

Original Article

How to Advance Palliative Care Research in South America? Findings From a Delphi Study

Carlos Eduardo Paiva, MD, PhD, Patricia Bonilla-Sierra, MD, Vilma Adriana Tripodoro, MD, PhD, Alfredo Rodríguez-Núñez, MD, Gustavo De Simone, MD, MSc, Liliana Haydee Rodríguez, MD, Edison Iglesias de Oliveira Vidal, MD, PhD, Miriam Riveros Ríos, MD, MSc, Douglas Henrique Crispim, MD, Pedro Pérez-Cruz, MD, PhD, Maria Salette de Angelis Nascimento, MD, PhD, Paola Marcela Ruiz Ospina, MD, Liliana de Lima, MHA, Tania Pastrana, MD, Camilla Zimmerman, MD, PhD, David Hui, MD, MSc, Eduardo Bruera, MD, and Bianca Sakamoto Ribeiro Paiva, PhD

Collaborative Group for the Advancement of Research in Palliative Care in South America (Los PampAS Group) *Palliative and Quality of Life*

Research Group (GPQual) (C.E.P., B.S.R.P.), Barretos Cancer Hospital, Barretos, Brazil; Department of Health Sciences (P.B.S.), Universidad Técnica Particular de Loja (UTPL), Loja, Ecuador; Instituto Pallium Latinoamérica (V.A.T., G.S.), Buenos Aires, Argentina; Palliative Care Program, Faculty of Medicine (A.R.N.), Pontificia Universidad Católica de Chile, Santiago, Chile; Italian Hospital of Buenos Aires (L.H.R.), Buenos Aires, Argentina; Internal Medicine Department, Botucatu Medical School (E.L.O.V.), São Paulo State University (UNESP), Botucatu, Brazil; Departamento de Cuidados Paliativos, Hospital de Clínicas (M.R.R.), Universidad Nacional de Asunción, Paraguay; Hospital das Clínicas, Faculdade de Medicina FMUSP (D.H.C.), Universidade de São Paulo, São Paulo, SP, Brazil; Sección Medicina Paliativa, Facultad de Medicina (P.P.C.), Pontificia Universidad Católica de Chile; Palliative Care Department (M.S.A.N.), Barretos Cancer Hospital, Barretos, Brazil; SES-Hospital Universitario de Caldas (P.M.R.O.), Manizales, Colombia; International Association for Hospice and Palliative Care (IAHPC) (L.L.), Houston, Texas, USA; Department of Palliative Medicine (T.P.), RWTH Aachen University, Aachen, Germany; Department of Supportive Care (C.Z.), Princess Margaret Cancer Centre, University Health Network, Toronto, Ontario, Canada; Department of Palliative Care, Rehabilitation, and Integrative Medicine (D.H., E.B.), The University of Texas MD Anderson Cancer Center, Houston, Texas, USA

Abstract

Context. Progress in palliative care (PC) necessarily involves scientific development. However, research conducted in South America (SA) needs to be improved.

Objectives. To develop a set of recommendations to advance PC research in SA.

Methods. Eighteen international PC experts participated in a Delphi study. In round one, items were developed (open-ended questions); in round two, each expert scored the importance of each item (from 0 to 10); in round three, they selected the 20 most relevant items. Throughout the rounds, the five main priority themes for research in SA were defined. In Round three, consensus was defined as an agreement of $\geq 75\%$.

Results. 60 potential suggestions for overcoming research barriers in PC were developed in round one. Also in Round one, 88.2% (15 of 17) of the experts agreed to define a priority research agenda. In Round two, the 36 most relevant suggestions were defined and a new one added. Potential research priorities were investigated (open-ended). In Round three, from the 37 items, 10 were considered the most important. Regarding research priorities, symptom control, PC in primary care, public policies, education and prognosis were defined as the most relevant.

