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CONCEPTIONS AND PRACTICES OF PRIMARY HEALTH CARE PROFESSIONALS REGARDING PALLIATIVE CARE

Concepções e práticas dos profissionais da atenção primária à saúde acerca dos cuidados paliativos

Concepciones y prácticas de los profesionales de la atención primaria de salud sobre los cuidados paliativos

Vitoria Goulart de Oliveira[2]
Beatriz Jorge Oliveira Gomes[3]
Ana Heloisa Gomes[4]
Eloah Boska Mantovani[5]
Patricia Chatalov Ferreira[6]
Sonia Silva Marcon[1]

ABSTRACT

Objective: to understand the conceptions and practices of Primary Health Care professionals regarding palliative care. **Method:** descriptive-exploratory study, with a qualitative approach carried out with professionals working in three Basic Units in a city in southern Brazil. Data were collected in June 2021, through face-to-face, audio-recorded interviews with 36 health professionals selected for convenience and subjected to content analysis, thematic modality. **Results:** many Primary Care professionals, especially community workers, technicians and nursing assistants, have little knowledge or a distorted view of palliative care, but in their daily lives they assist patients and families. **Final considerations:** although not sufficiently prepared, health professionals need to be together, guide and assist users and families who need palliative care, they therefore need to be made aware of the importance and benefits of palliative care and be properly equipped to provide this assistance that values its principles.

DESCRIPTORS: Palliative care; Primary health care; Continuity of patient care;

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[1] Grau Técnico, Paraná, Maringá, Brazil.
[2,3,4,5,6] Universidade Estadual de Maringá, Paraná, Maringá, Brazil.

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Corresponding Author: Sonia Silva Marcon ssmarcon@uem.br

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RESUMO

Objetivo: compreender as concepções e práticas dos profissionais da Atenção Primária à Saúde acerca dos cuidados paliativos. **Método:** estudo descritivo-exploratório, de abordagem qualitativa realizado com profissionais atuantes em três Unidades Básicas em município no sul do Brasil. Os dados foram coletados em junho de 2021, mediante entrevistas presenciais, audiogravadas junto a 36 profissionais de saúde selecionados por conveniência e submetidos à análise de conteúdo, modalidade temática. **Resultados:** muitos profissionais da Atenção Primária, sobretudo os agentes comunitários, técnicos e auxiliares de enfermagem, possuempouco conhecimento ou uma visão distorcida a respeito de cuidados paliativos, mas em seu cotidiano assistem pacientes e familiares. **Considerações finais:** embora não suficientemente preparados,os profissionais de saúde precisam estar junto, orientar e assistir usuários e familiares que necessitam decuidados paliativos, necessitam portanto serem sensibilizados quanto a importância e benefícios dos cuidados paliativos e serem devidamente intrumentalizados para prestar essa assistência que valorize seus principios.

DESCRITORES: Cuidados paliativos; Atenção primária à saúde; Continuidade da assistência ao paciente;

RESUMEN

Objetivos: comprender las concepciones y prácticas de los profesionales de la Atención Primaria de Salud sobre los cuidados paliativos. **Método:** estudio descriptivo-exploratorio, con enfoque cualitativo, realizado con profesionales de tres Unidades Básicas de una ciudad de Brasil. Los datos fueron recolectados en junio de 2021, mediante entrevistas presenciales, audio grabadas, a 36 profesionales seleccionados por conveniencia y sometidos a análisis de contenido, modalidad temática. **Resultados:** muchos profesionales, especialmente trabajadores comunitarios, técnicos y auxiliares de enfermería, tienen pocos conocimientos o una visión distorsionada de los cuidados paliativos, pero en su vida diaria asisten a pacientes y familiares. **Consideraciones finales:** aunque no están suficientemente preparados, los profesionales de la salud necesitan estar juntos, orientar y asistir a los usuarios y familias que necesitan cuidados paliativos, por lo que deben ser conscientes de la importancia y los beneficios de estes Cuidados y estar adecuadamente equipados para brindar esta asistencia que valora sus principios.

DESCRIPTORES: Cuidados paliativos; Primeros auxilios; Continuidad de la atención al paciente.

