Vol.65: e22210615, 2022
https://doi.org/10.1590/1678-4324-2022210615
ISSN 1678-4324 Online Edition

Article - Human and Animal Health

Overview of Perinatal Palliative Care in Brazil

Mario Cezar Saffi Junior[1]
https://orcid.org/0000-0002-4703-641X

Ana Maria Silveira Machado de Moraes[2]
https://orcid.org/0000-0001-8708-3125

Giovani Marino Favero[3*]
https://orcid.org/0000-0002-1946-3262

[1]State University of Ponta Grossa, Pharmaceutical Sciences Graduate Program, Ponta Grossa, Paraná, Brazil; [2]University Center of Maringá, Department of Medicine UNICESUMAR, Maringá, Paraná, Brazil; [3] State University of Ponta Grossa, Departament of General Biology, Ponta Grossa, Paraná, Brazil.

Editor-in-Chief: Paulo Vitor Farago
Associate Editor: Sinvaldo Baglie

Received: 30-Sep-2021; Accepted: 08-Nov-2021.

*Correspondence:gmfavero@uepg.br; Tel: + 55 42 3220-3002 (G.M.F.).

HIGHLIGHTS

- Palliative care in terminally ill patients has only been effective recently in Brazil.
- Fetuses or neonates unable to curecare received attention in 2017.
- Brazilian women´s characteristics directly influencing perinatal palliative care.

Abstract: Significant attention to palliative care in terminally ill patients has only been effective in Brazil since the year 2000, although there have been isolated actions since the 1980s. When the case involves fetuses or neonates unable to cure, communication and care with the family members only received attention and effective organization starting in 2017. Notably in the years 2015 and 2016 there was an epidemic of microcephaly and along with the persistent crisis of drug users has raised the indices of malformations to a level higher than 3 % of the world average. Here we aim the evaluation of: a) social, educational and spiritual profile of the mothers; b) structure of the specific teams related to palliative care in neonatology; c) recommendations and protocols currently used in the country. The method used is an electronic retrospective on databases and government data; evaluation of the location and composition of palliative care teams in the country. The data found clearly point out that for Brazilian women, the characteristics of regionality in the country, educational level, religiousness and quality of life directly influence pregnancy and the acceptance or not of the possibility of death, directly influencing perinatal palliative care, which, by the way, is still developing methodologies for this type of action.

Keywords: Palliative Care; Congenital; Terminally ill patients; Neonates unable to cure.

INTRODUCTION

Palliative care aims to improve quality of life of the terminally ill patient and his relatives, the relief of pain and suffering. This requires the early identification of the disease, constant periodic evaluations, treatment of pain and other physical, psychosocial and spiritual problems. This is the basis suggested by the World Health Organization in 2002 [1,2].

In Brazil, although isolated actions have existed since the 1970s, only in 1990 began to appear the first organized centers, mainly related to oncology, and in an experimental way. The first known action was at the Escola Paulista de Medicina, pioneered by Dr. Marco Figueiredo and, at the same time, at the National Cancer Institute (INCA), which in 1998 inaugurated a specific ward for Palliative Care. Later came the services of the Municipal Public Hospital of São Paulo, in the early 2000s.

An important factor for the growth of palliative care in the country was the founding of the National Academy of Palliative Care in 2005. The professional union around the same object was fundamental to promote quality and implement criteria for Palliative Care services. With the growth of the Academy, its relationship with the Ministry of Health, Ministry of Education and Federal Councils of health professionals has vastly expanded this type of service throughout Brazil.

Currently in Brazil there are approximately two hundred centers with some type of section related to Palliative Care, a number that was formed, practically, in the last decade. There is still a deficiency in the training of health professionals in Palliative Care, with little offer of specialization courses, postgraduate courses and residencies in this area.

In the case of palliative care in fetal medicine only in the last two years has been observed the implantation of the activity in this type of segment [3].

The contradictory complexity involved in the discovery of fetal malformation makes the need for a multidisciplinary team, differentially prepared, to be able to perform actions effectively. Pregnancy is usually associated with an expectation of joy, continuity and fulfillment. The moment of discovery of a serious problem in the formation of the future baby, associated with the corporal, hormonal, emotional and social changes of the mother makes the challenge of palliative care greater. Most fetuses with malformations diagnosed in Brazil are carried to term mainly due to late diagnosis, legal restrictions and personal choice [4,5,6].

The Brazilian health network still suffers from high neonatal mortality due to situations that could prevent deaths. Pilgrimage of pregnant women for childbirth, birth of children weighing less than 1.5 kg in hospitals without neonatal ICU, intrapartum asphyxia and late prematurity are still part of the local reality [7,8].

