



Social representations of Family Health Strategy professionals regarding palliative care for older adults

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Abstract

Objective: To comprehend the Social Representations of nurses, physicians, and dentists working in Primary Health Care (PHC) regarding Palliative Care (PC) for older adults. **Method:** This research was grounded in the Theory of Social Representations. Data were obtained through semi-structured interviews comprising closed-ended questions (socio-demographic and professional data) and open-ended questions (Describe your understanding of Palliative Care for older adults and Explain how you provide palliative care for the older adults under your care at this unit). For data analysis and organization, the Collective Subject Discourse technique was employed. **Results:** Regarding the question about what professionals understood about Palliative Care for older adults, four Central Ideas emerged: incurable diagnosis; biopsychosocial and humanized care for the older adult and family; quality of life; and health education. The five central ideas concerning how this care was conducted at the unit were: home visits; biopsychosocial and spiritual care for the older adult and family; activity groups; promotion of quality of life; and assistance at the moment of death. **Conclusion:** The data obtained allowed for the identification of the social representations of PHC professionals regarding PC for older adults, as well as its implementation. The understandings of PC are closely related to those advocated by the World Health Organization, with the exception of health education, which is a principle rather than a concept. These understandings also allowed for the identification of actions by nurses, physicians, and dentists that demonstrate how they provide palliative care for older adults.

Keywords: Palliative Care. Older Adults. Social Representation. Primary Health Care. National Health Strategies.

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INTRODUCTION

The aging process increases the likelihood of chronic diseases and frailties, necessitating care that addresses their needs in a comprehensive, equitable, and holistic manner¹. Considering this, coupled with longevity and the rise of certain illnesses, Palliative Care (PC) aims to provide dignity to both the individual and their family throughout the aging process.

The World Health Organization (WHO) defines PC as care provided to patients of all ages facing serious and life-threatening illnesses. Its objective is to contribute to better quality of life for patients and their families through early identification of pain, assessment, and treatment, promoting relief of physical, social, emotional, and spiritual symptoms², as well as a less painful death, integrated within an interdisciplinary field of health care³.

PC should not be confused with end-of-life care, as it is recommended from the diagnosis of a potentially fatal illness, a moment considered opportune for PC to be integrated into curative therapy⁴.

When addressing the comprehensiveness of service, the Health Care Network (HCN) aims to ensure this form of care, pointing towards an intersectoral, cooperative, polyarchic service, relating horizontally⁵. Primary Health Care (PHC) serves as the cornerstone for user and family within the HCN. The Family Health Strategy (FHS), embedded within PHC, demonstrates efficacy in providing the necessary guidance and support to patients in PC, thereby reflecting its essence and purpose⁶.

According to the WHO, patients indicated for PC, whose symptoms are controlled, can be directed to home care. As symptoms become more severe, there is a need for care coordination across different levels of complexity within the network².

Nevertheless, the main barriers highlighted by the WHO are accessibility to PC, the absence of policies, training, and preparedness of professionals, which are limited or even nonexistent, as well as access to essential medications for pain relief, such as opioids⁷.

In this sense, CP brings home care into chronic degenerative or terminal phase illnesses⁸, reinforcing the need for knowledge and preparedness of PHC teams for PC in older adults. Thus, the present research is guided by the following overarching question: What is the understanding of PHC professionals regarding palliative care in older adults?

In light of the foregoing, his research aims to comprehend the Social Representations of physicians, nurses, and dentists interviewed within the PHC related to palliative care for older adults.

METHOD

Qualitative research grounded in the assumptions of the Theory of Social Representations (TSR)^{9,10}, conducted in a medium-sized municipality in the interior of the state of São Paulo, Brazil. Among the 41 Family Health Units (FHU) in the municipality, ten units were selected based on the epidemiological and demographic profile with the highest older population; distributed across eight urban units, with two in each region, and two rural units. Participants were intentionally selected, i.e., senior-level professionals from the FHS.

The inclusion criteria comprised professionals with a higher education level, assigned to FHUs with a larger older population, considering demographic characterization. Professionals on vacation or on leave were excluded.

The data were obtained through semi-structured interviews conducted at FHUs between June and August 2022. The data collection instrument consisted of closed-ended questions (sociodemographic and professional data) and open-ended questions ("Please describe your understanding of Palliative Care for older adult" and "Please explain how you provide palliative care for older adult you care for in this unit"). Each interview lasted an average of 15 minutes, recorded in MP4 audio format, and transcribed in full.