INTRODUCTION

Palliative care (PC) is a care approach that seeks to promote quality of life by relieving pain and other physical, psychosocial and spiritual symptoms in people with incurable and progressive health conditions. It can be offered by different health professionals and at different levels, including Primary Health Care (PHC).[1]

Worldwide, around 56.8 million people need PC every year, but only 14% receive it.[2] The implementation of PC in Latin America is still in its infancy.[3] Although current legislation regulates home care and hospitalization, including PC, within the SUS, and Resolution 41 of 2018 proposes that health care networks (HCNs) identify the preferences of the person being assisted, as to the type of care and treatment they will receive, emphasizing that PC should always be available at all points of the HCN,[4] in Brazil there are still many difficulties in its implementation.[1]

In addition, PHC is considered the most advisable way to coordinate and provide health care to people in these conditions, given the proximity and bond of the health team with the daily life and reality of families, which can favor continuous, comprehensive, holistic and humanized care at home.[5] However, an integrative review that sought to identify the role of nurses in PHC with the theme of cancer concluded that the actions are centered on the biological aspect, and not on the biopsychosocial aspects of the human being.[6]

Even though this type of care is rarely practiced in Brazilian primary care, and when it is, it is done in an incipient way, making it a complex challenge.[7-8] Therefore, this problem should be explored in order to identify the difficultie)s experienced and subsidize public policies that contribute to the advancement of this approach in the country. In addition, it should subsidize materials and strategies for the continuing education of health professionals who will practice it. The aim of this study is to understand the conceptions and practices of PHC professionals regarding palliative care.

METHOD

A descriptive-exploratory study with a qualitative approach was carried out with PHC health professionals working in three Basic Health Units (BHU) in a municipality in the northwest of Paraná. The Consolidated criteria for reporting qualitative research (COREQ) instrument guided the presentation of this research report.

The municipality under study has an estimated population of 409,657 people, PHC is made up of 34 Basic Health Units (UBS), four Family Health Support Units (UASF), 82 Family Health teams (ESF) and population coverage of 86.46%.[9]

The inclusion criterion was working in the ESF/APS regardless of time. In turn, 10 professionals who were away on vacation or on leave during the data collection period were not included. Once the established criteria had been met, 36 professionals took part in the study.

The data was collected in June 2021, through face-to-face interviews, carried out in reserved rooms at the BHUs themselves. All the interviews were carried out by a nursing academic who had been duly trained in collecting and analyzing qualitative data and who had no relationship with the participants. During the interviews, a script drawn up by the authors was used, consisting of two parts, the first dealing with questions to characterize the participants and the second, questions relating to the conceptions and practices of health professionals in relation to palliative care, as follows: 1) What do you understand by palliative care? 2) In your opinion, which group of users should receive palliative care in primary care? 3) In your opinion, what is needed to make the implementation of Palliative Care in primary care viable? 4) What do you think about implementing Palliative Care in primary care? 5) What factors do you think limit or weaken the provision of palliative care in primary care? 6) Do you consider yourself capable of promoting Palliative Care in your practice? Why? What strategies do you use in palliative care?

The interviews lasted an average of 16.44 minutes and were audio-recorded after authorization, using a cell phone recorder. The data was transcribed in full by the researcher and subjected to content analysis, thematic modality, following the three stages proposed.10 Pre-analysis involved organizing, transcribing and separating the data set. This was followed by a floating reading of the material, with initial identification of relevant aspects based on the study's objective. In the material exploration stage, the data was classified and aggregated based on a thorough reading process, identifying common and more specific terms using colors, giving rise to previous categories. Finally, in the data processing stage, the previous categories were further developed by linking the empirical findings with the theoretical material, constantly considering the aim of the investigation and the themes emerging from the analytical process.[10]

The research respected all the ethical precepts guided by Resolution 466/2012 and 510/2016 of the National Health Council and its project was approved by the Standing Committee on Ethics in Research with Human Beings (Opinion No. 4.656.785). All the participants signed a free and informed consent form in two copies and, to ensure their anonymity, the extracts from their statements are identified with the initials of their professional category, followed by a number indicating the order in which the interviews were carried out (MED, ENF, AUX ENF, TEC ENF and ACS).

RESULTADOS

The 36 study participants ranged in age from 26 to 70, 30 (83.3%) were female, six were doctors (16.6%), six nurses (16.6%), five nursing technicians (13.8%), two nursing assistants (5.5%) and 17 community health workers (47.2%). As for marital status, 11 were single (30.5%), 16 were married (44.4%), five were in a stable union (13.8%), two were divorced (5.5%) and two were widowed (5.5%). Ten of the 12 higher education professionals had postgraduate degrees (specialization and/or master's/doctorate). Eleven professionals had been working for less than five years (30.5%), 14 for between five and ten years (38.8%), nine for between 11 and 20 years (25%) and two for more than 20 years (5.5%). Only eight professionals (22.2%) reported having already taken part in training on palliative care.