Conclusion. Potential strategies to improve scientific research on PC in SA were defined, including stimulating the formation of collaborative research networks, offering courses and workshops on research, structuring centers with infrastructure

Address correspondence to: Carlos E. Paiva, MD, PhD, Departamento de Oncología Clínica, Rua Antenor Duarte Villela, 1331, Barretos - São Paulo, CEP 14784-400, Brazil. E-mail: caredupai@gmail.com

Accepted for publication: 21 November 2022.

resources and trained researchers, and lobbying governmental organizations to convince about the importance of palliative care. In addition, priority research topics were identified in the region. *J Pain Symptom Manage* 2022;000:1–10. © 2022 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Key Words

Research, South America, palliative care, barriers, delphi method

Key Message

Priority research topics and a set of potential strategies to advance palliative care scientific research in South America were defined in this Delphi consensus study.

Background

The modern hospice movement, the current origin of palliative care (PC), originated in London (United Kingdom [UK]) under the leadership of Cicely Saunders.¹ In the UK, PC expansion reached a peak in the 1980s, but in the rest of Europe, the peak occurred a decade later. In the US, the number of PC services increased 267% in 20 years (1985 to 2005).^{2,3} The start of PC in South America (SA) occurred only after 1980, and there has been an escalation in the number of specialized services and of health providers in the last three decades;⁴ the growth rate was probably highest after the beginning of the current century. According to the 'Palliative Care Atlas in Latin America' there were only 2.9 PC services per million people in 2021 and almost half of them were located in Chile and Argentina.^{5,6}

In 2015, The Economist Intelligence Unit published, for the second time, a ranking of countries regarding quality of death. Among SA countries, the top ranked in 2015 were Chile (27th) and Argentina (32nd); Uruguay, Ecuador, Brazil, and Colombia were ranked only in 42nd, 39th, 40th, and 68th places among 80 countries, respectively.⁷ Recently, another systematized evaluation on quality of death and dying was conducted. The 81 countries evaluated were classified into categories ranging from A (best) to F (worst). The best SA countries (Uruguay and Colombia) were classified only in category C.⁸

Progress in PC necessarily involves scientific development.⁹ Recently, we identified an annual increase of 14% in the number of scientific publications by researchers from South America over the last 20 years. However, in general, the publications had low potential for scientific impact.¹⁰ Among the studies by SA authors, those highly cited and with the greatest scientific potential were the result of international research collaborations.¹¹ These findings suggest that the conduct of multicenter studies, with greater chance of

funding, in addition to the educational role of international reference centers may be relevant.

The Americas consists of North America, South America, Central America and the Caribbean. South America comprises 12 countries characterized by sharing many similar features in their population, culture, history, language and socio-economic development. South America, with 438 million inhabitants, represents 42% of the total population of the Americas.¹² Considering a total of 2.7 million deaths in 2019 (before COVID-19 pandemic)¹³ and a likely need for palliative care in at least 63% of the deaths,¹⁴ 1.7 million people who died in South America should have benefit from PC. However, according to the World Health Organization, only about 14% of people who need palliative care currently receive it. Much needs to be done to improve the quality of care and expand access to palliative care in this important region of the American continent.

Considering the more recent advancement of PC in SA and the cultural and especially financial characteristics that distinguish countries in SA from other continents, this study aimed to develop a set of recommendations to be disseminated in SA to advance scientific research by conducting a Delphi study.

Methods

Study Type

The Delphi method is an iterative, multi-stage process for developing consensus using at least two rounds of anonymous surveys.^{15,16}

The traditional Delphi Method was conducted to obtain a consensus regarding suggestions for changes to advance PC research in SA. In all rounds, even in those with closed-ended questions, a complementary space was reserved for the experts to provide their opinion and/or suggestions. The researcher who analyzed the answers did not answer the rounds of the study.

The questionnaires were designed to be self-explanatory, without ambiguities or contradictions; moreover, it was not necessary for the experts to do additional investigation to answer the questions. It is important to note that in this type of method the participant's

judgement and not necessarily the knowledge, is the focus of the investigation.

In rounds two and three, the experts received information regarding the aggregated answers from the previous rounds.