The sociodemographic and professional characterization data were presented in the form of simple and relative frequencies. For the organization

of qualitative data, the Collective Subject Discourse (CSD) technique was used, which consists of a set of procedures for tabulating and organizing data from oral statements of the interviewed professionals. The following steps encompass this technique: selection of key expressions (KE) from each discourse. KEs are continuous or discontinuous segments of discourse that reveal the main content of the obtained responses; identification of the central idea (CI) of each of these KEs, which is the synthesis of the content of these expressions; identification of similar or complementary central ideas; and gathering the KEs related to the CIs into a synthesis discourse, in the first person singular, which is the CSD¹¹.

The research was approved by the Human Research Ethics Committees (HRECs), under opinion 5,412,880 and CAAE 57598522.5.0000.5413. Before each interview, the objectives were explained, at which time the Informed Consent Form (ICF) was read, and voluntarily signed thereafter. In order to ensure anonymity, each participant was encoded with the initial letter of their profession (E = nurse, M = physician, and O = dentist) followed by a numerical sequence from 1 to 10. The interview audios were archived based on the professional category and organized into folders according to the unit interviewed. After the transcriptions, they were deleted.

DATA AVAILABILITY

All the dataset supporting the findings of this study will be available upon request to the corresponding author Luciana Meneguim Pereira de Queiroz - lumeneguimpq@gmail.com.

RESULTS

Out of the 30 professionals invited, 10 nurses, 9 physicians, and 9 dentists participated. The majority were in the age group between 41 and 50 years old, 82% were female, 36% had a time since graduation of up to 5 years, and 43% had a time of practice in PHC of up to 9 years.

Regarding the question "Please state your understanding of Palliative Care for older adults," four CIs were identified: Incurable diagnosis, Biopsychosocial and humanized care for older adults and family, Quality of life, and Health education (Chart 1).

In response to the second question, "Describe how you provide palliative care for older adults under your care in this unit", five CIs were identified: Home visits, Biopsychosocial-spiritual care for older adults and their families, Activity groups, Promotion of quality of life, and Assistance at the moment of death (Chart 2).

Chart 1. Central Ideas and Collective Subject Discourse of nurses, physicians, and dentists from Primary Health Care regarding the understanding of palliative care in older adults. Marília, SP, 2022.

Identification of central ideas	Collective Subject Discourse
Incurable diagnosis	I believe it's not about giving the cure to the patient. In palliative care, we acknowledge that perhaps they do not have those conditions, that there is no cure. It's a patient who is in the final stages of life, who no longer has any options left, but there's a possibility of providing comfort. Sometimes it's cancer, I don't know, AIDS. In these cases, the medical aspect has already been addressed. So, palliative care is when the patient already has a terminal diagnosis and it's not always about curing a particular condition. (E2, E3, E6, E8, E10, M6, M7, M9, O1, O5, O6, O8)
Biopsychosocial and humanized care for older adults and family	I believe it involves providing the greatest possible support, both for the patient and for the family, who accompany them through their final moments. It's about facilitating autonomy, humanizing care, listening, and creating a Singular Therapeutic Project for both the patient and their family. Because the family also becomes ill and suffers alongside the patient who is receiving palliative care. It involves offering both professional and psychological support to everyone involved. In most cases, this individual remains under the care of the family, where they receive attention, affection, and better care. This type of care should be integrated with the multiprofessional team. So, I understand this as palliative care, not only for the patient but also for their support network. (E1,2,4,9, M2,9, O2,4,6,8)
Quality of life	For me, it's about providing the older adult with a better quality of life related to aging. Dispensing comfort to those older adults, alleviating the suffering of pain, providing leisure, good nutrition, and attention, things they sometimes lack. It involves the presence of family members, the attention of others, and ensuring quality of life both inside and outside the home. So, for me, it aims to relieve pain while also taking a comprehensive look not only at their illness but at the human being, ensuring they have a voice in their treatment and autonomy in decision-making regarding their illness, between life and death. It involves keeping them nourished, maintaining good hygiene, being close to family and pets, maintaining that contact, ensuring quality of life in their final period of life, and providing a dignified death. (E2-10, M1,2, M4-10, O1,3,5,7,10)
Health education	I believe it's when we provide information, both to the patient and to the family, about the advantages and disadvantages of a procedure. For those who are dependent or have other limitations, we empower the caregiver, the family member. Sometimes the family tells the older adult that they have to take this or that medication, and they don't comply. When we explain, they can understand. There's also guidance on hygiene, which is always important for maintaining health. Often, people have the misconception that if they don't have teeth, they don't need to clean their mouth, and soft tissues end up developing a variety of lesions and diseases. These are the types of guidance we can provide in primary care. (E1,5, M1, O6,10)

Source: Authors.