After reading the interviews, we identified that the conceptions and practices of primary health care professionals are marked by their professional experience in primary care practices, which allowed us to identify the three categories described below.

Conceptions of palliative care

In their reports, some of the professionals under study showed that they had no or limited knowledge of PC. Some even have misconceptions and associate this type of care only with elderly people or patients with terminal illnesses, such as cancer.

> *I don't know how to answer you either, these things I don't know, I don't follow patients, terminal phases, these things, I don't know how to answer you.* (TEC ENF 1)
>
> *To be quite honest, I have no idea. The elderly, from what I've seen at the clinics, it's more elderly people that we see, us, the nurses, doctors* [...] (CHA 1)
>
> *So, most of them are cancer patients, but we see a lot of neurological and degenerative patients. There are a lot of palliative patients with neurological diseases, but this type of disease doesn't really attract much attention for palliative care.*(ENF 1)
>
> *Cancer, sometimes people with dementia, these things. It's more cancer, Alzheimer's, dementia that's more advanced. I think that's it. There must be more, but I can't remember at the moment.*(AUX ENF 1)
>
> *The elderly always come to mind first, right, because they're usually the people who need it most.* (CHA 3)

The above reports show that palliative care is often confused with continuous care, which is necessary to meet basic needs. On the other hand, professionals with some knowledge of PC related it to people with diseases that cannot be cured and also those with chronic diseases who seek assistance in primary care quite frequently. In this sense, they emphasized that the purpose of palliative care is to promote physical, social and spiritual well-being and pain relief.

> *Palliative care is the care we give to patients with chronic or terminal illnesses in order to improve their quality of life, and their physical, mental and psychological well-being.* (MED 1)
>
> *Palliative care? It's monitoring, right, for people who can no longer be cured, for chronic diseases, hypertension, a frail elderly person who has cancer or a palliative disease, I think.* (ACS 4)
>
> *Terminal care is when the patient is already at an advanced stage and there are no more invasive methods that can solve it. Then there is palliative care, which aims not only to incre-*

> *ase the patient's survival or care with medication. The focus is also on leisure care, religious care, inserting the patient into the environment, right?* (ENF 1)

Support for patients and families in home palliative care

Among the practices / actions developed in palliative care, the professionals highlighted emotional support for the patient and family and guidance on the main care to be carried out. It was also noted that this assistance is carried out through home visits, enabling the creation of a bond with the patient and their family.

> *We try to be friendly and empathetic, listen to people, see what they have to say* [...] *What we can do is basically limited to that. I'd also tell the person to talk to a psychologist, so that she can do something about it, give them better support.* (CHA5)
>
> *In my case, I usually advise the patient to suddenly go for a walk, do some physical exercise, or seek therapy* [...], *these alternative treatments. Because basically I work with suggestions, right, I guide, I visit, I make suggestions and if the city hall provides support I recommend it* (CHA 6)
>
> *Our strategy is home visits and guidance. Teaching the family how to take care of them, because this patient usually has a demand at home, right, not at the UBS. He wouldn't stay at the UBS for long, because if he's terminally ill, he'll either stay at home with the comfort of his family or he'll have to go to hospital.* (AUX ENF 1)
>
> *It would be the groups that we do, before the pandemic we were doing a hyperdia group, we also did a mental health group, which then gave advice on diets, on the correct use of medication, when you have to go to an emergency system, and also home visits for those who are already bedridden, or at home, or semi-at home, that's what we do in primary care.* (MED 1)

Factors that hinder palliative care in Primary Care

The health professionals in the study showed that, despite many efforts to provide assistance to patients in palliative care in a holistic and integral way, there are obstacles in the system that hinder the implementation of these practices, with the lack of training being pointed out as the main challenge.

> *I haven't had any preparation. I'm still in training, let's put it that way, because given the pandemic and the decrees, we're very confused and I haven't had any training yet.* (CHA 1)
>
> *The biggest obstacle is the lack of trained professionals, that's for sure. I think the first point would be trained professionals and the development of projects to bring these patients together in a certain team, to have a certain follow-up, to provide better living conditions.* (CHA 6)
>
> *There needs to be more preparation, especially for us who are health workers, because it affects our psychology and we're not prepared. It's happened to me, and we have a bond, we love people, we really like them, and then the patient dies. So... it messes with us too, right, and it's good to have psychological support, these things... As I said, you have to have the necessary preparation, with training for everything, the right way to welcome the person, what to say, because you can't just say anything, you have to be prepared.* (CHA 4)
>
> *What's needed is professional training, guidance* [...] *with that everyone could work better, right, I think that's it.* (ENF 1)

Another obstacle reported was the scarcity/limitation of professionals in primary care to meet the population's health demands, as well as the impossibility of offering adequate assistance to users' needs due to the lack of support from the Extended Family Health Center (NASF), which was abolished in the municipality.