Moderators

A group of three researchers analyzed the responses after each round of the survey. One Master's student had the role of cataloging the responses and organizing them into categories or percentages; the other two (BSRP and CEP) had the role of analyzing the results and planning the next round. Comments were compiled, grouped by theme and discussed by the moderator group after each round.

Panel Members

Although a minimum number of participants in a Delphi study is not defined, most studies have used more than 15 to 20 participants per round.¹⁷ Thus, we aimed to have at least 15 respondents for each round.

The panel of experts was formed by individual invitation to join the Los PAMPAS Research Group. The South American members were chosen for their experience and expertise regarding professional policies and/or teaching and/or research in PC. Those individuals with positions as president or vice-president of national professional associations in PC were considered as experts in professional policies. As experts in teaching, we selected individuals who coordinated a PC course with students coming from various South American countries; as an expert in research, we selected individuals with more than 10 scientific publications in PC and at least two of them with international collaborators. The group of South American experts was increased by two participants from outside SA with prior experience collaborating with SA researchers (CZ and DH) so contribute with their external perspective doing research with regional leaders. Three researchers native to SA living in other countries (EB, LL and TP) provided expertise in teaching, research and/or politics. Initially 25 individuals were invited, with 18 members accepting to participate.

Delphi Survey Rounds and Agreement Criteria

Web-based surveys were sent to participants using the SurveyMonkey software (San Mateo, CA, USA) between June 30, 2021 and September 9, 2021. The Delphi study consisted of three rounds separated four to six weeks apart. The duration of each round was three to four weeks. Weekly e-mail reminders were sent to nonresponders.

In a previous unpublished study, we investigated the main research barriers reported by 167 South American PC health care professionals using a validated brief version of the Barriers to Palliative Care Research

Questionnaire.^{18,19} The eight most relevant general barriers (lack of funding, lack of time, lack of trained professionals, lack of research collaborations, lack of representatives in policy and funding agencies, patient recruitment problems, lack of English fluency, and problems with Research Ethics Committees) and two frequently reported individual items (lack of infrastructure and lack of valid health assessment instruments) were considered suitable for Round one, composed with open-ended questions. Furthermore, the experts had the opportunity to add other barriers not included among the open general questions. In addition, a final question asked whether the participant thought it was important to define an "agenda" of topics to be researched as a priority in SA (Supplementary Material 1).

In Round two, all individual responses regarding ways to reduce barriers for PC research were analyzed and organized into individual items with responses ranging from 0 (not at all important) to 10 (extremely important). In addition, a question about the main research topics (in a possible priority research agenda) was included (Supplementary Material 2). Only items with at least 80% of the participants scoring an importance level of eight or more were retained in the survey for Round three.

In Round three, each expert was asked to mark, from the total number of items obtained from round two, the 20 most important. All items contained the percentage of answers from round two that were selected by the Delphi participants (which could or could not be used by the expert to facilitate their response). Items that were considered to be among the 20 most important at least 75% of the time were considered reach consensus. In addition, among the items to be included in the priority research agenda, the evaluators were asked to mark only those they considered most relevant (Supplementary Material three). With regards to that subject, the criterion for consensus was also that items were marked at least 75% of the time (high agreement). A second level of agreement (not initially planned) was added for the priority research themes when there was more than 50% and less than 75% agreement (moderate agreement).

Comments were compiled, grouped by theme and discussed within the moderator group after each round. Descriptive statistics were used to summarize the data. Study data were managed using the Statistical Package for the Social Sciences (SPSS; version 20.0, Chicago, Illinois).

Ethical Aspects and Funding

The present analysis is part of a larger study evaluating barriers to conducting research on PC in SA and mapping the scientific production in PC within the region in the last 20 years (Los PAMPAS Study;

approved by the Research Ethics Committee of Barretos Cancer Hospital under number 1704/2018). This study was funded by the São Paulo State Research Foundation (FAPESP, 2018/09836-8).