Chart 2. Central Ideas and Collective Subject Discourse of nurses, physicians, and dentists in Primary Health Care regarding 'How you provide palliative care for the older adults you attend to here in the unit'. Marília, SP, 2022.

Identification of central ideas	Collective Subject Discourse
Home visits	Here in the unit where I work, we conduct routine visits. Community health workers perform these visits regularly for preventive and palliative care. For bedridden patients, we have periodic visits for catheter changes, exchanging information, because they usually also consult specialists, which goes beyond primary care. Visits are always scheduled, although lately we haven't been able to do as many due to Covid, although we always keep an open channel of communication with the family of these patients, especially those in palliative care. So, what we can do for them is to monitor, conduct home visits when necessary. In dental practice, the majority are edentulous and use dentures. I check for ill-fitting dentures, provide wound care, extract any mobile teeth. I also provide guidance on oral cancer, oral hygiene. (E1,3-6,8-10, M1,2,5,7,8, O2,5-8)
Biopsychosocial-spiritual care for older adult and family	I make it a point to listen when they come in for a consultation. If they report any episodes of falls, any discomfort in any limb, or any complaints, I pay attention because that's what they appreciate. And when there's a problem, I try to resolve it with the team in the best way possible. I initially talk to the older adult. If I notice a loss of function, I talk to the family with the aim of restoring their daily activities, such as caring for plants, attending a mass, or listening to country music. And I always try to listen to the caregiver, if there are any health issues, if they are experiencing any muscle pain, how they are doing emotionally, if they can go out, if they work outside the home or not. The family feels very comfortable coming to the unit whenever they need to clarify any doubts. (E2,4,10, M2,9,10, O5)
Activity groups	I have a walking group here at the unit, not only for older adults, although they make up the majority. And it's not just about walking. There's stretching with the physical educator, physiotherapist, and there's a conversation, an exchange of ideas, both during stretching and during the walk. There's a community health worker who participates in this group, she spends some time with each group of older adults talking about various topics. We also have an occupational therapy group for crafts; we are mainly resuming activities with those older adults who can move around and come to the unit. (E5,8,9, M8)
Promotion of quality of life	I strive to provide comfort to the extent of my capabilities, so that they can feel better. There was a case of an older woman who developed a pressure ulcer; she was well cared for, we treated the ulcer, obtained the necessary materials, prescribed antibiotics, and the daughter began to come to terms with the fact that there wasn't much more to be done... except to provide comfort and dignity to her mother. That's what we emphasized a lot in this past month, providing comfort. Older adults may lose some motor function for oral hygiene, so we provide guidance on hygiene, both for them and for their caregivers. Therefore, we prioritize care, we apply dressings, at least to ensure they don't feel pain and to prevent infection. (E3,5, M1,2,8, O1,4,6,7)
Assistance at the moment of death	The community health worker and I often assist during the time of death. We provide all the support to the family at that moment. On Tuesday, we had a death here of a patient who was already 100 years old, bedridden due to Alzheimer's, and highly demented. She had been bedridden for three years, completely dependent. She took her last breath in our arms, and the daughter was grateful. We helped with tasks such as closing the mouth, changing clothes, praying with the family holding hands, looking for documents, calling the funeral home... the family is often very lost during such moments. (E1,2, M1)

Source: Authors.

DISCUSSION

The Theory of Social Representations (TSR), also known as the theory of common sense or naïve knowledge, contributed to the proposed investigation by seeking to understand how the knowledge produced by science is transformed within the social fabric – within consensual universes; or even how that which is unfamiliar becomes familiar, how the distant is made proximate for everyday practical life¹⁰.

In response to the first question, "Discuss your understanding of Palliative Care for older adults", the following CIs were constructed after analyzing each testimony: (1) Incurable diagnosis, (2) Biopsychosocial and humanized care for older adults and their families, (3) Quality of life, (4) Health education (Chart 1).

The CI 1 "incurable diagnosis" is associated with the Social Representation (SR) of PHC professionals for non-resolvable diagnoses, which are chronic and/or terminal but amenable to management. This CI is present in the definition of palliative care PC, conceptualized as comprehensive care provided to patients in cases where the disease lacks curative resolution, and aimed at patients and families facing issues related to potentially fatal illnesses⁴.

