and to their caregivers which will include information on the availability of support services, training and capacity

building of caregivers and/or family; development of communication abilities; approach to the family and/or caregivers toward reconciling PC with professional life, including psychosocial support to avoid the strain due to this activity; exchange of experience with other caregivers.

In the cases referred, although the team tried to offer formal support from the UBS, the respondents noticed that the burden on the family still exists and this situation ends up generating suffering and loneliness, feelings with which both the family and the ESF team have dealt¹⁵. This requires training of the professionals of the PHCS for therapeutic communication and active listening.

In this study poor communication between professionals and caregivers and / or family related were also detected not only to the patient's situation, but also to the PC. As seen, category 2 indicates these difficulties, which reflect ethical problems linked to respect for the autonomy of patients and families. Among the ethical conflicts concerning autonomy identified in the survey, it highlights the disclosure or not to the patient of the diagnosis of disease out of therapeutic possibilities and the agreement or disagreement with the omission of this diagnosis requested by the family. Such problems are discussed based on the bioethical theme of "breaking bad news". Any information that affects radically and definitively the prospects for the future of the recipient is considered bad news. The lack of sincerity or the concealment of the truth in these cases affects the right to autonomy, since in order to enable the active participation of the patients in making decisions regarding their treatment, it is essential that they be aware of the disease that affects them, its severity and possible developments as well as the benefits and harms of the treatments available²⁷.

The request by family members of non-disclosure of the diagnosis to the patient can match the professional's choice when the latter, intentionally, also prefers to adopt a deceptive conduct, consistent with their own difficulties to cope. On the other hand, when deciding to establish open and insightful communication with everyone involved, it is observed that the situation provides an ethical conflict, requiring special attention in the management of this relationship²⁶. Therefore, the main ethical issue is connected to the just moral adequacy of the use of truth to be established with the patient and to the management of the relationship with the family.

These professionals have a paradox of values, because on the one hand, they feel relieved by the

end of the patient's suffering and on the other, they anguish over before the pain picture that death brings with it²⁸. A study²⁵ identified the importance of educating physicians in specifically targeted communication for PC, indicating that learning must come from practical experience. However, this perception contrasts with the existing literature, which points out the positive effects of training in communication through interactive training. The present study demonstrated that the reports of these professionals may be associated with reluctance to participate in role play sessions.

The difficulties for the more fluid and true communication between staff, family and patient are due, among other reasons, to the repulse that the theme of death causes, when exposing the finitude of human life. PC professionals are not prepared to deal daily with human weaknesses concerning life and death - these weaknesses which can interfere with communication and interpersonal relationships.

Such questions lead to a reflection on the extent to which the revelation of truth will consist in beneficial action to the patient and the family, when we know that the knowledge of the disease can trigger the worsening of the physical and emotional state of the patient. These factors contribute for the disclosure, and more especially the predictions of rapid evolution, not to happen in a clear and objective manner²⁷.

However, this approach may entail, among the main ethical consequences, stimulating paternalistic and protective attitudes towards the patient and therefore interference in the full exercise of their autonomy. Difficulties in the field of communication diagnostic and prognostic out of therapeutic possibilities diseases contributed to the spread of the "white lie" or "benevolent falsehood," terms used to support - despite its difficult moral justification - deceit in professional-patient communication²⁷.

The verbal and nonverbal communication, when used appropriately, is proven effective therapeutic measure. It is one of the basic pillars of care at end of life, it helps to reduce the psychological stress of the patient and caregivers, when promoting the sharing of suffering and pain^{29,30}.

However, communication in the dying process needs to move beyond its informative function. It must be empathetic, compassionate, expressing attention and care messages through words, postures and attitudes. This requires professional attention mainly focused on the patient, not just on the dis-

ease; only then they may understand the different dimensions of the other, their experiences and behaviors³⁰. With this, flow and the adequacy of communication are facilitated and at the same time, priority is given to autonomy, acceptance and social support - factors which help reduce the emotional, social and financial burden on patients, families,³¹ and even health professionals.

Study carried out with health professionals working in palliative care in representative institutions in this area of care in São Paulo, Brazil³², showed the importance they attributed to interpersonal communication in the terminally phase of life. However, the same study revealed that these professionals have little knowledge of the techniques and verbal communication and non-verbal strategies, which ultimately compromise the individualized care of the needs of each patient and his family. Thus, the research demonstrates the importance of proper training of teams to develop communication skills, as these skills are not merely acquired with practice time.