Changes in the socio-family profile are faster than the evolution / adaptation of health systems. The Brazilian family today is formed by an average of 3.8 people per household, with an average of 2.7 children per couple. In relation to schooling, 65% have the average level of study and only 15% are graduated. Alterations in the female profile is what draws the most attention. The Social Indicators Synthesis (SIS) of the Brazilian Institute of Geography and Statistics (IBGE) showed that: 38.4% of the female population between 15 and 49 years do not have children and maternity has been postponed. An important factor in these analyzes is that 87% of the Brazilian population condemns abortion, and 82% of the family members would support pregnancy in any situation [12,13]. Thus, there is a complexity of factors that shape Brazilian pregnant women, and this is an important factor for the effectiveness of actions in Neonatal Palliative Care.

The need for palliative care in neonatology is evident all over the world, also in Brazil, due to its particularities, such as the extension of the territory, logistics, regional structure, income distribution, education and the low existence of specialized centers. The objective of this paper is to describe the: a) social, educational and spiritual profile of the mothers; b) structure of the specific teams related to palliative care in neonatology; c) recommendations and protocols currently used in the country.

MATERIAL AND METHODS

The method applied is an integrative review. Ratislavová et al. (2019) and Whittemore and Kanfl (2005) [14-15] and non-experimental studies and providing a broad understanding of a given subject. Data are being collected from primary articles available in scientific databases conducted across Medline/Pubmed, Scielo, SCOPUS, Science Direct, Web of Science and Wiley; and government databases published from 2003 to February2nd, 2021.

Initially, the first step was to identify the problem, with extensive discussion in the work team. Then, a vast mapping of works related directly or indirectly to the subject is being carried out, aiming at combining the empirical and theoretical literature in order to identify the knowledge gap related to palliative care in neonatology, theory review and methodological evaluations, as well as definition of concepts from the data.

The paperwere selected with an initial focus on the general history of the study in palliative care in Europe, the United States and Brazil, followed by the search for the description of specific centers for Neonatology applied to palliative care. The other researched works were to generate a comparative evaluation in face of the data found and tabulated on the specific Brazilian characteristics objectified in our work.

Numerical evaluation of the relationship between selected variables such as gestational age, mother's age, malformation, human development index, presence of general palliative center was carried out from government bases such as the Brazilian Institute of Geography and Statistics (IBGE), Ministry of Health, National Academy of Palliative Care and other works in Portuguese.

The evaluation of the palliative care groups, their composition and the basic protocols were carried out through searches on sites such as the National Academy of Palliative Care, and individualized communication with each center registered in one of these locations.

The third step was the evaluation of the data found, followed by the analysis, which is the fourth step described in the integrated review studies. The evaluation was predominantly quantitative, comparing the data collected from the government databases in relation to the selected articles. The final step is the synthetic presentation of the the whole study.

The project was approved with the CAAE identification number: 30323219.0.0000.5539.

RESULTS

The presence of Palliative Care Centers is directly proportional to the Human Development Index (HDI), economic prosperity of each region, consequently, which have more inhabitants and doctors.

Table 1 shows that the richest region of the country, the Southwest, has the largest number of inhabitants, doctors and palliative care centers. In this table we can reinforce this relative proportionality of urbanization, HDI, doctors and palliative care centers, being the North region the most economically fragile and, consequently, with less medical assistance. The data were compiled after a survey conducted with information from the Brazilian Institute of Geography and Statistics and the National Academy of Palliative Care.

Table 1. Number of Palliative Care Centers, Inhabitantes and its proportion by Brazilian regions.

Regions	Palliative Care Centers (n)	Inhabitants (Million)	Inhabitantes/Palliative Care Centers	Inhabitants/physitian	Human Development Index
South	39	28	718000	445,4	0,754
Southeast	105	81	771500	353,3	0,766
North	06	16,3	2716666	953,3	0,667
Notheast	39	53	1360000	749,6	0,663
Midwest	11	14,5	1318000	474,4	0,757

The composition of the health professionals of each Palliative Care Centers is shown in Table 2. As expected, all the teams evaluated presented doctors, nurses and psychologists. Among other health professionals, physiotherapists appear more frequently. The information was obtained after research on the website of several institutions that are registered with the National Academy of Palliative Care, when the characteristics of each group was not available on the website, contact was made to obtain them.

Table 2. Composition of the health professionals Palliative Care Centers by Brazilian regions.

