

Research groups in palliative care: the Brazilian reality from 1994 to 2014

Grupos de pesquisa em cuidados paliativos: a realidade brasileira de 1994 a 2014

Grupos de investigación en cuidados paliativos: la realidad brasileña de 1994 a 2014

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ABSTRACT

Introduction: Palliative care is currently the responsible for rating the quality of a person's life by his health-disease process. **Objective:** To characterize the Brazilian research groups of Palliative Care registered in Directory of Research Groups of the National Counsel of Technological and Scientific Development between 1994 and 2014. **Methods:** A documental research, with a qualitative and exploratory-descriptive approach, using the keyword "Palliative Care", where were found 16 objects of analysis.

Results: The first research group of Palliative Care was created in 1994; there were a significant rose of new groups in the years of 2011 and 2012. The number of research lines of each group varies between two and nine lines. They are distributed in an unequal form among the country regions, 44% were located on Southeast region, followed by 37% on Northeast region, 13% on the Midwest and 6% on the South region. The groups are composed by researchers, technical and students; being students, the majority of these groups' participants. **Conclusion:** In spite of the several analyzed groups, there is a need of a formation of new groups in this unexplored area.

Keywords: Palliative Care; *Academias e Institutos*; Research Groups.

RESUMO

Introdução: Os cuidados paliativos atualmente são responsáveis por qualificar a qualidade de vida da pessoa diante do processo de saúde e doença. **Objetivo:** Caracterizar os grupos de pesquisa brasileiros em Cuidados Paliativos cadastrados no Diretório de Grupos de Pesquisa do Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq) entre 1994 a 2014. **Métodos:** Pesquisa documental, qualitativa, exploratório-descritiva, com a palavra-chave "Cuidados Paliativos", onde foram encontrados 16 objetos de análise para esse estudo. **Resultados:** O primeiro Grupo de Pesquisa em Cuidados Paliativos foi criado em 1994, havendo um aumento significativo grupos nos anos de 2011 e 2012. O número de linhas de pesquisa de cada grupo varia entre duas e nove linhas. Estão distribuídos de forma desigual nas regiões do país, 44% estão localizados na região Sudeste, seguido de 37% na região Nordeste, 13% Centro-oeste e 6% na região Sul. São compostos por pesquisadores, técnicos e estudantes, sendo estes a maioria dos participantes. **Conclusão:** Apesar de haver analisado vários grupos, ainda existe uma necessidade de formação de novos Grupos nesta área pouco explorada.

Palavras-chave: Cuidados Paliativos; *Academias e Institutos*; Grupos de Pesquisa.

RESUMEN

Introducción: Los cuidados paliativos actualmente son los responsables por la calificación de la calidad de vida de una persona delante su proceso de salud-enfermedad. **Objetivo:** Caracterizar los grupos de investigación brasileños Cuidados en el Paliativos registrados en Directorio de Grupos de Investigación del Consejo Nacional de Desarrollo Científico y Tecnológico (CNPq) entre 1994 y 2014. **Métodos:** Investigación documental, cualitativa, exploratoria-descriptiva, con la palabra-clave "cuidados paliativos", donde fueron encontrados 16 objetos de análisis para la contemplación de este estudio. **Resultados:** El primer grupo de investigación en cuidados paliativos fue creado en 1994, con un aumento significativo de nuevos grupos en 2011 y 2012. El número de líneas de investigación de cada grupo varía de dos a nueve líneas. Están distribuidos de forma desigual en las regiones del país, el 44% se localiza en el sureste, seguido de un 37% en el Nordeste, el 13% del Medio Oeste y el 6% en el Sur. Son compuestos por investigadores, técnicos y estudiantes, que son la mayoría de los participantes del grupo. **Conclusión:** A pesar de los diversos grupos analizados, hay una necesidad de formar nuevos grupos en esta área poco explorada.

Palabras clave: Cuidados Paliativos; *Academies and Institutes*; Grupos de Investigación.

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INTRODUCTION

With the prolonged life expectation and the aging of the population, the profile of diseases changes considerably, prevailing the chronic diseases. The majority of these diseases is related to the loss of functionality compatible with the physiology, resulting in a loss of force, vigor and systemic reactions. Less than 10% of the population of 65 years of age or over is free from chronic hindering, whereas more than 10% relate a medium of five simultaneous chronic diseases¹.

