

ORIGINAL ARTICLE

CARE IN PRIMARY HEALTH CARE FOR DIGNITY AT THE END OF LIFE

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**Highlights:**

1. CHW are central in identifying the need for palliative care in PHC.
2. Home visits support care for dignity in terminally ill people.
3. At the end of life, patients are referred from PHC to other RAS services.

PRE-PROOF

(as accepted)

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**ABSTRACT:**

This study aimed to describe the care carried out by professionals from Primary Health Care staff aiming at promoting dignity for people at the end of their lives at home and to understand the facilitating and hindering aspects. This is qualitative research with 12 professionals from five Family Health Strategies. Semi-structured interviews were carried out between October

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and November 2022, the results of which were organized in the Atlas.ti program and subjected to content analysis. The study made it possible to describe the care provided by Primary Health Care professionals to promote dignity for people at the end of life. Participants were nurses, doctors, nursing technicians and community health workers, who reported that they did not frequently care for people at the end of life. The identification of these people in the service occurs through community health agents, medical records and direct search for the service by patients and family members. To try to promote dignity, home visits and referrals to health services are strategies to ensure longitudinality of care as well as welcoming, access to specialized staff and effective communication with those involved in care. Furthermore, it was possible to understand the facilitating and hindering aspects of care. Dialogue, qualified staff, insertion of family in care and staff monitoring are factors that facilitate dignity-centered care. Work overload, limited resources, weaknesses in communication and weakened family ties make it difficult to maintain the dignity of people at the end of their lives at home.

**Keywords:** Patient Care Team; Primary Health Care; Respect; Terminal Care; Palliative Care; Qualitative Research.

## INTRODUCTION

End of life can be understood as the days, weeks or months that precede death. It is also a prolonged period in which patients, families and professionals understand the limitations of the disease, focusing on promoting comfort.<sup>1</sup> It can refer to transition of location and goals of care, which when offered in accordance with the principles of palliative care can improve signs and symptoms in the most diverse dimensions.<sup>2, 3</sup>

Palliative care (PC) is holistic, which aims to improve the quality of life for people with serious illnesses experiencing health-related suffering, especially at the end of life, encompassing families and caregivers.<sup>4</sup> In Primary Health Care (PHC), PC can be carried out by staff in the territory, linked to the Basic Health Units (BHU) of each municipality.

PHC is a type of care that offers care that encompasses the individual, the family and the community through multidisciplinary actions with the purpose of promoting and recovering health.<sup>5</sup> PHC team face challenges in providing PC, such as the structure of patients' place of death, professionals' mistaken perception of the end-of-life process, death and mourning, in addition to difficulties in identifying individual and family needs regarding home care.<sup>5</sup>

In recent decades, the home has become a central space directly related to a good death and dignity promotion at the end of life, occupying an important space in discussions, programs and policies on PC.<sup>6</sup> Dignity is understood as a non-relative, intrinsic value that every rational being understands something as an end in itself.<sup>7</sup>

In Brazil, among the government initiatives for dying with dignity at home are the *Programa Melhor em Casa* (Better at Home Program)<sup>8</sup> and Resolution 41 of October 31, 2018, which include, among other aspects, the offer and organization of home PC in the Brazilian Health System<sup>9</sup>. To promote home care, it is essential that patients who need PC are identified and, therefore, assisted through plans adjusted to their main problems. Furthermore, medical-hospital care technology provision, such as supplies, equipment, exams and medications, can be used at home to control symptoms and promote comfort.<sup>8</sup>

Furthermore, there is a lack of primary studies that relate dignity and the end of life. The topics of the studies have dealt, for instance, with concepts and definitions,<sup>10,11</sup> factors that interfere with its promotion or maintenance,<sup>12,13,10</sup> therapeutics<sup>9,10,13</sup> and strategies for promoting dignity<sup>12,15,16</sup> and little approach to PHC.<sup>11</sup>

Given the context, the objectives were to describe the care carried out by professionals from PHC team aiming at promoting dignity for people at the end of their lives at home and to know the facilitating and hindering aspects of care aimed at promoting dignity for people at the end of their lives at home.

## Materials and Methods

This is qualitative research, carried out in five BHUs with a Family Health Strategy (FHS), in a municipality in southern Brazil.