The provision of adequate attention to patients who require PC is responsibility to be shared by health professionals in different parts of the service network. The commitment of qualified professionals, duly supported by the health care system programs, can help align the preferences of patients and their families with the care plans³³, providing better quality of life when a cure is impossible. Such an attitude can also benefit the health professionals themselves, as support, preparation and sharing contribute to decrease the stress and suffering they experience.

The PHCS team would have to be prepared for some PC actions such as the control of low complexity symptoms, preventing aggravations and the emotional support of families, including during the mourning period.

Final Considerations

Among the professionals PHCS, the experience of meeting families with patients in need of

palliative care is now a reality. These situations they live generate ethical challenges, particularly with regard to communication among the team, patient and family and lack of emotional and institutional support to caregivers, whose wearing and injuries resulting from the care burden are clearly perceived by the team.

Due to the care peculiarities in PHCS, the teams know they are responsible for the health of the family and the caregiver, as they have to respond to the needs of the person in palliative care. This size and scope of care generate overload for professionals.

Preparing professionals and incorporating programs that integrate, in an articulate way, the PC in the PHCS in the health network will contribute to the humanization and integrality of care, since these actions could help reduce the dropout and the suffering of patients and their families. The training of human resources in PC, including emotionally prepared to deal with these patients and their families, and the continuity of patient care in the transition from curative to palliative are factors that favor the humanization, completeness and obtaining more appropriate answers to the ethical challenges faced by the teams in meeting people whose continuity of life is threatened.

Home care of capillary coverage in in the PHCS and the possibility of people to choose to die at home with relatives bring out the need to include, in some way, the PC at this level of attention. In hospitals there are already a few services or PC teams, but in the Brazilian PHCS they hardly exist. Nor is there concern to include the PHCS topics facing the care of persons in need of PC in the qualification and training of professionals.

Compulsory subject in the training of these professionals to deal with situations of end of life, the question of "how to tell the truth" to the families and patients involves strengthening the skills and expertise to empathic and therapeutic communication. These considerations have to be considered within the limits of a study of scientific initiation of an exploratory nature, even though their results find consistent support in the literature on the subject.