The Brazilian Institute for Geography and Statistics (IBGE) presented on national level data counting 23 million aged persons, representing 11.8% of the Brazilian population. Life expectation raised to 74 years, varying between women (77.7 years) and men (70.6 years)².

Health assistance services do also feel this panorama of transformations. The hospitals attend more and more clients depending on comfort care, be it for being at a terminating stage or for being bearer of a life ending disease without cure. The challenges in care providing interfere with the performance of health professionals who, besides scientific knowledge, have to rethink their attitude towards human mortality and delivering care with dignity³.

Preoccupied with this global scenario, the European Association for Palliative Care (2013)⁴ presents the Palliative Care as strategies to improve the quality of life of aging persons and their families, approaching the problems associated with the life-threatening diseases preventing and alleviating sufferings through early identification and scrupulous evaluation of pain and other physical, psychological, social and spiritual problems.

Palliative Care is commonly associated with oncology although it may be attributed to any terminal situation. This fact correlates to the statistics of 70% of the diagnosed patients with cancer being about to die of the disease that is accompanied with much suffering. Within this estimation, there are 7,000 services of Palliative Care in over 90 countries, whereas Brazil counts only 40 centers specializing in this therapy. Evaluations are that until 2020 approximately 15 million persons will be diagnosed, requiring an expansion of Palliative Care⁵.

Palliative Care originates in the hospice movement systemized by Cecily Saunders and collaborators who represent and divulge the philosophy of care as opposite to the centralized vision of curing. Cecily Saunders is responsible for the foundation of St. Christopher's Hospice in 1967, an environment that permitted children to a place of care, study and research in the analysis of painful experiences of over a thousand patients, treating them with effective pharmaceutical resources together with socio-psychological and spiritual support resulting in an improvement of quality of life in a terminating process. The essence of the significance of the philosophy of Palliative Care may be understood through one of its famous phrases:

I care because you are you, I care until the last moment of your life and we will do everything we can, not only to

help you die in peace, but also to help you live until your dying day⁶.

The World Health Organization defined the concept of Palliative Care in 1990 and redefined it in 2002 aiming to emphasize the prevention of suffering:

An approach to improve the quality of life of patients and their families faced with problems associated with life-threatening diseases by means of prevention and alleviation of suffering by means of early identification, correct evaluation and treatment for the pain and other problems of physical, psychosocial and spiritual order⁷.

Palliative Care is associated with patients of neoplasia or other chronic degenerative disease like dementia, Parkinson, heart failures, renal failures and chronic obstructive pulmonary disease, especially when there is no expectation of curing. It is a working model that is not focused on the disease but on the patient within his history of life and family, from the process of falling ill until death. It promotes psychological, social and spiritual comfort. The movement for Palliative Care initiated in Brazil in the 1980's the first services being organized in Rio Grande do Sul, São Paulo and Santa Catarina⁸.

Records of the Brazilian National Academy for Palliative Care (ANCP) show a surging of Palliative Care in the 1980's and a significant growth from the year 2000 with the consolidation of existing services and the foundation of others⁹.

In 1983 the WHO together with the Cancer Committee creates a research team to define politics of pain control and hospice care that should be references for all the world⁹.

Palliative Care, in a national setting, gains importance in October of 1997 with the foundation of the Associação Brasileira de Cuidados Paliativos (ABCP) This association was founded by a group of professionals already realizing palliative actions trying to divulge the philosophy of the care, join the services and improve knowledge of the thematic, be it in the context of internalization, ambulatory or at home already existent in Brazil¹⁰.

Based on the European Association for Palliative Care, the Brazilian Association devolved its statute adapted to its national reality where the objectives are: providing the scientific and professional vehicle between those practicing and studying disciplines related to caring of chronic degenerative illnesses in advanced and terminal stages; improve the quality of services delivered; foment research; develop and council curricular and academic programs in the health area; promote the quality of life of the sick at different levels of attention and study and discuss ethic problems and their implications for the Palliative Care practice¹¹.

