

Building bases for palliative care in primary care: experience report of the Manto Project

Construindo bases para os cuidados paliativos na atenção primária: relato de experiência do Projeto Manto

Construyendo bases para los cuidados paliativos en atención primaria: informe de experiencia del Proyecto Manto

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ABSTRACT

Introduction: This is an experience report about the idealization and implementation phase of the Manto Project of Palliative Care Assistance, developed in a primary care facility at Caruaru (Pernambuco, Brazil). **Methods:** Manto Project had a continuing education strategy for the multidisciplinary team and a comprehensive assistance to the health of palliative care patients and their families. **Results:** The project impacted the reality of work and the care of more than one family health team; it promoted and reinforced care unit/family bonds with team and consolidated itself as a good practice and successful experience in primary health care and Sistema Único de Saúde. **Conclusions:** The Manto Project experience challenges the reality of Brazil's northeastern interior in the context of economic crisis, weaknesses in health care professional team training and continuing education of health care workers.

Keywords: Primary health care. Palliative care. Interdisciplinary placement.

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RESUMO

Problema: Trata-se de um relato de experiência sobre a idealização e a fase de implantação do Projeto Manto de Assistência em Cuidados Paliativos, desenvolvido em uma unidade básica de saúde do município de Caruaru (PE). **Método:** O Projeto Manto contou tanto com estratégias de educação continuada da equipe multiprofissional como com assistência integral à saúde do paciente em Cuidados Paliativos e acolheu 12 usuários nessa fase. **Resultados:** O projeto impactou a realidade de trabalho e cuidado de mais de uma equipe de saúde da família; promoveu e reforçou vínculos de unidades de cuidado pessoa/família com as equipes e consolidou-se como boa prática e experiência exitosa na Atenção Primária à Saúde e no Sistema Único de Saúde. **Conclusão:** A experiência do Projeto Manto desafia a realidade do interior do Nordeste brasileiro em um contexto de crise econômica, fragilidade na formação de profissionais e educação permanente de trabalhadores da saúde.

Palavras-chave: Atenção primária à saúde. Cuidados paliativos. Práticas interdisciplinares.

RESUMEN

Problema: Es un informe de experiencia sobre la fase de idealización e implementación del Proyecto Manto de Asistencia en Cuidados Paliativos, desarrollado en una unidad básica de salud en el municipio de Caruaru (PE). **Método:** El primer ministro tenía estrategias de educación continua del equipo multiprofesional, así como asistencia integral para la salud del paciente en cuidados paliativos y dio la bienvenida a doce usuarios en esta etapa. **Resultados:** El proyecto impactó la realidad del trabajo y la atención de más de un equipo de salud familiar; promovió y reforzó los vínculos de las unidades de atención de personas/familias con los equipos y se consolidó como una buena práctica y una experiencia exitosa en Atención Primaria de Salud y el Sistema Único de Salud. **Conclusión:** La experiencia de Proyecto Manto desafía la realidad del interior del Noreste de Brasil en un contexto de crisis económica, fragilidad en la formación de profesionales y educación permanente del personal de salud.

Palabras clave: Atención primaria de salud. Cuidados paliativos. Prácticas interdisciplinarias.

INTRODUCTION

The epidemiological transition underway worldwide, linked to the vertiginous change in the population's illness profile, has supported a reorientation in health care scenarios. Questions about the care of a longer-living population and, consequently, one more exposed to illnesses from chronic-degenerative diseases and cancer, among others, are a large part of the debate in public health.¹ However, it is also necessary to discuss the sustainability of different health systems in the world in a reality marked by technological advances and profound changes in professional training in health and in the relationship between professionals and patients. Developing countries such as Brazil also face a triple burden² of disease. Chronic conditions coexist with infectious diseases and external causes such as accidents and violence, fighting for the highest mortality rates, with significant numbers related to non-communicable diseases and injuries, including cardiovascular diseases, cancer, respiratory diseases and diabetes.^{3,4}

Comprehensive health care nowadays assumes attention to the promotion, prevention, diagnosis, treatment and rehabilitation of people under the most diverse conditions. In this context, palliative care (PC) emerges as a modality of care that understands the role of curative objectives and prioritizes the proportionality of care strategies in the face of irreversible diseases or conditions, which will lead the person and their family to the finitude of life.