> *I think it would be fundamental, for example now that we've lost the support of the NASF that we used to have, the question of the support of physiotherapists, nutritionists, I think this is fundamental for palliative care. So it's something we've lost a lot, and it used to be part of primary care, so I think it's a question of the whole, right, a multi-professional team in primary care.* (MED 1)
>
> *Sometimes I think the lack of professionals is an important problem, there's a lack of doctors, my team has been without a doctor for a while.* (CHA 2)
>
> *I think the lack of staff, you know, information. It's just that it covers a lot of things, so... Basic health care isn't geared towards just one thing, so not everyone will have all the information about what needs to be done about it.* (TEC ENF 2)
>
> *Lack of professionals now that the NASF has ended, it's gotten really bad, right, because there used to be physiotherapists, speech therapists, nutritionists* [...](CHA 6)

DISCUSSION

Primary care is the citizen's main and first point of contact with the health care system/network, and is considered to be the organizer of people's transit and itinerary between the different levels of care.[11] Knowing the people who live in the Health Unit's catchment area, identifying general and specific characteristics of their health conditions and providing access to differentiated care for those who need it is essential. This includes the early inclusion of people with incurable conditions in palliative care and their families, which will enable them to be monitored more closely, their unique needs to be valued, and referrals to be made when necessary. The literature shows an improvement in the quality of life of patients who are beyond therapeutic possibilities and their caregivers as a result of being included in palliative care.[12]

In relation to palliative care, PHC in Brazil can act on two fronts: one aimed at providing more qualified care, which necessarily involves training health professionals by offering courses and even at team meetings, when specific topics and cases of users from the area covered by the Basic Unit are discussed. The second front, in turn, could include the development of actions aimed at raising community awareness about the definition and importance of PC, emphasizing its benefits when introduced early. This could certainly contribute to greater acceptance of palliative care by patients and their families. These actions can take place in open meetings, specific meetings for caregivers and addressing the issue in municipal councils.[11]

Although PC requires the work of a team, nursing professionals are seen as key to its success, as they are primarily responsible for monitoring the patient's clinical situation. To this end, they collect data related to the level of pain, the results of therapeutic treatments, the presence of side effects, among other aspects.[11] Thus, the nursing team has a closer relationship with patients and users, both in PHC and in hospitals, and this is no different in relation to people undergoing PC. Through home visits, nursing professionals can identify the day-to-day needs experienced by patients and their families, offer support, help with pain management, teach strategies aimed at promoting comfort, and therefore reduce the caregiver's burden.

The lack of knowledge and unpreparedness of primary care professionals to work in PC, as pointed out by the practitioners in the study, has already been highlighted in three literature reviews carried out by Brazilian researchers, despite having different objectives, such as: (a) mapping the available evidence on the main topics investigated in PC in PHC;8 (b) understanding the role of Primary Health Care health professionals in the face of palliative care;13and (c) analyzing scientific evidence on the implementation and performance of care in PHC,[11] which demonstrates that this unpreparedness constitutes a serious problem for the implementation of PC in the PHC setting.

The lack of knowledge on the subject, coupled with the absence of in-service education policies aimed at training professionals in a more subjective approach, leads them to literally avoid this type of patient and their families. This "avoidance" is, to a certain extent, understandable, because not only do professionals feel powerless, but they can also experience their mental health being compromised, as they create bonds with these patients and their families, since for some time they live with their anxieties, doubts, hopes, despair, suffering and limitations.

Some of the professionals in this study said they had no knowledge of PC, while others had misconceptions about the subject, which shows how much they need training in this area.[8,11,13] It is important to note that PC at home refers to a multi-professional care approach that aims to provide comfort and quality of life to people with serious, advanced or terminal illnesses who choose to remain in their own homes.[15] However, in order to do this, they need the support of a healthcare team that is prepared to communicate effectively, offer emotional, technical and informational support, know how to work as a team and handle unusual symptoms and situations.