Data were produced between October and November 2022 through a semi-structured interview.<sup>17</sup> Health professionals aged 18 or over, who had the ability to communicate verbally, linked to the service for at least three months and who agreed to the audio recording of the interview, were included. A total of 22 professionals were invited to participate in the research, but only 12 agreed to participate. The sampling technique used was snowball. Initially, a key informant was invited to participate in the research and later, after each interview, the recommendation and contact information of another PHC health professional was requested so that they could be invited to participate in the study.

The interviews were carried out in the interviewees' work environment in a private room, and lasted between 12 and 50 minutes, in addition to being audio recorded and transcribed into documents on Google Documents management application platform. They were guided by a protocol that consisted of questions that dealt with care for people with serious, advanced illness, at risk of death in relation to frequency of care, identification of patients, organization of care, perception of physical, psychological, social and spiritual arising from the disease. Furthermore, questions were asked about the meaning of dignity and dignified death, factors that facilitate and hinder care in promoting dignity, care actions that promote dignity and their impact on people's lives. The transcriptions totaled 95 pages and were carried out by the first author of this article, having been reviewed by the research supervisor.

Subsequently, content analysis<sup>18</sup> was used based on six stages: data organization and preparation; careful reading of all collected data; detailed analysis with data coding; categorization of the main findings based on codes; representation of information based on subcategories organized by similarity; and interpretation and extraction of meaning from the results based on the researcher's inference and understanding of the research findings.

Data were managed and coded using the Atlas.ti demo version, resulting in 21 codes assigned to 237 excerpts. In this article, PHC care for dignity at the end of life will be addressed, identified from 11 codes, divided into two subcategories.

Regarding ethical considerations, Resolution 466 of December 12, 2012 was respected, and the study was approved by the Research Ethics Committee, under Opinion 5,651,793.

## **Results and discussion**

All interviewees were female, and their professions ranged from nurses, doctors, nursing technicians and a community health worker (CHW). They were between 30 and 55 years old and their time working at the BHU where they worked varied between eight months and 20 years. Regarding specializations, seven professionals reported having FHS, family medicine, clinical management, occupational health, occupational nursing, dermatological nursing, dermatology, epidemiology, public health, active methodologies, assistance projects and master's degree in science. Only three professionals reported having participated in a course focused on PC.

**((Re)organizing the work process: identification and reception of people at the end of life in PHC in times of pandemic**

The interviewees mentioned that they identify people at the end of life through CHWs, medical records, request for exams and direct search for the service by family members or patients, according to the following statements<sup>5</sup>.

Most of these patients are identified by health workers, who are from within the community, make home visits and learn about patients who have been hospitalized or who have received a serious diagnosis. (Interviewee 10)

We identified it through visits from community health workers, through spontaneous demand assistance when they come, or a family member comes to the unit and sometimes through contact with the hospital by the hospital social worker or even by the hospital staff [...]. (Interviewee 2)

When most patients have a problem like this, or suspect something, they come here, look for BHU to ask for tests to be sure or confirm, in this case, then they end up telling us. (Interviewee 5)

The strategic role that CHWs play in identifying patients in need of PC can be seen from the statements. Thus, professional training is essential, as carried out in studies<sup>19,20</sup> that proposed training this category on PC as an intervention. Both authors lack of CHW knowledge on the subject and, in this way, sought to expand CHW qualification towards the identification of patients with palliative needs, as they considered reflection and improvement on the subject in practice relevant.

The participants in the present study did not mention knowing or using scales to identify the need for PC. Some reported that, although there are end-of-life patients in the context in

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<sup>5</sup> The transcriptions maintained each participant's individualities, and their expressions were reported, according to what was said, in order to preserve the language used. The suppression of slang, repetitive expressions and "language defects" was carried out to facilitate reading and understanding for readers.

which they work, this is not a significant number. In contrast, others expressed having more direct contact with these patients.