According to the World Health Organization, PC is defined as the approach that aims to promote the quality of life of people and their families in the face of threatening diseases through early identification and careful assessment of pain and other physical, psychological, social and spiritual problems. It also highlights the importance of understanding this modality of care in all phases of the individual's life.⁵

It is estimated that 70%⁶ of people who die annually in Brazil would benefit from PC. Many of them, however, are concentrated in hospital beds, often receiving inadequate care, still guided by a mostly

curative practice that favors invasive methods and hard technologies. This scenario strengthens the fact that Brazil was the 42nd country, among 80, in the ranking of the 2015 Quality Index of Death, which takes into account, in addition to the socio-epidemiological characteristics of the population, the availability of PC and the provision of a therapeutic arsenal to control pain and other end-of-life stressors.⁷

From the perspective of PC, the multidisciplinary work and the interdisciplinary nature of health care are the paths for the realization of comprehensive care proposed by Cicely Saunders, founder of St. Christopher's Hospice in England and main disseminator of PC throughout the world.⁸ In the practical sense of this action, the control of physical symptoms, difficult communication in health, teamwork, assessment and prognosis of functionality, as well as the consideration of ethical and bioethical aspects in light of the total suffering predisposed by finitude .

Regarding the way a PC team works, the National Academy of Palliative Care (ANCP)⁹ systematized it on basis of levels of care: at one end, community-level care, operated by the Family Health Strategy (FHS)), passing through intermediate levels to the other extreme, with PC offered by a specialized team at the hospital, outpatient or home level, with their own inpatient beds and capacity to train professionals in the area.

From the structure presented, it is understood that the practice of PC not only should not be restricted to secondary and tertiary care, but also needs to include primary health care (PHC), which is the most appropriate level of care for the provision of and coordination of PC in countries with universal health care.^{10,11,12}

The objective of this study was to report the experience of implementing the Projeto Manto de Assistência em Cuidados Paliativos (Mantle of Assistance in Palliative Care Project), describing its impact and performance in the community and in the local health network.

METHODS

The Manto Project was developed in Caruaru (PE), a city of 350,000 inhabitants, located 130 km from Recife and which has 64 Family Health Units (USF), where the study was conducted at the USF Santa Rosa II. This scenario had 4,000 registered users and a team consisting of a doctor, nurse, nursing technician, dentist, oral health person and six community health people (CHA), in addition to a team from the Family Health Support Center (NASF) — this consists of a physical education professional, a physiotherapist, a psychologist and a social worker. Its purpose was mixed, both in terms of assistance to patients and families and in terms of education for the health professionals involved, meant to build PC skills. At that time, the aim was not to elaborate an evaluation of the actions and interventions carried out.

The Project was implemented with the support of the Department of Primary Care of the Municipal Health Department of Caruaru after a demand was presented by the community itself.

In August 2017, a user presented to the team doctor with anxieties related to a recent syndromic diagnosis, in a private health service, of pancreatic cancer in her husband. A home visit was scheduled to evaluate the patient, and a 64-year-old man was identified with a history of severe wasting syndrome associated with progressive cholestatic syndrome for three months, in addition to pain in the upper abdomen. In addition, due to communication problems in the diagnostic investigation process, there was intense associated family stress, expressed by the wife and two children, which characterized expressed total pain due to the severity of the illness of the father of the family. Uncertainties were at the base of the anguish experienced by the family when faced with the finitude of the loved one.

The demand exposed the health team to reflect on fundamental issues for the assistance to this family unit, such as: the specificity of the care that that the user demanded; welcoming a family in distress, with attention to its history; and respect for the autonomy of a person in finitude and ways to provide health care proportional to the needs, without adding futile interventions or unnecessary suffering.

The emergence of uncertainties in the care provided to this family revealed the health team's lack of preparation to take care of a system (patient and loved ones) suffering from a serious and incurable disease, which was progressing to death. In meetings to discuss the work process, this team determined that it would be necessary to adjust their practices with a view to offering quality care and welcoming to the disease processes, losses and finitude of the family unit in question and others in the proximity. In this context, the Manto Project was structured, with the objective of sensitizing and training the family health team in PC fundamentals, given the resources that the PHC and the local health network had at their disposal.

The choice of name was inspired by the etymology of the term "palliative", which comes from the Latin word pallium and means "mantle" or "blanket", an element that was used to protect pilgrims from the weather on the way during the crusade in medieval Europe. Considering that the information collected for the preparation of this work involved only secondary data (notes from the multidisciplinary team), without identifying the people (patients) involved, it was not necessary to involve the local Ethics Committee for Research with Humans.