Results

From the total of 18 experts, 17 (94.4%), 15 (83.3%) and 16 (88.9%) participated in rounds one, two and three, respectively. Among the 18 panel members, five were Brazilian, five Argentinian, two Chilean, three Colombian, and one Venezuelan; two were born in countries outside South America. Of those born in Argentina, one currently lives in the USA and the other in Paraguay. Among the natives from Colombia, one lives in Germany and another in the USA. Of the 18 members, 11 (61.1%) were selected for the expert panel mainly because of their research activities, 6 (33.3%) because of political activities with the palliative care medical societies, and 1 (5.6%) because of educational activities. Regarding academic background, there were 16 physicians, one nurse, and one clinical psychologist.

From the responses to the open-ended questions in round 1, 60 individual items were created with potential suggestions for overcome research barriers in PC. Also in Round 1, 88.2% (15 of 17) of the experts agreed that it would be important to define a priority research agenda.

In Round two, out of 60 items, the 36 most relevant ones were identified (at least 80% of the experts scoring importance eight or more). Besides these 36 items, an additional item was added, suggested by one of the experts during Round two. [Table 1](#) depicts the 36 items selected in Round two for further evaluation in Round three in order of importance.

In Round three, of the 37 items evaluated, 10 were considered the most important, since in at least 75% of the time they were considered among the 20 most relevant. Among the items with the highest agreement, we can cite "encourage the formation of research networks" (100%); "provide physical infrastructure and human resources to support research development" (100%); "centers of excellence in palliative care could be catalysts for collaborative research networks (94%); "research courses could be offered by regional/national centers of excellence in palliative research" (88%); and "conduct multicenter research" (88%) ([Table 2](#)).

Regarding priority research topics, two levels of agreement were defined. High agreement ($\geq 75\%$ agreed it was a priority topic; five different topics) and moderate agreement ($\geq 50\%$ agreed it was a priority item; eight different topics). Among the research topics with high agreement, symptom control (87.5%),

Table 1
The Most Relevant Suggestions to Overcome Research Barriers from Round 2

Rank	Item	N	% ^a
1	Research courses could be offered by regional/national centers of excellence in palliative care research	15	100
2	Encourage the formation of research networks, including both research experts and junior personnel, in order to train those with less experience	15	100
3	Financially support the creation of academic positions at regional universities to ease the work of researchers	15	100
4	Conduct multicenter research	15	100
5	Train the researchers on how to write research grants	14	93.3
6	Encourage collaborations between clinicians and scientists	14	93.3
7	Facilitate international exchange of clinicians with interest in research between South America and high-income countries	14	93.3
8	Palliative care centers of excellence could be catalysts for collaborative research networks	14	93.3
9	Investment in clinician researchers with interest in palliative care (e.g., career awards) with protected time	14	93.3
10	Provide physical infrastructure and human resources (statisticians, translators, etc.) to support the development of the research	14	93.3
11	It is necessary to lobby through the different local palliative care associations at the level of ministries of health and science and technology to make them aware of the importance of PC research.	14	93.3
12	Encourage palliative care representation on ethics committees	14	93.3
13	Encourage a closer interaction with the Research Ethics Committees so that they can gradually understand bioethical particularities regarding palliative care	14	93.3
14	Design workshops on how to do grant applications, how to identify potential donors or funders and how to request funding from public/government agencies	13	86.7
15	Establish regional/national Centers of Excellence in Palliative Care research	13	86.7
16	Design courses and workshops for research training in the field of palliative care.	13	86.7
17	Establish fellowship programs with a combination of clinical work and online teaching. By doing this several hospitals with low number of faculty can help each other in maintaining good education	13	86.7
18	Conducting collaborative research that requires minimal onsite work and centralize data management and analysis in institutions with capability	13	86.7
19	Establish collaboration with other areas that could have more funding available	13	86.7
20	Facilitate international exchange of clinicians with interest in research between South American countries	13	86.7
21	Encourage palliative care team members by co-authoring papers ("feeling of a team")	13	86.7
22	Encourage health managers of the need for clinicians to have time allocated for research, as changing the focus of work can decrease burnout rates and improve work efficiency	13	86.7

(Continued)