As we are working at a Basic Health Unit, it is not part of our daily routine to deal with patients in these conditions, but, sporadically, we do come across these confrontations, but it is not part of our daily routine, they are sporadic. (Interviewee 2)

Yeah, actually, I did not particularly assist much in the area. Generally, the person who monitors is the doctor, the nurse at the unit, and if it is very serious, they are hospitalized, you rarely have a patient like that at home [...]. Patients in these conditions generally do not stay at home, as they are hospitalized. (Interviewee 8)

Professionals did not identify how frequent care is provided to patients at the end of life. Perhaps this occurred because they believed that care for them should take place in the hospital. It is believed that the service organization affects the number of people who are assisted at the end of life and during the illness process. The use of scales/tools can assist in identifying patients who require PC, factors related to dignity at the end of life and in developing a care plan.<sup>21</sup> In Brazil, the Patient Dignity Inventory (PDI – Br) is a validated tool composed of 25 items that assess patients' feelings regarding the disease and loss of dignity.<sup>22</sup>

Participants also reported different ways of providing patient care, converging on the priority given to home visits.

We try to make visits, we try to divide them into teams, as the issue of visits is well divided by team, nurse and medical resident, mainly, we divide them by team. The rest of the patients are not so divided by team, and they can come here for consultation any day [...]. (Interviewee 9)

Generally, we have a team meeting, and it is increasingly difficult at this point for nurses to be able to participate (laughs), but we always had a protected space that was a weekly meeting with workers and for them to bring their demands [...]. (Interviewee 12)

In fact, we don't organize, we don't do a family risk scale, and then we would have to go from family to family, that would be ideal. [...], but we get a lot of people who come to reception; are basically by spontaneous demand. (Interviewee 1)

Palliative care is very basic. What we learn is when nursing shows us [...]. We visit people and find out from them and we talk to the doctor, “Look, the patient’s situation is this”. (Interviewee 5)

Home visits are central elements in care organization and are carried out according to BHU staff availability. Furthermore, it turns out that staff meetings are important. Home visits are considered a different opportunity for care, as they take place in the family environment. They allow a more humanized and welcoming care to be provided, strengthening bonds between the parties involved. This type of care is included in the role of health professionals in the Brazilian National Primary Care Policy (PNAB - *Política Nacional de Atenção Básica*).<sup>23</sup>

The interviewees indicated that the COVID-19 pandemic and work overload interfered with the (re)organization of the staff’s work process and the ability to assist people at the end of life in the unit.

With the pandemic, several diseases that were more stable became more acute. They are unstable, but with a risk to their health and more serious; there are few who are in need of more specific care. But we realize that greater attention would be needed for patients with chronic diseases, as they have become much worse, right? (Interviewee 1)

The ideal is far from happening at this time, especially post-pandemic, especially with the health crisis in relation to the lack of professionals in both nursing and medical professionals. This demand was generated post-pandemic from people who were late in their routine exams, with chronification of diseases, worsening of chronic diseases. So, I think we’ve entered a circle, a snowball that we can’t seem to find our way out of, and these other demands, however important, they are not in the foreground, they should be, but they are in the background. So, I think the assistance is very bad at the moment. (Interviewee 2)

[...] we have a high demand of patients here at BHU that I cannot abandon to go and provide this specific care, we don’t have time like that, a shift, an afternoon to do this [...]. Because here at the health center we can assist 78 people in a day, so there is a lot of demand! We don’t have time, but this is caused by a lack of professionals, many things [...]. (Interviewee 7)

It is clear that the pandemic also interfered with patients' behavior regarding health care, failure to undergo exams and worsening of chronic diseases. A study carried out with cancer patients showed that the pandemic influenced health care and that there were restrictions on access to health services, delays in exams, postponement and rescheduling of surgeries, decreased demand for health services and, consequently, advancement of the disease.<sup>24</sup> Furthermore, the need to reorganize health services emerged with the aim of meeting the particularities of COVID-19 and maintaining health care monitoring for those who need it and already had support. Necessary actions to be developed by PHC included treating mild cases of COVID-19 and referring more serious cases to other services, which ended up reducing the focus on health prevention and care for chronic and advanced diseases.<sup>25</sup>

A study with professionals from the PHC nursing staff showed that the main challenges of care management were related to administrative obstacles, such as lack of materials, medications and professionals, work overload and lack of FHS coverage and failures in referral and counter-referral. It was mentioned that all these factors compromise the quality of care provided to the population, causing demotivation in professionals' work.<sup>26</sup>

Faced with the difficulty of meeting the demands of patients at the end of life, PHC professionals tend to refer them to other services considered points of care in the network.