Almost half of the professionals in the study were CHWs, who play an important role in linking users to the health service, mainly through home visits, the purpose of which is, among other things, to carry out active searches and monitor the health conditions of the families in their micro-area.[15] Although they have no specific training, in addition to registering family members, CHWs carry out various other activities in these visits, such as health guidance, clarifying how the health services work and identifying the needs of families. They therefore need to be prepared to work with families with members undergoing PC.[8]

Among the important points in implementing this type of care in PHC, empathy, qualified listening and valuing cultural aspects stand out.8 It is essential that all health professionals who assist these patients and their families master communication strategies, such as sensitive listening and understandable and objective speech.[11] Therefore, it is necessary to expand the purpose of Palliative Care to an integrated care network, in order to promote its strengthening and the exercise of ethical and sensitive care that these patients need at this crucial time.[17]

Other members of the health team, apart from the CHW, albeit less emphatically, also showed limited knowledge of PC. These findings corroborate the results of a study carried out in the state of Minas Gerais, Brazil, with 181 nurses, which found that they had limited knowledge of its definition and the philosophical principles that guide this approach. These results led the authors to emphasize the need for continuing education to delve deeper into the subject and to equip the multi-professional team to implement this care.[3]

It should be noted that until recently, PC care was focused solely on the final phase of life and only on cancer patients, which justifies many professionals' conception that such care is only intended for terminally ill patients with the aim of promoting quality at the end of life, which is erroneous.[12] PC should be available to both patients and their families throughout the process of diseases that threaten the continuity and quality of life - such as chronic degenerative diseases - and also during bereavement. This type of care should therefore be implemented at the different points of care.[8]

The participants in the study emphasized that this care mainly involves emotional support and guidance aimed at the patient's comfort and well-being, as well as carrying out basic activities related to maintaining daily life. However, they recognize difficulties in dealing with these issues due to shortcomings in the training process, since these issues are not adequately addressed, especially from the CP's perspective. A descriptive study carried out in PHC shows that although the subject of death and dying is discussed during academic training, the focus is still on restoring health.[16]

In addition to being part of the syllabus of undergraduate health courses, PC also needs to be included in Permanent Health Education (PHE) proposals.[8] In addition to these issues, the implementation of PC in PHC requires teamwork with a multidisciplinary approach and effective family participation, information sharing through an appropriate communication system, adequate coordination between the various levels of care and also with other sectors, in order to favor and guarantee access to services in a timely manner, equity, social security, social rights, among others.[8]

Another obstacle pointed out by the participants in the study was the shortage of professionals, aggravated by the lack of support from professionals who were part of the Expanded Family Health and Primary Care Center (NASF-AB). The dismantling of this care policy certainly compromises and may even make it impossible to provide comprehensive health care to the population, especially for people undergoing PC in PHC.[7]

Despite the many difficulties, it should be emphasized that PHC, due to its greater proximity to users, is a point in the care network with great potential to ensure that PC is actually implemented in accordance with its principles. In this sense, nurses, who are sometimes the team leaders and care managers in this area of care, despite the many responsibilities they already have, need not only to seek their own training, but also to contribute to the training of other team members. There is also a need to implement strategies to raise public awareness of this issue.[11]

FINAL CONSIDERATIONS

Muitos profissionais da Atenção Primária, sobretudo as agentes comunitárias e auxiliares e técnicos de enfermagem, possuem pouco conhecimento ou uma visão distorcida a respeito dos cuidados paliativos. Contudo, em seu cotidiano de trabalho, embora despreparados eles precisam estar junto, orientar e assistir usuários e familiares que necessitam desse tipo de cuidado.

Isso é preocupante, pois a inexperiência e a falta de capacitação geram insegurança em relação ao que fazer e ao como agir em situações específicas, privando pacientes e familiares de receberem os benefícios que os CP podem proporcionar.No âmbito da APS, apesar da proximidade geográfica com os domicílios dos usuários, alguns profissionais evitam uma maior aproximação com estes pacientes. Outros, no entanto, apesar do desconhecimento a respeito da temática, de se sentirem limitados e não adequadamente preparados, realizam visitas domiciliares, estabelecem vínculo e procuram assistir pacientes e familiares em suas necessidades e de modo a proporcionar apoio e conforto emocional.

Conclui-se que profissionais e a população em geral devem ser sensibilizados quanto a importância e benefícios dos cuidados paliativos. Deste modo, todos poderão ter mais disposição para aprender sobre e para prestar e receber cuidados paliativos.

Como possíveis limitações do estudo tem-se o fato de os participantes serem, em sua maior parte, profissionais sem formação superior e muitos sem formação específica na ára da saúde, como os agentes comunitários. Contudo, os resultados são válisdos pois na prática são eles que estão mais próximos da população adstricta. Estudos futuros poderiam focar na participação de profissionais de nível superior, visto que eles podem não só direcionar a atuação da equipe, além de promover a capacitação dos demais membros de modo a tornar viável, quando necessário, uma assistência focada nos propósitos dos cuidados paliativos.

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