RESULTS AND DISCUSSION

As triggers for the project, two strategies were listed:

1. Continuing education of the multidisciplinary team and
2. Comprehensive assistance to the patient's health in PC.

Continuing education of the multidisciplinary team

Given the lack of theoretical and practical knowledge about PC among the team, there was a need for a pedagogical proposal that could encourage its members to acquire knowledge about the peculiarities of this practice. To this end, the Awareness Course on Palliative Care was designed, structured into five meetings held at the USF Santa Rosa II, with a total workload of 20 hours of theoretical and practical activities, as described in Chart 1, throughout the first semester of the year 2017.

A methodology was proposed that included the participants' prior knowledge while adding the various professional categories present, respecting autonomy and interprofessionalism. Therefore, active teaching-learning methodologies were chosen as a strategy for building competence (knowledge, skills and attitudes) aimed at care in finitude. Regarding the adopted learning strategies, problem-based learning (PBL), team-based learning (TBL), problematization, role-play skills training and collaborative learning throughout the activities schedule were used. .

The course was attended by three doctors, three nurses, a dentist, four receptionists, two nursing technicians, five undergraduate nursing students and 14 community health workers, totaling 32 people.

Comprehensive assistance to the patient's health in palliative care

The attention of users included in the Project followed a line of care designed by the health team and which began with the uptake carried out by the doctor and the reference community agent, throughout

Chart 1. Schedule of the sensitization course on palliative care directed at the interdisciplinary health care team of the Manto Project of Assistance in Palliative Care in primary health care. Authors' data.

Central theme of the meeting	Objectives	Methods
Principles of SUS, PHC and palliative care	Recall the place of PHC and FHS in SUS.	
Manto Project: what is it about?	Define the main and secondary objectives of the Manto Project.	Workshop; Critical reading of narratives and scientific articles.
What is my role in the Manto Project	Establish the roles of health care professionals involved.	Team-based learning; Dialogic exposition.
Difficult communication in health	Define guidelines for building an empathic, compassionate and nonviolent communication toward the user, the community and the health care team involved in the whole care process.	Team-based learning; Dialogic exposition Role playing.
Death and dying: humanism and sensibilities in health	Welcoming the experiences of people and the biography of the professionals involved, creating work strategies that include the biography of each person.	Team-based learning; Film club; Round table.

SUS: Unified Health System; PHC: primary health care; FHS: Family Health Strategy.

2017. It should be noted that one of the objectives of the second meeting of the Awareness Course on Palliative Care was to guide the CHA regarding the indications of the PC to favor the identification of users who could benefit from inclusion in the project.

At the time of each search, the patient and his family were introduced to the palliative care proposal and the actions proposed by the Manto Project, followed by the project actions in cases where they agreed to participate. Initially, an anamnesis instrument that covered the domains described in Chart 2,¹³⁻²¹ was applied, generally using two pre-scheduled meetings of about 50 minutes to complete.

Once included in the Project, users and their families were invited to participate in the therapeutic group called "A Roda da Vida" (the Wheel of Life), whose meetings took place once every three weeks and had the participation of the multidisciplinary health team. This space was inspired by the principles of comprehensive community therapy and based on deep experiences of dialogue and sharing, where themes such as death, pain and suffering were discussed, supported by fraternity and collective welcoming. The meetings lasted about two hours.

Furthermore, users were directed to interprofessional consultations, shared by the nurse, dentist and NASF team. These consultations aimed to introduce new users to the entire team and identify global clinical demands, complementing the Multidimensional Approach Diagram (MAD) and the joint problem management plan (Figure 1).

During the second half of 2017, the proposal's implementation period, 12 users were included in the Project. Their ages ranged from 8 to 72 years, with an average of 52.3 years. The underlying pathologies found, which justified palliative care, are described in Chart 3. Some facts were pointed out by the multidisciplinary health team as the main barriers to the implementation of the proposed care. The first concerned the poor dialogue with the specialized level of care that shared the care of these users. In most situations, there was no sharing of behavior (change of chemotherapy protocol, re-staging, clinical follow-up with imaging tests, etc.) between the specialized care team and the PHC team responsible for managing the user, this being the main vehicle of information.

Chart 2. Anamnesis instrument developed for the Manto Project of Assistance in Palliative Care in Primary Health Care. Authors' data.