Table 1
Continued

Rank	Item	N	% ^a
23	Raise awareness in the general population about the importance of palliative care as a topic of public interest	13	86.7
24	Stimulate the participation of palliative care representatives in funding agencies	13	86.7
25	Make strategic alliances with post-graduate programs (MBA, Master, etc.) in other areas, such as public policy, political science, etc., where students can do their theses or master's theses in palliative care institutions	13	86.7
26	Research institutions could promote opportunities for their students and workers to improve their English language skills	13	86.7
27	Centers of excellence in Palliative Care research could promote ethical debates and invite relevant people for discussions	13	86.7
28	Create groups of experts for PRO instrument validations.	12	80
29	Create a registry with information on national and international funds to which to apply.	12	80
30	Seeking grants that would provide protected time for clinicians	12	80
31	Include palliative care in the curricula of health care professions (undergraduate)	12	80
32	Strengthen the teaching of palliative care in graduate courses (master's and doctorate)	12	80
33	Create a web page with all the research projects under development and how to collaborate with them.	12	80
34	Keep measures to a minimum number and make sure they are simple and short	12	80
35	Include professionals in the team with fluency in the English language to facilitate for the whole team	12	80
36	Encourage the discussion of articles in English	12	80

^aPercentage of answers with importance rated as 8 or more.

PC in primary care (81.2%), public policies (81.2%), education (75%) and prognosis (75%) were defined (Table 3). Fig. 1 illustrates the stages of the Delphi study.

Discussion

In the present study, using a Delphi method, a group of experts defined potential ways to overcome the barriers that limit the development of scientific research in PC in SA. Identified strategies to boost scientific investigations included the establishment of collaborative research networks; educational strategies (research courses and workshops); investment in physical infrastructure and human resources; and lobbying at the governmental level about the importance of research for advancing PC. The results of this study can be used by national PC associations, institutions that promote and fund research, and local governments to plan strategies

Table 2
The Most Relevant Suggestions to Overcome Research Barriers Selected from Round 3

Rank	Item	N	% ^b
1 ^a	Encourage the formation of research networks, including both research experts and junior personnel, in order to train those with less experience	16	100
2 ^a	Provide physical infrastructure and human resources (statisticians, translators, etc.) to support the development of the research	16	100
3 ^a	Palliative care centers of excellence could be catalysts for collaborative research networks	15	94
4 ^a	Research courses could be offered by regional/national centers of excellence in palliative care research	14	88
5 ^a	Conduct multicenter research	14	88
6 ^a	Establish regional/national Centers of Excellence in Palliative Care research	13	81
7 ^a	Facilitate international exchange of clinicians with interest in research between South America and high-income countries	12	75
8 ^a	Investment in clinician researchers with interest in palliative care (e.g., career awards) with protected time	12	75
9 ^a	It is necessary to lobby through the different local palliative care associations at the level of ministries of health and science and technology to make them aware of the importance of PC research	12	75
10 ^a	Design courses and workshops for research training in the field of palliative care	12	75
11	Financially support the creation of academic positions at regional universities to ease the work of researchers	11	69
12	Train the researchers on how to write research grants	11	69
13	Encourage palliative care representation on ethics committees	11	69
14	Encourage collaborations between clinicians and scientists	10	63
15	Design workshops on how to do grant applications, how to identify potential donors or funders and how to request funding from public/government agencies	10	63
16	Establish fellowship programs with a combination of clinical work and online teaching. By doing this several hospitals with low number of faculty can help each other in maintaining good education	9	56
17	Conducting collaborative research that requires minimal onsite work and centralize data management and analysis in institutions with capability	9	56
18	Establish collaboration with other areas that could have more funding available	9	56
19	Encourage a closer interaction with the Research Ethics Committees so that they can gradually understand bioethical particularities regarding palliative care	8	50
20	Encourage health managers of the need for clinicians to have time allocated for research, as changing the focus of work can decrease burnout rates and improve work efficiency	8	50
21	Raise awareness in the general population about the importance of palliative care as a topic of public interest	8	50
22	Create groups of experts for PRO instrument validations	8	50

(Continued)