As there have been two of my patients, one with skin cancer and the other with breast cancer, who were referred by the GERCON systems to undergo treatment with an oncologist. [...]. Patients will be assessed to see their condition, whether or not it is a case of PIDI. A person in the case that is not PIDI will only have the referral to which they should go to undergo treatment, chemotherapy or radio. [...] If we know a place where they can get it for free or there is a group that helps, like AAPECAN, then we can refer that person to these groups so they can get free medication or other support. (Interviewee 5)

And we refer a lot to psychology to [name of public university], to [name of private university], to [name of private university], if a patient is able to pay and to CAPS as well and the mental health outpatient clinic [...]. (Interviewee 9)

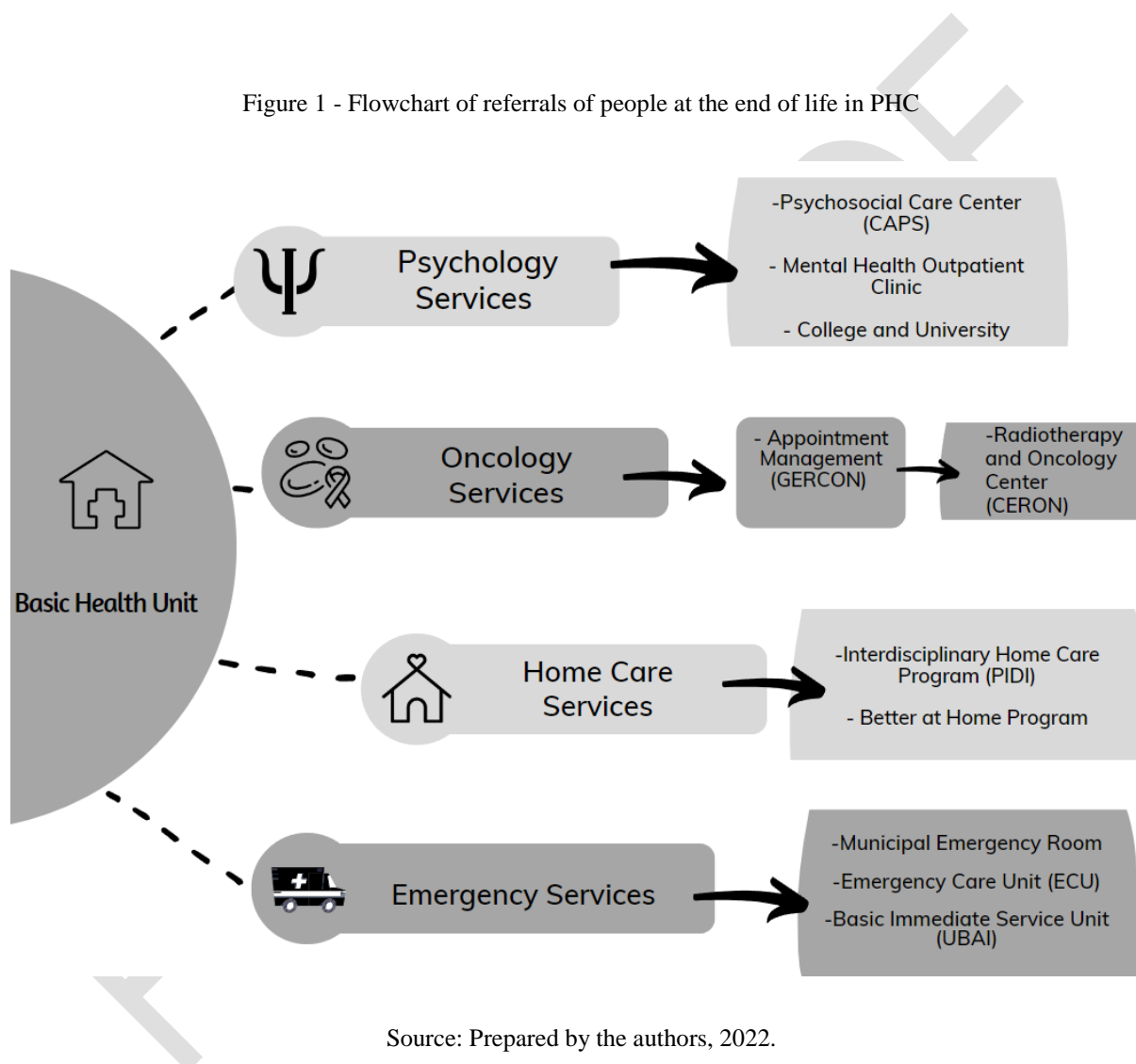
[...] there's nothing here at BHU, there's only one captopril to take right away and that's it, there's nothing. So, we always say, "Look, we have to go to an emergency, at the ER