Domain	Data under analysis	Instrument
Biographical history (knowing the person)	Sociodemographic data	Semi-structured questionnaire
	Structure of family life	Genogram
	Current and remote contexts of suffering	Semi-structured questionnaire
	Religiosity	Duke Religious Index (DUREL) ¹³
	Spirituality	Spirituality Self-Rating Scale (SSRS) ¹⁴
Clinical history (knowing the person in their illness experience)	Personal history	Semi-structured questionnaire
	Family history	Semi-structured questionnaire
	Life habits	Semi-structured questionnaire
	History of current illness	Semi-structured questionnaire
	Therapeutic itinerary	Semi-structured questionnaire
	Functionality	Palliative Performance Scale (PPS) ¹⁵ Karnofsky Performance Status (KPS) ¹⁶
	Performance and autonomy	Katz Scale ¹⁷
Stressful symptoms		Edmonton Symptom Assessment Scale (ESAS) ¹⁸
	Pain	McGill Brief Pain Questionnaire ¹⁹
	Cognition	Mini-Mental State Examination
	Humor	Yesavage Geriatric Depression Scale – short version ²⁰
Diagnosis and approach to human suffering	Total pain	Multidimensional Approach Diagram (MAD) ²¹
Joint problem management plan		

The second referred to the difficult access to essential medications for the treatment of pain and other common conditions in PC. Yet another obstacle was the unavailability of death certificates (DC) at the health unit.

The Project used the tension generated by the presence of a care unit (person/family) in intense suffering in the area to provoke changes in the management of work and education of the team, directing them to the acquisition of new knowledge, skills and attitudes related to PC. Acting on two axes considered central to the aforementioned transformation, namely, health education and the analysis of the team's work process, the project allowed for the appreciation of the emotional dimension in health work in a co-management of activities, building pacts with affectionate tone, as Vasconcelos argues.²²

Another aspect highlighted by the set of Project actions was the collective construction of a vision of essential care as stated by Boff,²³ that is, infusing all activities with care, whether directed to the person/family unit or the professionals themselves. Such construction of the sense of care in the team is a catalyst for the live work in an act described by Merhy,²⁴ which is profoundly relational and full of meaning. Nevertheless, the Manto Project structured a complex patient assessment method, composed of validated instruments and resources for a family approach and global understanding of the person, such as genogram and MAD.

In addition to the contributions in the dimensions of the person/family unit and the team, the generation of a new way of doing health in the FHS also creates tensions for local management. This tension was exposed in difficulties such as restricted access to special medications, such as