The Ministry of Health recognizes the need for Palliative Care and pain control for the health problems within the Brazilian population. To this end, it published Decree GM/MS nº 19, of 03 January 2002, establishing the National Program for Assistance for Pain and Palliative Care, causing broader discussions of the thematic and capacitating professionals. It also revises adequate

attitudes towards care of patients with chronic degenerative diseases or in a life-terminating phase. On national level, various studies and initiatives alert to the importance of Palliative Care on all levels of health attention¹².

The philosophy of Palliative Care seeks to integrate death into life and opposes the therapeutic obstinacy and the idolatry culture of biological aspects. It does aspire to neither speed up nor delay death, but seeks to relieve pain and other symptoms, integrating social and psychological aspects of care. As it offers strategies to patients to live an active life until death, approximating the family and offering support for them to deal with the disease and the mourning⁶.

Recognizing the importance of this philosophy for the care of the human being in all the completeness of its life, and the need for expansion of produces knowledge, it is justified to study the actual relevancy of the theme in national and international settings. Research groups are understood to be science developing strategies for innovation and technology with ethical-social compromises. This reflects in the improvement of quality of life of society through responsible professional practices, especially those in health areas.

Thus, the choice of data search in the Directory of Research Groups by the National Council for Scientific and Technological Development (CNPq) as field for study justifies itself for containing actualized information on research groups active throughout the country. It presents data with respect to human resources (researchers, technicians and students) to lines of research and specialties, as well as presenting the institution to which the group pertains and its geographical localization. The Directory of Research Groups aims to favor the interchange of information and knowledge produced by the scientific community in a non-exhaustive, agile and precise manner. Besides serving as a means of communication, the Directory of Research Groups is an excellent tool used for the planning and managing of activities in the area of science and technology, as well as responsible for the preservation of the history of research in Brazil¹³.

We corroborate with researchers who confirm that the Research Groups are instruments that qualify the institutions with scientific and technological subsidies, to attend to the demands of the historical and social context to which it is inserted. It permits amplification of the possibilities of production by the researches as is incentivizes insertion of new integrant as from graduation, favoring their permanence through scholarships for productivity and scientific initiation. This research space collaborates with the integration between researchers, students and community¹⁴⁻¹⁶.

The study had the objective of characterizing Brazilian research groups on Palliative Care registered in the Directory of Research Groups by CNPq in the period between 1994 and 2014.

METHODS

The study at hand is documental, qualitative, explorative-descriptive, realized through parameterized procurement in the Directory of Research Groups in Brazil by the CNPq. This Directory contemplated the inventory of active national Research

Groups, containing information on participating human resources of the Groups (students, technicians and researchers), the lines of current research, specialties of knowledge, scientific, technological and artistic production in Brazil¹⁷.

The starting point of the historic excision of the study with the year 1994 is justified since it was the year of the first register of de Research Group in the area of knowledge of Palliative care in the CNPq research directory. We choose as ending date July 2014 with the idea of contemplating growth and development of the theme until the present day.

The study was realized from May to June 2014, localizing 29 Research Groups. Of those 13 Research Groups were excluded as 12 groups were certified as "Not Actualized for over twelve months" furnishing data on divergent researchers and students in the field of indicators of human resources of the Group and one of the Research Groups had a duplicate entry, being counted only once. For the elaboration of this study, 16 Research Groups were objects of analysis.

To localize the Research Groups we used the link "Search Groups" entering the keyword "Palliative Care". Following research field were selected: consult by group, group name, name of research line and keyword from the research line.

To reach the study's objective, found results were organized in Excel 2007 and following date of the 16 Groups were analyzed: institute to which it pertains, year of registration in the Directory, number of lines of research, number of technicians, students and researches with respective titles, confirmation of certified (actualized) Group. Analysis of data was carried out through statistical tabulation resulting in the construction of graphics and tables allowing a better visualization of the discussion and results of the study.

Since this is a documental study in the CNPq Directory of Research Groups whose available contents are public domain, this study did not need to be submitted to the Committee on Ethics for Research with Human Beings. The researches however followed all ethic prescriptions developing the study, analysis and divulgation of the results¹⁶.