[Emergency Room], at UBAI [Basic Immediate Care Unit], at ECU [Emergency Care Unit]. (Interviewee 7)

The importance of referral and counter-referral systems stands out, which contribute to comprehensive care for patients with serious illnesses. Thus, a flowchart was created (Figure 1) with the referrals of people at the end of life in PHC.

Figure 1 - Flowchart of referrals of people at the end of life in PHC



It is believed that referrals are important to maintain the longitudinality of care as well as order assistance. However, it is understood that, despite them, it is still necessary to monitor health problems in the territory by PHC health professionals, something that proved to be fragile in the scenario investigated.

Considering that PHC is the preferred entry point for users into the health system, the full functioning of Health Care Network (RAS - *Rede de Atenção à Saúde*) allows for adequate sharing of information between health services, guaranteeing continued and comprehensive care. For the transition between services to be an effective experience for users, there must be a harmonious relationship between professionals and systems.<sup>27</sup> In this regard, it is emphasized that PC provision must occur at any point in the RAS. Above all, PHC has the function of coordinating and monitoring people with life-threatening illnesses in its territory together with the Expanded Family Health Center (NASF-AB - *Núcleo Ampliado de Saúde da Família*), with the support of other points in the network when necessary.<sup>9</sup>

**“Sometimes just listen and welcome the person”: actions developed by professionals from PHC team to promote dignity**

Regarding care actions to promote dignity, participants highlighted home visits, reception and specific interventions, such as guidance on bed mobilization and symptom management.

I think the issue of home visits is super important for you to make frequent returns too... [...] returns as much as necessary, we try to talk a lot with the family member too, there is support here. (Interviewee 9)

Actions... I think welcoming, I think we welcome users and families, [...] we make ourselves available, it could be a 20-minute visit, but you went, you made yourself available, you sat there on the side of them, at the same height, eye to eye, touched them, held their hands, in addition to pain relief or if it is a pressure injury, whatever you have to deal with while nursing, treating a respiratory infection, in addition to that underlying disease that you are having to treat and of the other factors [...]. (Interviewee 12)

During illness, I think maybe that's what it is, we try to associate and combine medication according to people's reality. We can guide care, like when lying down “Ah, there's no mattress”, so put a blanket underneath, [...] we can provide dressing material, help with dressing care and sometimes just listen [...]. (Interviewee 11)

[...] we try to work on pain management; we try to work with the family, ways to keep this patient more comfortable; we try to emphasize the issue of hygiene, the issue of company, often it's not what to eat, it's how to eat. Sometimes it's that most protective hand; we try to provide them with their needs regarding materials to prevent possible injuries, health guidelines to avoid damage during this prolonged period that they are bedridden, and we try, within the minimum that we have, to at least carry out nursing visits on a more periodic basis [...]. (Interviewee 2)

The actions described allow us to assess that, as far as possible, care actions are developed that can promote dignity. Taking care of the aspects inherent to the body, as seen in the statements, concerns the intrinsic condition of dignity in which it can be linked to the way each person understands and recognizes their value. Qualified listening to personal narratives allows a recovery of dignity, making people feel present in their own stories.<sup>29</sup>

From this perspective, it is worth highlighting that healthy interpersonal relationships allow us to recognize the complexity of human beings, and the quality of this interaction influences dignity. When there is physical disability, psychological, moral, existential and spiritual distress, it is essential that health professionals promote respect, hope and collaborate with bodily integrity maintenance, since they are factors considered intrinsic to dignity and allow autonomy preservation.<sup>28</sup>

Regarding psychological support for patients monitored by the service, this support was found to be weak in PHC, as there was only one unit.