The International Association for Hospice and Palliative Care defines it as holistic care aimed at individuals throughout their life cycle, experiencing health-related suffering, particularly in the context of serious illnesses and those nearing the end of life, thus emphasizing the representation of the incurable diagnosis¹².

When the incurable nature of a condition is acknowledged, it must be approached ethically, recognizing the active process of dying. Older adults, whether they have chronic, advanced, or terminal illnesses, require dignified treatment¹³.

Addressing the finitude with the older adult who presents a serious, life-threatening illness requires addressing life, regardless of the stage it is in, as Palliative Care (PC) affirms life and considers death as a natural process. Therefore, PC is applicable from the beginning of the disease concomitantly

with modifying therapy, both for older adults and their family members^{2,4}.

In light of this premise, SR of the interviewed professionals related to the care provided to older adults and their families is presented by CI 2 "Biopsychosocial and humanized care for older adults and families."

PC aims to alleviate suffering while adding quality to life and the dying process, being recommended for both the patient and family members at any stage of the illness, as the dyad often presents expectations and/or needs that require attention. This proposal targets both formal and informal caregivers, as in the face of an incurable illness, emotional triggers are activated, as well as physical and social strain^{14,15}. In the majority of cases, it is spouses, children, and daughters-in-law who are already older themselves, caring for older adults. This highlights the need to care for this dyad, requiring support from the healthcare team, as well as planning and caregiving actions¹⁶.

In such cases, the PHC team should strengthen the bond with this dyad, identifying early any type of pain and suffering, given that illness generates anxieties and changes in their lives^{14,15}.

CI 3 "Quality of life" is related to the SR of well-being during this end-of-life period. The WHO conceptualizes quality of life as the perception that each human being has of their needs, addressing self-realization and their possibilities for it, as well as their physical, psychological, social, and economic health¹⁷. In this sense, PC aims to promote quality of life for patients and their families in the face of life-threatening illnesses⁴.

The majority of the older adult population reports pain as a limiting factor in their activities of daily living. Early identification and treatment of pain in all human dimensions, in a coordinated manner, enable the promotion of quality of life¹⁸.

The perception of quality of life for older adults is not solely based on pain relief. Social interaction, affection, maintenance of health, and financial stability are also identified as components of quality

of life. In this sense, institutionalized older adults suggest that social interaction also holds significance, indicating that quality of life encompasses the biopsychosocial aspects of older individuals, aligning with the goals of palliative care and the concept of total pain¹⁹.

CI 4 "Health Education" refers to the SR of the professional as an educator. It is indisputable that family members receive guidance regarding care at each stage experienced. Therefore, PHC professionals focus their actions on health education through educational practices for the assigned population, aiming at quality of life through planning, coordination, and direction of activities and programs between the population and the team²⁰.

Although professionals present the CI "Health Education," the definition of PC itself does not explicitly refer to this, with education being inserted into its principles through the support system provided to families and older adults, as well as through the multidisciplinary approach, including needs assessment and counseling⁴.

The National Academy of Palliative Care (ANCP - Academia Nacional de Cuidados Paliativos), in conjunction with the Brazilian Society of Geriatrics and Gerontology, released a booklet that addresses multidisciplinary guidance for caregivers of older adults in PC, specifically in the end-of-life stage, where PC becomes exclusive. The purpose is precisely health education²¹.

In relation to the second question "How do you provide palliative care for the older adults you care for in this unit," the following CIs were identified: (1) Home visits, (2) Biopsychosocial and spiritual care for the older adult and family, (3) Activity groups, (4) Promotion of quality of life, (5) Assistance at the time of death (Chart 2).

CI 1 "Home visits" is associated with the SR of professionals for home care assistance. Home care is directed towards specific demands that can be resolved at home, particularly in terminal illnesses²². To achieve this, an assessment of the older adult and available resources is necessary, as well as planning and organization²³.

This type of assistance reduces hospitalizations; however, it should not be seen as dehospitalization. Its main characteristic is the proximity of the patient at home with their preferences, ensuring personalized care and coordination with other palliative modalities²⁴.

One of the barriers encountered is precisely the lack of these resources and professional preparation, which ultimately results in hospitalizations due to deteriorations that could be attended to and treated at home²³.

The CI 2 "Biopsychosocio-spiritual care for older adults and families" refers to the SR of a holistic and humanized approach, an idea corroborated by the principles of CP⁴.