ANALISIS AND DISCUSSION OF DATA

Analyzed data state that the first RG (Research Group) on Palliative Care was created in 1994 and titled "Pain Symptoms Control and Palliative Care, pertaining to the University of São Paulo (USP) As can be observed in the Table 1, only five RG were created from 1994 to 2009. Nevertheless, as from 2010 we verify a considerable growth with the emerging of 11 new Groups with a major concentration of registrations between 2011 and 2012. This fact may be related to emerging expansion politics of higher education in Brazil, occurring over the last decade¹⁸.

The research groups contribute to the organization an operationalization of the production of knowledge and favor the discussion between specialist of different areas on the same thematic. Relating to palliative care, the RG promote the deepening and articulation of the philosophy with the practice of concrete new forms of care as well as reflect on the end of life and

Table 1. Number of RG on Palliative Care by year if register with CNPq, Florianopolis, 2014

Year of register of RG with CNPq	Nº of RG inserted in CNPq
1994	1
1999	1
2004	1
2007	2
2010	1
2011	4
2012	4
2013	1
2014	1

Source: Database from the Directory of Research Groups CNPq, 2014.

the best alternatives for the one being cared of. Corroborating with this affirmation, realized study¹⁹ emphasizes one of the obstacles faced by professionals in the practice of palliative care is the lack of knowledge on this therapeutic modality.

In this sense, the importance of the Research Groups is recognized for the development and formulation of politics to incentivize the improvement of strategies to improve quality of life and support on the moment of death and the dying process.

As referring to the analysis of number of lines in research on Palliative Care, Table 2 reveals that the number of lines varies from 02 to 09, giving a medium of 5 lines of research per Group. Denomination of the lines "representing agglutinating themes of scientific studies founding in investigative tradition where projects originate whose results have mutual affinities"²⁰. This being so, all scientific production by the researchers, students and technicians involved in the Research Groups is directly related to de lines of research instituted by the Group, originating from projects at hand.

This data demonstrates the potential scientific production in Brazil, characterized by the researcher's compromise from his area of knowledge to develop new founded technologies, as well as to the promotion of existing ones.

The research lines of the RG on Palliative Care present an interdisciplinary and multicultural character of the theme, for approaching different disciplines and areas of care as: spirituality, medical science, psychology, sociology, education, and others.

We can also classify the Groups on localization, as shown in Graph 1.

In relation to the institutes to which the groups pertain attention is drawn to the fact that not one research group with a research line was registered in the southern region of the country. In this categorization of the RG we identify that 44% are in the southeastern region and 37% in the northeast, being those the regions with the higher concentration of studies on Palliative Care. This fact may be explained by the southeastern region

represent more than half of the GNP (Gross National Product) of the country inducing a larger concentration of finance for the centers of excellence and human resources²¹.

The growth of the number of RG in the northeast is coherent with the economic growth of the region, as well as being a response to the investments made by the federal government to restructure and expand universities related to the Ministry of Education in regions distant form the principal centers of production of knowledge in the country^{22,23}. Facing this data it is important to underline that the principal scientific event in the area of Palliative Care, the "International Congress on Palliative Care", was realized in 2013 in the state of Pernambuco.

We also observe an uneven concentration of RG in comparison with the northern region (no registered Group), which reveals the difficulties of the expansion of distribution of resources as incentives to research in Brazil, in virtue of the continental dimensions of our country and its regional peculiarities.

The data referring to the distribution of resources by the Coordination of Improvement of Personnel of Superior Level (Capes), over de period 2002 to 2012, demonstrate that the southeastern region received investments of R\$ 5.6 billion, a valor 15% larger that that destined for the other regions. The northern region received the amount of R\$ 370 million, the central eastern region, R\$ 650 million and the northeast R\$ 1.7 billion and the south R\$ 2.1 billion²⁴.

For a better identification of the composition of the RG we present the data in a frame (Table 3) separating the integrands as student, technician or researcher, conforming the registers in the CNPq Directory. Some Groups classify only the Doctors (PhD) as researchers, others consider specialists and Masters (MBA) as well, even if they are still students.