Health professionals	South	Southeast	Midwest	North	Northeast	Total
Doctors	100%	100%	100%	100%	100%	100%
Nurses	100%	100%	100%	100%	100%	100%
Physiotherapists	63%	75%	71%	39%	54%	64%
Nutritionists	56%	61%	48%	48%	50%	58%
Social workers	100%	100%	96%	88%	90%	98%
Psychologists	100%	100%	100%	100%	100%	100%
Speech therapists	28%	27%	25%	11%	15%	21%
Pharmacists	21%	45%	37%	11%	15%	38%

The presence of specific centers for palliative care in neonatology in Brazil is still recent, but the need is urgent, if we take into consideration, initially, the profile of the Brazilian mother, who despite being in clear social evolution, still has low levels of education and gender equality. Table 3 shows the profile of Brazilian women mothers, their education level and the number of children they have.

Table 3. Education level and the number of children of the Brazilian´s mothers profile.

Schooling among Brazilian women	Percentage	Children (n)
Higher Education Complete	12,5	1,14
Complete primary education	25	1,34
Elementary school complete and incomplete high school	14	2,54
No education and incomplete elementary school	47,8	3,09

The level of educational attainment has a clear effect on the number of children and, also, on the acceptance or not of diseases that have the possibility of an imminent death. The introduction and effectiveness of palliative care in neonatology has a direct relationship in efficiency with schooling.

Another important factor to be considered is religiosity. Brazil, being a multicultural country, has a diversity of beliefs. Tables 4 and 5 shows this religious diversity and the relationship with racial identification, age, sex, education and the region.

Table 4. Religious diversity and the relationship with racial identification, age.

ReligionofBrazilians	Religionby sex	Religionby color	Religionby age
• Catholic: 50%	Catholics:	Catholics:	Catholics:
• Evangelical: 31%	• Women: 51%	• Brown: 41%	• 16 to 24 yearsold: 13%
• No religion: 10%	• Man: 49%	• White: 36%	• 25 to 34 years: 17%
• Spiritist: 3%	Protestants:	• Black: 14%	• 35 to 44 yearsold: 18%
• Umbanda, candomblé orother Afro-Brazilianreligions: 2%	• Women: 58%	• Yellow: 2%	• 45 to 59 years: 26%
• Other: 2%	• Man: 42%	• Indigenous: 2%	• 60 yearsorolder: 25%
• Atheist: 1%		• Others: 4%	Protestants:
• Jewish: 0.3%		Protestants:	• 16 to 24 yearsold: 19%
		• Brown: 43%	• 25 to 34 years: 21%
		• White: 30%	• 35 to 44 years: 22%
		• Black: 16%	• 45 to 59 years: 23%
		• Yellow: 3%	• 60 yearsorolder: 16%
		• Indigenous: 2%	
		• Others: 5%	

Table 5. Religious diversity and the relationship with sex, education and the region

Religionbyeducation	Family Income	Country Region
Catholics	Catholics	Catholics
• Fundamental: 38%	• Upto 2 minimumwages: 46%	• Southeast: 45%
• Medium: 42%	• From 2 to 3 minimumwages: 21%	• South: 53%
• Superior: 20%	• From 3 to 5 minimumwages: 17%	• Northeast: 59%
Protestants	• 5 to 10 minimumwages: 9%	• Midwest: 49%
• Fundamental: 35%	• More than 10 minimumwages: 2%	• North: 50%
• Medium: 49%	Protestants	
• Superior: 15%	• Upto 2 minimumwages: 48%	Protestants
	• From 2 to 3 minimumwages: 21%	
	• From 3 to 5 minimumwages: 17%	• Southeast: 32%
	• 5 to 10 minimumwages: 7%	• South: 30%
	• More than 10 minimumwages: 2%	• Northeast: 27%
		• Midwest: 33%
		• North: 39%

The causes of stillbirths in Brazil show that the sum of socioeconomic values influences this type of death. The social difference is clear when we find that the causes of death are more directly associated with the mother. Table 5 shows data from the Brazilian National Health System with the deaths during the gestational period in 2014.

Table 6. Causes of stillbirths in Brazil.

Cause of Stillbirth	
Congenital syphilis	0.70%
Affections of the mother	12.13%
Maternal complications during pregnancy	3.77%
Complications of the placenta, umbilical cord or membranes	17.24%
Child-birth complications	1.25%
Intrauterine hypoxia	22.71%
Fetal death without a definite cause	20.76%
Affections in the perinatal period	2.73%
Other causes	18.72%

DISCUSSION

In the United States there are about 212 Perinatal Palliative Care Programs, of which only 25% are part of Fetal Diagnostic Center Programs [16]. In Brazil, until 2017 there was no record of a specific palliative care center for neonatology. Today the most qualified urban centers have adaptations in their palliative care centers for this situation. The number of fetal malformations in Brazil is higher than the standard of 3% of European ref countries as seen in Table 5, making clear the helplessness of families.