It would be ideal to have a psychologist available, as we do here at our BHU. We have a social worker who ends up playing this role, a bit like a psychologist. I always say to [name of social worker], "You had to do psychology!" because it helps a lot. It would be ideal for us to have a service to go home, but if a patient can walk and is feeling well, CAPS is very complete. (Interviewee 7)

We have a psychiatric consultation on Wednesdays, but it is not specific to this audience. Every patient in themselves is treated. (Interviewee 10)

At BHU [Basic Health Unit] itself, we do not have psychological support. We don't have it... and what happens, we have psychological support, but then it's CAPS

[Psychosocial Care Center], the mental health outpatient clinic where it's more complicated to provide this care at home, so, at first, we don't have it. (Interviewee 12)

There is a gap in psychological support for patients with advanced illnesses. Although the psychologist is not part of the minimum FHS team, it is worth highlighting that there is support staff that were created with the aim of increasing the solvability of FHS team's actions in PHC. Among these staff, NASF stands out, which offers matrix support from specialists through negotiations with FHS team and may have a psychologist in its composition, in order to contribute to the care of the population by ensuring the comprehensiveness and longitudinality of care.<sup>30</sup>

As a prerequisite for PC, the presence of a multidisciplinary staff is necessary since human beings' suffering is comprehensive. The articulation of different areas allows a greater coverage of the needs of patients and their families, remedying whatever is possible to guarantee the well-being of those involved. Thus, it appears that human beings' psychic states are responsible for the cascade of other distressing symptoms such as pain, with psychologists being the people responsible for recognizing the organic causes of the emotional factor, capable of understanding the language of what is said and what is implied.<sup>31</sup>

As factors that facilitate dignity promotion, professionals mentioned aspects related to the reality of care and what would be ideal.

I think the fact that we are a large staff makes this care at home easier and I think that access to these palliative care staff also makes it easier. Some families make this easy too. (Interviewee 10)

What helps us here is that when a person, for instance, is a cancer patient and is in serious condition, we have faster access to get things than having the patient come here and talk to a doctor [...]. Of course, it makes it much easier if they have all the exams, the biopsy, everything, because the doctor takes a look and can direct them to the right oncology department that they need to be referred to as quickly as possible. (Interviewee 5)

I think it's always conversation and guidance. Our part as a professional is to talk and guide, as it is for anyone else. Whether in a hospital bed or a patient who is bedridden at home, how can we provide comfort for that patient? (Interviewee 8)

Ah, the ideal would be for us to have support from the entire staff, doctors, nurses, social workers, nutritionists, especially... make follow-up visits, I don't know, every two weeks. If necessary, request tests, having psychological support is essential, we don't have it available, that would be ideal. (Interviewee 7)

I think a facilitating factor would be access to a multidisciplinary staff, access to medications, opioids, all these types of medications, as not all patients always have this access. And general access, we live in a world where, right here, in the unit, we should have... if there were two more doctors, we might be able to reach the basics, but we can't even reach the basics. (Interviewee 4)

When there is respect for people and physical and emotional needs are met with priority, there is an existence of extrinsic dignity, which is influenced by the way interpersonal relationships occur. These relationships favor dignity perception, since when a person is seen as a social being, it is possible to understand their dimension. Extrinsic dignity is related to social status, mutual respect, privacy, provision of social support and concern for others and the quality with which relationships are established for planning future actions.<sup>28</sup>

Professionals feel frustrated at not being able to offer more to patients considering the high demand for services, the economic situation and the lack of professionals to guarantee adequate assistance. This finding converges with a study that aimed to analyze the care itinerary of patients who received exclusive PC in a sector of an oncology hospital. This itinerary was demarcated by several barriers to access to treatments, and the need for adaptation by all parties involved in care production is clear.<sup>32</sup>

As factors that hinder care to promote dignity, participants expressed weaknesses in communication and family ties, slowness in care flows to start treatment and socioeconomic vulnerability. Furthermore, they highlighted aspects that could be qualified, such as availability of resources and improvement in demand, as they are still frustrated at not being able to offer the best support due to workload.