Faced with the aging process and finitude, older adults experience biopsychosocio-spiritual distress, often resulting from losses of functions and social roles, as well as the death of loved ones, thus requiring a redefinition of their uniqueness and wholeness²⁵.

Care directed towards older adults and their families should be multidimensional, valuing the biography of both, their values, and preferences⁴. To achieve this, the multidimensional approach diagram addresses various aspects of the human being, including physical, emotional-psychological, social-familial, and religious-spiritual dimensions, assisting professionals in planning their actions alongside the family²⁶. Although these actions are present PHC, there is currently no tool or training to guide this type of action.

The CI 3 "Activity Groups" relates to the SR of health professionals such as physical activity groups and occupational therapy, corroborated by the increasing prominence of physical activity in PC across all age groups, providing physical and mental benefits, as well as rehabilitation in the face of life-threatening diseases such as cancer²⁷.

In this perspective, physical activity can be an ally in the face of chronic diseases to promote quality of life. There is also an impact on emotional, social, and spiritual dimensions, which are priorities of the National Health Promotion Policy. Although

health professionals understand the factors that impact quality of life, the patient's perspective is often different^{27,28}.

Regarding occupational activities, the occupational therapy professional aims to comprehensively optimize basic, instrumental, and advanced activities of daily living, attentive to limitations and difficulties, while preserving the dignity and autonomy of the older adult²⁹.

The CI 4 "Promotion of quality of life" is associated with the SR of care focused on comfort and relief of signs and symptoms. Within the healthcare scope, it does not only aim for physical comfort related to techniques and procedures; it encompasses physical, emotional, social, spiritual, and environmental dimensions, recognizing the older adult as the protagonist of their story, seeking to maintain harmony among these dimensions within their limitations and potentials³⁰.

These care practices align with the objectives of PC, as its policy proposes that its actions address physical, social, and mental well-being, involving social, economic, cultural, spiritual, and civil participation, while preserving the autonomy of the older adult, even in their vulnerabilities³¹.

The CI 5 "Assistance at the moment of death" is associated with the SR of professionals providing assistance during and immediately after death. This CI is strengthened by the principles of PC, which offer a support system during illness and grief, in any healthcare setting and at all levels of care^{4,24}. Consequently, the home is often identified as the place where people feel safest and most comfortable, ensuring a good death³².

Assistance during death generates significant uncertainties among professionals, as it is still insufficiently addressed or discussed in undergraduate courses. It requires the need to identify the active dying process, as well as care in the immediate post-death period and grief³³.

The identification of the active dying process is of paramount importance, where there are physical

signs and symptoms, as well as a manifest need by the individual to resolve pending matters involving social, psychological, and spiritual dimensions. This planning involves effective communication among the team, patient, and family³⁴.

When addressing the preferences of older adults in the final stages of life, advance directives are a legally significant tool, as they ensure that their wishes are expressed and recorded regarding serious or irreversible illnesses, guiding the team towards dignified care³⁵.

CONCLUSION

The data obtained allowed for the comprehension of the Social Representations (SR) of healthcare professionals from the Family Health Strategy (FHS) regarding Palliative Care (PC) for older adults, as well as its implementation within the scenario of Primary Health Care (PHC).

These professionals regard PC as a comprehensive, biopsychosocial, and humanized approach to care for older adults and their families in the face of an incurable diagnosis, emphasizing quality of life and health education. This understanding aligns with national and international concepts of PC, with the caveat of health education, which is a principle rather than necessarily a concept.

In the implementation of PC directed towards older adults in PHC, the collective points out actions carried out through home visits, biopsychosocial care for older adults and their families, activity groups, promotion of quality of life, and assistance at the moment of death. These understandings have allowed the identification of actions by nurses, physicians, and dentists that demonstrate how these professionals provide palliative care for older adults.

While this study may be limited by the fact that only university professionals from the FHS participated, the understanding of their SR brings their insights and concrete actions on how they implement PC in PHC.

AUTHORSHIP

- Luciana M. P. de Queiroz - Conception, Data Collection, Analysis and Interpretation, Writing Curation - drafting and critical review - Final approval.
- Carlos A. Lazarini - Conception, Data Collection, Analysis and Interpretation, Writing Curation - drafting and critical review - Final approval.
- Elza de F. R. Higa - Conception, Data Collection, Analysis and Interpretation, Writing Curation - drafting and critical review - Final approval.

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