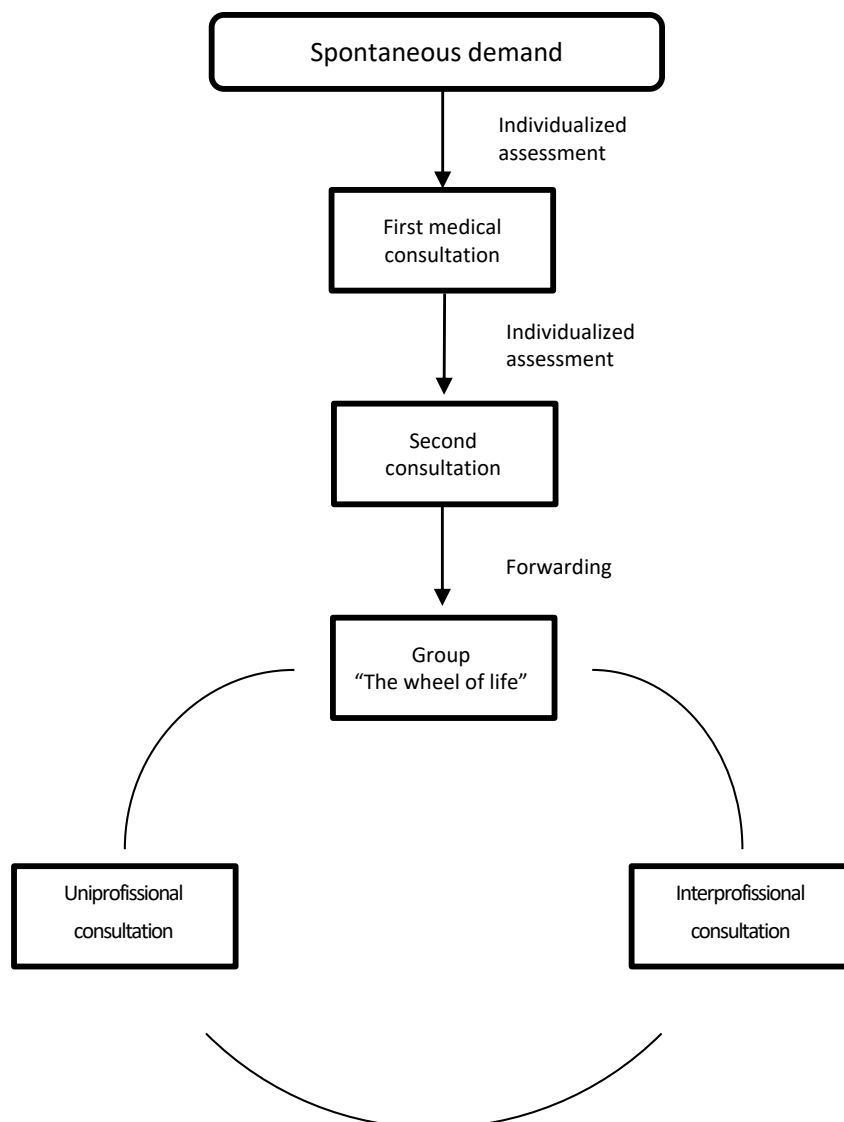


Figure 1. Flowchart of the Manto Project of Assistance in Palliative Care in Primary Health Care. Authors' data.

Chart 3. Description of the underlying pathologies found in users included in the implementation phase of the Manto Project of Assistance in Palliative Care in Primary Health Care. Authors' data.

Underlying pathology	Number of users
Pancreatic cancer	1
Vascular dementia	1
Alzheimer's disease	1
Multiple myeloma	1
Multiple sclerosis	1
HIV infection/AIDS	2
Non-progressive chronic encephalopathy	1
Breast cancer	2
Cervical cancer	1
Chronic myeloid leukemia	1

opioids for pain control and laxatives for the treatment of constipation, both common symptoms in PC; sparse dialogue and obtaining counter-reference of medium and high complexities for the PHC team and unavailability of DO for that team. In these situations, doctrinal principles of the SUS,²⁵ such as equity in health care and comprehensive care, were called into question. Thanks to the hard work that produced and consolidated bonds, the team and the assisted community were partners in the dialogue with the local management with the aim of resolving arguments in a sustainable way for the system, resulting in achievements such as the availability of DC in the unit under the responsibility of the team physician and guaranteed flow for the dispensing of laxative drugs such as bisacodyl and lactulose in the unit.

The bureaucratic hurdle determined by the Clinical Protocol and Therapeutic Guidelines for Chronic Pain,²⁶ published by the Ministry of Health in 2012, must be pointed out to access to medicines such as morphine, methadone, gabapentin and codeine through the Specialized Component of Pharmaceutical Assistance. As the funding of the latter is the responsibility of the states, the respective health departments restrict access to medication to those with only two codes in the International Classification of Diseases (ICD-10), R52.1 (i.e., intractable chronic pain) and R52.2 (i.e., other chronic pain), with prescription made by SUS health units that “meet the specialty corresponding to the pathology” mentioned. Thus, inconsistency arises due to confusing interpretations of this specialty, which may include anesthesiology, rheumatology, clinical oncology or geriatrics in the state of Pernambuco, excluding family and community medicine (FCM) from this list. Taking into account the central role of FCM in the management of personal care and the difficulties related to the dialogue between PHC and specialized care and access to the latter, this inconsistency limits a better management of chronic pain situations (often related to the cancer) in the PHC by the family and community doctor.

The Manto Project impacted the work and care reality of more than one family health team; it promoted and reinforced links between individual/family care units with the teams and consolidated itself as a good practice and successful experience in PHC, in the SUS, challenging the reality of the interior of Northeastern Brazil in the context of economic crisis, weakness in the training of professionals and in the continuing education of health care workers. Emphasizing the component of interdisciplinary and community teamwork developed throughout the initiative, new studies can consider this experience as a starting point for structuring the provision of palliative care in PHC, especially with the encouragement and strengthening of communities compassionate,^{27,28} empowering patients, family members and other stakeholders to care for people with PC needs. Furthermore, this experience can and should be replicated in other PHC contexts with a view to increasing the supply of PC in these scenarios. Additionally, studies can assess the perceptions of users and professionals about the care proposal, as well as its impact on the quality of life of patients and families.

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CONFLICTS OF INTEREST

None to declare.

AUTHORS' CONTRIBUTIONS

AGCF: Project administration; investigation; writing – first draft; validation.

AFS: Project administration; formal analysis; conceptualization; writing – editing and proofreading.

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