Communication, right... sometimes I think it's a failure in communication, both from the patient and from us [...] sometimes professionals don't value it. They know it's a serious illness or that they're at the end of their lives and so they don't value what people are saying, right? I think that makes it difficult [...]. (Interviewee 1)

I think what makes it difficult is the delay. [...] because the delay in discovering is also the delay in the search, it is always more difficult. But the worst factor is when you are forwarded and it takes time. And you go after it and it still takes a while. Then you have to go to court to obtain your right to undergo treatment. (Interviewee 5)

I think that promoting dignity is promoting comfort within the family. But we know that there are families who are unable to provide this support and there are families whose understanding is different [...] and that there are still few palliative care staff as well. Therefore, it is not always possible to cover all users. But I think that this idea that people have, both professionals and users... that they have to go to the hospital, I still think that this is something that makes it difficult to have this more dignified care. (Interviewee 10)

Hindering factor, so it's an issue of caregivers, because sometimes people don't have caregivers or are unable to provide care, they don't know how to read, they don't know how to handle medication... or they're stressed, overwhelmed... it's also a matter of having free medication, because it's missing in the municipal pharmacy, it's missing in the BHU, it's missing everywhere... the very structure you have, because sometimes you need a respirator, probe, I don't know, something else. And sometimes we don't have this through the SUS, it's not so easy to get, some things are, others aren't. (Interviewee 9)

Family, because sometimes they want us to leave them alive, regardless of comfort. (Interviewee 3)

[...] it certainly has an impact... but what do I want to tell you with this... there are many more people who need our care and we are not reaching them and this frustrates me as a nurse, because I know that I am overwhelmed by the demand, that I can't get out... but there is another need at home with serious illness, with chronic illness, with terminal illness that we would also have to help. [...] (Interviewee 12)

Communication was an element frequently mentioned in professionals' statements. Therefore, it is important to highlight that, in the care process, it is necessary to maintain clear communication and open dialogue with patients and their families. Psychosocial distress is

evident and becomes more widespread as there is precariousness in systems and assistance, considering that the diagnosis of a serious illness directly affects the autonomy of the people who are affected, since autonomy is related to the existential sphere of human beings.<sup>32</sup>

In this context, it is clear that social, economic and structural weaknesses can directly influence health actions and dignity (non) promotion. Factors such as abandonment, lack of materials and equipment, lack of professional training and lack of human resources directly affect the quality of care offered, which may result in misthanasia, which opposes the notion of dignity and dignified death provision. These attitudes are seen as hindering the guarantee of fundamental rights offered by the State, including health care.<sup>33</sup>

The logic of PC and support during the end of life is relevant, as it represents a new management of dying with preservation of dignity, as illness in itself causes social exclusion in which people become limited in view of their condition. The practice of misthanasia reaffirms this situation by highlighting the loss of respect for human beings who are maintained under conditions considered unworthy.<sup>33</sup>

The applicability and development of PC in Brazil is still recent. For changes to occur, taboos surrounding finitude must be minimized, and governmental goals must be established, which must be prioritized, aiming at the quality of health services based on patients' and families' interests. It is necessary to overcome existing obstacles, improve the logistics of material resources and services according to each region's availability.<sup>34</sup>

## Conclusions

This research made it possible to describe the care carried out by professionals from primary health care staff aiming at the dignity of people at the end of their lives at home and to understand the aspects that facilitate and hinder this process. The limitations were the small number of participants and a restricted scenario, as only a few FHS were selected and not all of them in the municipality.

It was found that CHWs are essential in the process of identifying patients in need of PC, and it is important to standardize the assessment of perception of dignity through validated instruments, even though these are incipient in Brazil. It was found that professionals see hospital settings as the most appropriate places to care for people at the end of life for considering the lack of structure and medications necessary to control symptoms and care in

various situations of social and economic vulnerability at the end of life, which interfere with dignity promotion and perception.

Home visits were mentioned as an important care tool, despite having been hampered and thus reduced during the COVID-19 pandemic. Furthermore, during this period, the overload of professionals increased, requiring the reorganization of services to meet the imposed demand. In view of this, it was identified that referring patients to other RAS services was and is a frequently used strategy.

Finally, dialogue, qualified staff, family insertion in the context of care, advance examinations and staff monitoring were cited as facilitators to promote dignity. Limitation of resources, work overload, weaknesses in communication, weakened family ties, lack of material and human resources negatively interfere with maintaining dignity.

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