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Referências

1. Cervelin AF, Kruse MHL. Espiritualidade e religiosidade nos cuidados paliativos: conhecer para governar. *Esc Anna Nery*. [Internet]. 2014 [acesso 7 abr 2015];18(1):136-42. Disponível: <http://dx.doi.org/10.5935/1414-8145.20140020>
2. Vega T, Arrieta E, Lozano JE, Miralles M, Anes Y, Gomez C et al. Atención sanitaria paliativa y de soporte de los equipos de atención primaria en el domicilio. *GacSanit*. [Internet]. 2001 [acesso 7 abr 2015];25(3):205-10. Disponível: http://scielo.isciii.es/scielo.php?script=sci_arttext&pid=S0213-91112011000300006&lng=es&nrm=iso
3. Queiroz AHAB, Pontes RJS, Souza AMA, Rodrigues TB. Percepção de familiares e profissionais de saúde sobre os cuidados no final da vida no âmbito da atenção primária à saúde. *Ciênc Saúde Coletiva*. [Internet]. 2013 [acesso 7 abr 2015];18(9):2615-23. Disponível: <http://dx.doi.org/10.1590/S1413-81232013000900016>
4. Fundo das Nações Unidas para a Infância (UNICEF). Cuidados Primários de Saúde. Relatório da Conferência Internacional sobre cuidados primários de saúde; 1978, 6-12 set.: Alma-Ata, URSS. Brasília: Unicef; 1979.
5. Canella DS, Silva ACF, Jaime PC. Produção científica sobre nutrição no âmbito da atenção primária à saúde no Brasil: uma revisão de literatura. *Ciênc Saúde Coletiva*. [Internet]. 2013 [acesso 30 abr 2015];18(2):297-308. Disponível: <http://dx.doi.org/10.1590/S1413-81232013000200002>
6. Cardoso DH, Muniz RM, Schwartz E, Arrieira ICO. Cuidados paliativos na assistência hospitalar: a vivência de uma equipe multiprofissional. *Texto & Contexto Enferm*. [Internet]. 2013 [acesso 7 abr 2015];22(4):1134-41. Disponível: <http://dx.doi.org/10.1590/S0104-07072013000400032>
7. Mitchell G. Primary palliative care: facing twin challenges. *Aust Fam Physician*. [Internet]. 2011 [acesso 7 abr 2015];40(7):517-8. Disponível: <http://www.racgp.org.au/download/documents/AFP/2011/July/201107mitchell.pdf>
8. Baliza MF, Bousso RS, Spineli VMCD, Silva L, Poles K. Cuidados paliativos no domicílio: percepção de enfermeiras da Estratégia Saúde da Família. *Acta Paul Enferm*. [Internet]. 2012 [acesso 7 abr 2015];25(spe2):13-8. Disponível: <http://dx.doi.org/10.1590/S0103-21002012000900003>
9. Pisco L. Reforma da atenção primária em Portugal em duplo movimento: unidades assistenciais autônomas de saúde familiar e gestão em agrupamentos de centros de saúde. *Ciênc Saúde Coletiva*. [Internet]. 2011 [acesso 7 abr 2015];16(6):2841-52. Disponível: <http://dx.doi.org/10.1590/S1413-81232011000600022>
10. Floriani CA, Schramm FR. Desafios morais e operacionais da inclusão dos cuidados paliativos na rede de atenção básica. *Cad Saúde Pública*. [Internet]. 2007 [acesso 30 abr 2015];23(9):2072-80. Disponível: <http://dx.doi.org/10.1590/S0102-311X2007000900015>
11. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 13ª ed. São Paulo: Hucitec; 2013.
12. Oliveira RA, coordenador. Cuidado paliativo. [Internet]. São Paulo: Cremesp; 2008 [acesso 23 maio 2015]. Disponível: http://www.saude.sp.gov.br/resources/ses/perfil/profissional-da-saude/grupo-tecnico-de-acoes-estrategicas-gtae/saude-da-pessoa-idosa/livros-e-revistas/livro_cuidado_paliativo.pdf
13. Sousa ATO, França JRFS, Santos MFO, Costa SFG, Souto CMRM. Cuidados paliativos com pacientes terminais: um enfoque na Bioética. *Rev Cubana Enfermer*. 2010;26(3):123-35.
14. Vargas MAO, Vivan J, Vieira RW, Mancia JR, Ramos FRS, Ferrazzo S et al. Ressignificando o cuidado em uma unidade especializada em cuidados paliativos: uma realidade possível? *Texto & Contexto Enferm*. [Internet]. 2013 [acesso 7 abr 2015];22(3):637-45. Disponível: <http://dx.doi.org/10.1590/S0104-07072013000300009>
15. Sanches MVP, Nascimento LC, Lima RAG. Crianças e adolescentes com câncer em cuidados paliativos: experiência de familiares. *Rev Bras Enferm*. [Internet]. 2014 [acesso 7 abr 2015];67(1):28-35. Disponível: <http://dx.doi.org/10.5935/0034-7167.20140003>
16. Mehta A, Chan LS, Cohen SR. Flying blind: sources of distress for family caregivers of palliative cancer patients managing pain at home. *J Psychosoc Oncol*. [Internet]. 2014 [acesso 7 abr 2015];32(1):94-111. Disponível: <http://www.tandfonline.com/doi/pdf/10.1080/07347332.2013.856057>
17. Carduff E, Finucane A, Kendall M, Jarvis A, Harrison N, Greenacre J et al. Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources. *BMC Fam Pract*. [Internet]. 2014 [acesso 7 abr 2015];15:48. Disponível: <http://www.biomedcentral.com/content/pdf/1471-2296-15-48.pdf>
18. Whei-Mei JS, Ping-Ju H, Min-Li C, Mei-Hsiang L. Experiences of family of patient with newly diagnosed advanced terminal stage hepatocellular cancer. *Asian Pac J Cancer Prev*. [Internet]. 2013 [acesso 7 abr 2015];14(8):4655-60. Disponível: <http://dx.doi.org/10.7314/APJCP.2013.14.8.4655>
19. Sousa AI, Silver LD, Griep RH. Apoio social entre idosos de uma localidade de baixa renda no município do Rio de Janeiro. *Acta Paul Enferm*. [Internet]. 2010 [acesso 7 abr 2015];23(5):625-31. Disponível: <http://dx.doi.org/10.1590/S0103-21002010000500007>