Another important data is the register of the category "technician" in the directory. We observe that the majority of the RG do not have a technician integrating in the group. The absence of this professional may endanger the progress of research activities, since this integrant is recognized as important part in the maintenance of physical resources, as we as the promotion of articulation between education and research²⁵. The role of the technician in the RG varies according to its field of operation and level of education. Activities performed by this professional in the RG are defined as indicated in de Brazilian Classification of Professions¹⁷.

Thus, some RG identify professionals acting in practice as technician, for instance, professionals acting in health service may be Specialists, Masters or Doctors. Other groups consider the professionals that are directly involved in the execution of the research.

It was also identified that the category with the highest number of registers were students. Consulting their curricula, we identify them as graduation and post-graduation students.

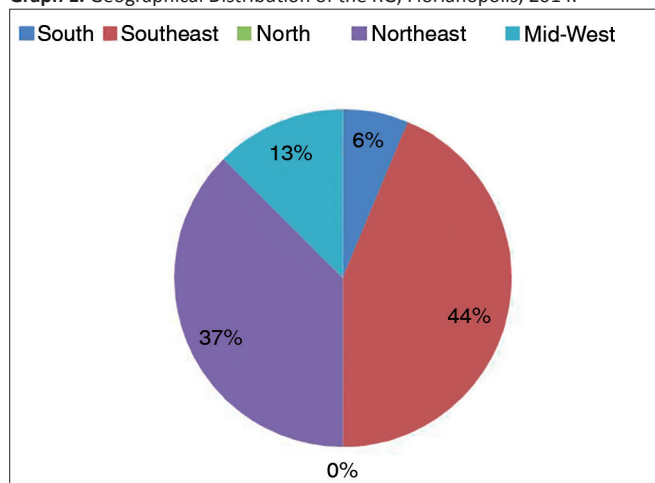
The impressive number of students pertaining to the RG may be related to the progressive augment of Scientific Initiation

Table 2. Number of lines of Research by RG and institutions in Brazil, Florianopolis, 2014

Research group	Nº of research lines	Institution
Pain Symptoms Control and Palliative Care	8	University of São Paulo - USP
Study and Research Group on Phenomenology and Phenomological Psychology	9	Federal University of Maranhão - UFMA
Study and Research Group on Nursing	6	School for Medicine and Public Health of Bahía - EBMSP - Salvador
GEPISE Interdisciplinary Study and Research Group on Health and Nursing	5	Federal University of Campina Grande - UFCG
Interdisciplinary Laboratory for Applied Research on the Clinical Practice in Oncology	4	University of Brasilia - UnB
GPCENF Research Group about Care in Nursing	6	State University of Bahia - UnEB
Interdisciplinary Laboratory for Studies and Research on Health Anthropology	3	Federal University of the State of Rio de Janeiro - UNIRIO
Palliative Care and Quality of Life in Relation to Health	9	Faculty Pio XII - FPXII - Espírito Santo.
Health for the Aged	6	State University of Londrina - UEL
Interdisciplinary Study and Research Group on Oncology	3	Fluminense Federal University - UFF
Technology for Clinical Care of Pain	4	State University of Ceará - UECE
Interdisciplinary Nucleus HRAN	5	High School of Health Sciences - ESCS - Brasília
Laboratory for Thanatology and Psychiatry in other Medical Conditions	5	Federal University of Rio de Janeiro - UFRJ
GECEM - Study Group about Care in Nursing	6	Federal University of Bahia - UFBA
Dead, Terminality of Life and Human Development	2	Federal University Juiz de Fora - UFJF
NIPPEL - Interdisciplinary Nucleus on Research on Loss and Mourning	4	University of São Paulo - USP

Source: Database from the Directory of Research Groups CNPq, 2014.

Graph 1. Geographical Distribution of the RG, Florianopolis, 2014.



programs in Brazil and of stricto sensu post graduation in the country. These programs incentivize youth to research at the level of specialization, master and doctor, the formation of new researchers contributing to technological and scientific advance of the country²⁰. In the area of nursing, for instance, there are presently 98 programs of post-graduation in nursing, representing a growth of 251.28% as from 2010 when there were only 39 RG.