The large number of newborns with malformations found in Brazil contrasts with the low number of palliative centers specialized in fetal medicine. Table 1 shows an average proportion of one Palliative Care Center in Neonatology for every 964 thousand inhabitants. It should be noted that places with these specific characteristics started to exist a little over three years ago in Brazil. The creation of organizations for the attempt of uniformity are older than the centers themselves.

As expected, the number of children is proportional to the mothers' education level. Table 3 exemplifies this pattern found in Brazil and other emerging countries in Latin America. Table 4 assesses religiosity in the country, and the majority, greater than 95% of the population, has some type of belief. Thus, the acceptance of the malformation / death ends up being related to this important aspect.

Relating the number of children, the mother's schooling and regalia, this sum is important for the definition of the aid strategy for families that will go through the process of accepting the imminent death of such a young relative.

Spirituality and religion are part of the Brazilian life, studies show a small percentage of atheists and agnostics in the country. Christian religions are the most prevalent, as seen in Table 4. According to some studies, spirituality and religion are important for the hope and acceptance of the end of life, directly influencing people's physical and mental capacity. Most works related to spirituality and palliative care are focused on elderly or adults with terminal illnesses. A recent Danish study addresses the relationship between parent´s religious / spiritual beliefs after pregnancy or neonatal loss. The work noted that women tend to report more to spirituality and religiosity than men in an eminent crisis. Part of the response to death during pregnancy or neonatal death is supported by religion / spirituality, and, in this study, part of those evaluated demonstrated questions of faith after death.

In addition to the beliefs, the educational level is important for the strategy to be used in the comfort and acceptance of the end of life in neonatology. Table 3 shows the number of children per mother and their level of education. As in most countries, the lower the individual education, the greater the number of children and, consequently, the more educated women have fewer children, usually one. The country also has a large number of teenage mothers, similar to other countries in Latin America. Thus, the most likely scenario to be faced by the palliative care team in neonatology is a pregnancy or baby with little life expectancy for a young mother, with little educational instruction and religious belief.

A research group from the Federal University of Santa Catarina proposed a hierarchical model for fetal death in Brazil: 1) Distal factors related to socioeconomic demographic conditions, skin color, socioeconomic score, education, marital status and maternal age; 2) Intermediates, which include maternal biological characteristics, morbidity, diabetes, syphilis and hemorrhage in the third trimester of pregnancy, behavioral such as smoking and alcoholism, reproductive with previous deaths and nuliparity; 3) Proximal, involving prenatal care, prenatal adequacy, pilgrimage, fetal malformations [17].

The specialized locations, including the Palliative Centers in Neontaology, have a basic, core, standard of professionals, with the doctor, nurse, psychologist and social worker in all consulted. The presence of other professionals such as nutritionist, pharmacists, physiotherapists and speech therapists, among others, is conditioned to the size of the center and, especially the wealthiest regions of the country. This basic composition of Palliative Care Centers is similar around the world. The suggestive pattern for palliative care centers in neonatology could follow the guidelines of San Diego (California-USA), with a multiprofessional team, with nurses, social work, chaplaincy, doctors, who routinely make home visits to family members. Aspects of this center should consider: 1) Establishing eligibility criteria for palliative care; 2) Evaluation and action in family care; 3) Documentation and communication; 4) Pre-birth care (individual assessment of each family member involved and special focus on the mother); 5) Transition from postnatal care to palliative care; 6) End of care; 7) Support after the end of palliative care [18-20].

The presence of the Palliative Care Centers in Neonatology is directly related to economic capacity, human development index, and, in Brazil, the presence of medical schools plays an important role in this concentration. The country as a whole has an average of 1.92 doctors for every 1000 inhabitants, however, northern states, such as Amapá, have an average of 0.76 / 1000 and the state of Rio de Janeiro has a concentration of 3, 57/1000 inhabitants.

This evaluation shows a brief but updated overview of the conditions of Brazilian pregnant women who may need perinatal palliative care in a country that is still developing methodologies for this type of action, relating local characteristics.

Conflicts of interest: The authors declare that they have no conflict of interest.