20. Fratezi FR, Gutierrez BAO. Cuidador familiar do idoso em cuidados paliativos: o processo de morrer no domicílio. *Ciênc Saúde Coletiva*. [Internet]. 2011 [acesso 7 abr 2015];16(7):3241-8. Disponível: <http://dx.doi.org/10.1590/S1413-81232011000800023>
21. Persson C, Benzein E. Family health conversations: how do they support health? *Nurs Res Pract*. [Internet]. 2014 [acesso 7 abr 2015];(2014). Disponível: <http://www.hindawi.com/journals/nrp/2014/547160>
22. Santos AL, Rigotto RM. Território e territorialização: incorporando as relações produção, trabalho, ambiente e saúde na atenção básica à saúde. *Trab Educ Saúde*. [Internet]. 2010 [acesso 6 maio 2015];8(3):387-406. Disponível: <http://dx.doi.org/10.1590/S1981-77462010000300003>
23. Brasil. Lei nº 8.842 de 4 de janeiro de 1994. Dispõe sobre a política nacional do idoso, cria o Conselho Nacional do Idoso e dá outras providências. [Internet]. [acesso 1º maio 2015]. Disponível: https://www.planalto.gov.br/ccivil_03/leis/l8842.htm
24. Moreira MD, Caldas CP. A importância do cuidador no contexto da saúde do idoso. *Esc Anna Nery*. [Internet]. 2007 [acesso 6 maio 2015];11(3):520-5. Disponível: <http://dx.doi.org/10.1590/S1414-81452007000300019>
25. Pype P, Symons L, Wens J, Van den Eynden B, Stes A, Deveugele M. Health care professionals' perceptions towards lifelong learning in palliative care for general practitioners: a focus group study. *BMC Fam Pract*. [Internet]. 2014 [acesso 7 abr 2015];15:36. Disponível: <http://www.biomedcentral.com/1471-2296/15/36>
26. Molina EH, Nuño-Solinis R, Idioaga GE, Flores SL, Hasson N, Média JFO. Impact of a home-based social welfare program on care for palliative patients in the Basque Country (SAIATU Program). *BMC Palliat Care*. [Internet]. 2013 [acesso 7 abr 2015];12:3. Disponível: <http://www.biomedcentral.com/1472-684X/12/3>
27. Geovanini F, Braz M. Conflitos éticos na comunicação de más notícias em oncologia. *Rev. bioét. (Impr.)*. [Internet]. 2013 [acesso 7 abr 2015];21(3):455-62. Disponível: http://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/view/854/942
28. Almeida CSL, Sales CA, Marcon SS. O existir da enfermagem cuidando na terminalidade da vida: um estudo fenomenológico. *Rev Esc Enferm USP*. [Internet]. 2014 [acesso 7 abr 2015];48(1):34-40. Disponível: <http://dx.doi.org/10.1590/S0080-623420140000100004>
29. Pessini L. Lidando com pedidos de eutanásia: a inserção do filtro paliativo. *Rev. bioét. (Impr.)*. [Internet]. 2010 [acesso 7 abr 2015];18(3):549-60. Disponível: http://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/viewFile/584/590
30. Araújo MMT, Silva MJP. Communication with patients in palliative care: favoring cheerfulness and optimism. *Rev Esc Enferm USP*. [Internet]. 2007 [acesso 7 abr 2015];41(4):688-74. Disponível: <http://dx.doi.org/10.1590/S0080-62342007000400018>
31. Rodrigues PHA, Rabello CAFG. Saúde da família e cuidados paliativos infantis: ouvindo os familiares de crianças dependentes de tecnologia. *Cad Saúde Pública*. [Internet]. 2007 [acesso 7 abr 2015];23(9):2072-80. Disponível: <http://dx.doi.org/10.1590/S1413-81232010000200013>
32. Araújo MMT, Silva MJP. Estratégias de comunicação utilizadas por profissionais de saúde na atenção à pacientes sob cuidados paliativos. *Rev Esc Enferm USP*. [Internet]. 2012 [acesso 7 abr 2015];46(3):626-32. Disponível: <http://dx.doi.org/10.1590/S0080-62342012000300014>
33. Kelley AS. Treatment intensity at end of life-time to act on the evidence. *The Lancet*. [Internet]. 2011 [acesso 7 abr 2015];378(9800):1364-5. Disponível: [http://dx.doi.org/10.1016/S0140-6736\(11\)61420-7](http://dx.doi.org/10.1016/S0140-6736(11)61420-7)

Participation of the authors

Hieda Ludugério de Souza, Cássia Regina de Paula Paz and Karine Generoso Holh participated in the collection of data and writing the text. Elma Lourdes Campos Pavone Zoboli supervised the conception of the article and participated in the writing and final review. Mariana Cabral Schweitzer participated in the writing and in the final review and Juliana Dias Reis Pessalacia participated in the final review.

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