The researchers represent the base of educational support. Guarantee an elevated level of qualification of the research, which is fundamental for the scientific and technological development of the country. According to the titling registers of researchers registered in the CNPq Directory, we identify the majority as being doctors, followed by masters as can be seen in Graph 2.

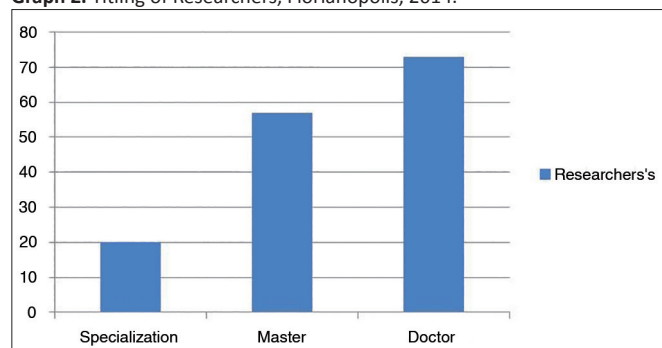
The census realized by CNPq in 2014 shows that the number of researchers active doctors in the country represent 65% of the total of researchers registered in Brazilian RG. To Elizabeth

Table 3. Integrant in Research Groups, Florianopolis, 2014

Research group	NE	NT	NP
Pain Symptoms Control and Palliative Care	6	0	3
Study and Research Group on Phenomenology and Phenomological Psychology	12	0	14
Study and Research Group on Nursing	55	0	22
GEPISE Interdisciplinary Study and Research Group on Health and Nursing	7	0	15
Interdisciplinary Laboratory for Applied Research on the Clinical Practice in Oncology	7	3	9
GPCENF Research Group about Care in Nursing	19	0	11
Interdisciplinary Laboratory for Studies and Research on Health Anthropology	4	0	7
Palliative Care and Quality of Life in Relation to Health	13	0	14
Health for the Aged	1	0	7
Interdisciplinary Study and Research Group on Oncology	12	0	9
Technology for Clinical Care of Pain	19	0	5
Interdisciplinary Nucleus HRAN Medicine ESsC	5	0	10
Laboratory for Thanatology and Psychiatry in other Medical Conditions	16	1	4
GECEM - Study Group about Care in Nursing	17	0	8
Dead, Terminality of Life and Human Development	13	0	5
NIPPEL - Interdisciplinary Nucleus on Research on Loss and Mourning	11	1	7
Total	215	5	150

NE: Number of students; NT: Number of technicians; NP: Number of researchers. Source: Database from the Directory of Research Groups CNPq, 2014.

Graph 2. Titling of Researchers, Florianopolis, 2014.



Balbachevsky (professor of the Faculty of Philosophy, Literature and Human Sciences at São Paulo University, researcher in the area of science and innovation) much of these new doctors conclude their study and continue with science, creating new research groups in institutions that did not have a research tradition²².

Participation of students at master and doctor levels in the research groups is important as they are to be the new researchers of the group and the relation of the members shows an intense production of the group. Besides, the area of palliative care is in expansion in Brazil and needs new professionals interested in acting in care, education, research and extension.

Research has a fundamental importance in the development of practices and new technologies of care, besides the exploration of new themes of interest for this area. Scientific

production assists in the dissemination of information and understanding of various themes.

FINAL CONSIDERATIONS

The presented results permit us to know and characterize the Research Groups for Palliative Care existent in Brazil and registered in the CNPq Directory. There was an augment in the number of RG on Palliative Care registered in the CNPq over the last decade, although uneven spread over the various regions of the country, with registered groups, which leads us to think there is a need for better financial and technical incentives for the expansion of a uniform spread of the groups over the whole of Brazil.

Considering the aging population and de emerging of chronic diseases through the augmented life expectation of the population, it becomes necessary to promote and foment the capacitation of human resources in Palliative Care, aimed to promote new knowledge in the various regions of the country with respect to the theme.

We suggest new research considering the scientific production of the Research Groups on Palliative Care, as well as the individual production of researchers involved in the mentioned Research Groups. Scientific research on Palliative Care will permit the expansion of knowledge on the subject and, by consequence of the professionals to be capacitated to realize an attendance of quality conform the developing of care technology.

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