REFERENCES

1. Organization WEC on CPR and ASC; WH. Cancer pain relief and palliativecare : report of a WHO expert committee. World Heal Organ [Internet]. 1990; Available from: http://www.who.int/iris/handle/10665/39524
2. Morita T, Akechi T, Sugawara Y, Chihara S, Uchitomi Y. Practices and Attitudes of Japanese Oncologists and Palliative Care Physicians ConcerningTerminal Sedation: A Nationwide Survey. J Clin Oncol [Internet]. 2002 Feb 1 [cited 2019 Jan 22];20(3):758–64. Available from: http://www.ncbi.nlm.nih.gov/pubmed/11821458
3. Bernardes LS, De Almeida Jesus RC, Oliveira FF, Guerra Benute GR, Gibelli MABC; Bertolassi Nascimento N et al. Family Conferences in Prenatal Palliative Care. J Palliat Med; 2020 Oct. 23(10):1349-56.
4. De Araújo MMT, Da Silva MJP. Communication strategies used by health care professionals in providing palliative care to patients. Revista da Escola de Enfermagem da USP; 2012 Jun [cited 2019 Jan 30];46(3):626–32. Available from: http://www.scielo.br/scielo.php?script=sci_arttext;pid=S008062342012000300014;lng=pt;tlng=pt
5. Shulth W, Karck U, Wilhelm C, Reisch S. Parents' needs after ultrasound diagnosis of a fetal malformation: an empirical deficit analysis. Ultrasound Obstet Gynecol. 1994;4:124-9. doi: 10.1046/j.1469-0705.1994.04020124.x.

6. Titapant V, Chuenwattana P. Psychological effects of fetal diagnoses of non-lethal congenital anomalies on the experience of pregnant women during the remainder of their pregnancy. J ObstetGynaecol Res. 2015;41(1):77-83. doi: 10.1111/jog.12504.
7. Marçola B, de Barbosa M, Maria S, Polastrini V, Tiziana R, Ceccon J, et al. Revista Paulista de Pediatria. 2017 [cited 2019 Jan 30];35:125–9. doi: 1590/1984-0462/;2017;35;2;00012
8. Lansky Sônia, Friche Amélia, Silva Antônio Augusto, Campos Deise, Bittencourt Sonia, Carvalho Márcia, et al. (2014). Birth in Brazil survey: neonatal mortality, pregnancy and childbirth quality of care. Cadernos de Saúde Pública. 30. S192-S207.
9. De Souza WV, Militão de Albuquerque MFP, Vázquez E, Albuquerque Bezerra LC, Gouveia Mendes AC, Lyra TM, et al. (2018). Microcephaly epidemic related to the Zika virus and living conditions in Recife, Northeast Brazil. BMC Public Health. 18(1):130. Doi: 10.1186/s12889-018-5039-z.
10. MINISTÉRIO DA SAÚDE. Ministério da Saúde confirma relação entre vírus Zika e microcefalia. 2015. http://www.brasil.gov.br/saude/2015/11/ministerio-dasaude-confirma-relacao-entre-virus-zika-e-microcefalia.
11. Braga C, Luna CF, Martelli CMT, de Souza WV, Cordeiro MT, Alexander N, et al. Seroprevalence and risk factors for dengue infection in socioeconomically distinct areas of Recife. Brazil Acta Trop. 2010;113:234–40
12. Estatística, Brasil. (2020). Anuário estatístico do Brasil / Instituto Brasileiro de Geografia e Estatística. SERBIULA (sistemaLibrum 2.0).
13. Ferreira Pombo M. Family, filiation, parenthood: new arrangements, new questions. Psicologia USP 30. 2019 https://doi.org/10.1590/0103-6564e180204.
14. Kateřina Ratislavová, Radka Bužgová, Jana Vejvodová. Perinatal palliative care education: An integrative review. Nurse Education Today. 2019; 82:58-66, ISSN 0260-6917,
15. Whittemore R, Knafl K. The integrative review: updated methodology. J. of Advanced Nursing. 2005;52:546-53.
16. Dost Burhan, Bozkurt Hilmi. Retrospective analysis of inpatients in a recently established palliative care center. Annals of Medical Research. 2019;26(12):2866. Doi: 10.5455/annalsmedres.2019.09.586.
17. Medeiros Vieira MS, Medeiros Vieira F, Frode T, d'Orsi E. Fetal Deaths in Brazil: Historical Series Descriptive Analysis1996-2012. Maternal and child health J.2016; 20(8):1634. https:/10.1007/s10995-016-1962-8.
18. Marc-Aurele K, Hull A, Jones M, Pretorius D. A fetal diagnostic center's referral rate for perinatal palliative care. Annals of Palliative Medicine.2017; 6. 312-312. Doi: 10.21037/apm.2017.03.12.
19. Balaguer A, Martín-Ancel A, Ortigoza-Escobar J, Escribano J, Argemi J. The model of Palliative Care in the perinatal setting: a review of the literature. BMC pediatrics.2012; 25; https:/doi.org/12. 25. 10.1186/1471-2431-12-25.