Table 2
Continued

Rank	Item	N	% ^b
23	Create a registry with information on national and international funds to which to apply	8	50
24	Encourage palliative care team members by co-authoring papers ("feeling of a team")	7	44
25	Make strategic alliances with post-graduate programs (MBA, Master, etc.) in other areas, such as public policy, political science, etc., where students can do their theses or master's theses in palliative care institutions	6	38
26	Centers of excellence in Palliative Care research could promote ethical debates and invite relevant people for discussions	6	38
27	Create a web page with all the research projects under development and how to collaborate with them	6	38
28	Create specific funding opportunities for scholarships for undergraduate and graduate students for PC research projects (extra item)	6	38
29	Facilitate international exchange of clinicians with interest in research between South American countries	5	31
30	Strengthen the teaching of palliative care in graduate courses (master's and doctorate)	5	31
31	Stimulate the participation of palliative care representatives in funding agencies	4	25
32	Include palliative care in the curricula of health care professions (undergraduate)	4	25
33	Include professionals in the team with fluency in the English language to facilitate for the whole team	3	19
34	Research institutions could promote opportunities for their students and workers to improve their English language skills	2	13
35	Seeking grants that would provide protected time for clinicians	1	6
36	Encourage the discussion of articles in English	1	6
37	Keep measures to a minimum number and make sure they are simple and short	0	0

^aItems selected as most important.

^bPercentage of response where the item was considered among the 20 most important.

to advance PC research and better direct resources, which have generally been scarce in SA.

The Delphi methodology has been used by several authors in order to better assess region-specific needs. A previous study²⁰ used a two-round modified RAND/UCLA Delphi (14 experts) to develop a set of macro indicators of PC development in Africa. A similar methodology (two-round Delphi, 13 experts) was used by others to define marinizations of PC development in the Eastern Mediterranean Region.²¹ Recently, Krause et al.²² used a four-round Delphi study to develop a new tool to assist healthcare professionals to recognize patients who may have unmet PC needs in Africa. A major limitation was the low participation rate (12%), since only 14 experts participated in the Delphi panel out of 116 invitations. A Chinese two-round Delphi

Table 3
Classification of Priority Research Topics

Rank	Item	N	%
1 ^a	Symptom control: identification of the most prevalent and uncomfortable symptoms, cost-effectiveness studies, education in symptom control, search for new therapies using traditional medicinal products, etc.	14	87.5
2 ^a	Palliative care in primary care: how to integrate palliative care into primary care	13	81.2
2 ^a	Public policies: determine strategies for the development of palliative care	13	81.2
4 ^a	Education in palliative care	12	75.0
4 ^a	Prognostication: most accurate tools and models, how to communicate prognosis, importance of prognostication in patient care	12	75.0
6 ^b	Criteria for the evaluation of services at the regional and country levels	11	68.7
6 ^b	Quality of death and dying and socio-cultural related aspects	11	68.7
8 ^b	Nononcological palliative care: determine criteria for admission to palliative care programs	10	62.5
8 ^b	Home care: organization, benefits provided, work with caregivers and families.	10	62.5
10 ^b	Community: need for information, involvement, training, recognition of myths and barriers to access to palliative care.	9	56.2
10 ^b	Advance care planning, advance directives and goals of care	9	56.2
10 ^b	E-health and telemedicine: focus on patients living in remote locations	9	56.2
13 ^b	PC associated costs and funding	8	50.0
14	Interdisciplinary teamwork and role of the health team in different levels of care	7	43.7
14	Timely referral to palliative care	7	43.7
14	Access to opioids	7	43.7
14	Decision-making process / decisional conflicts	7	43.7
14	Palliative care in acute settings (e.g., emergency departments)	7	43.7
19	Hospice: development of the model of care, characteristics, costs, etc.	6	37.5
19	End of life care core outcomes set	6	37.5
19	Research in ethics issues (euthanasia, assisted suicide, wishes to hasten death, etc.)	6	37.5
19	Spiritual care	6	37.5
23	Caregiver and family burden	5	31.2
23	End-of-life care preferences	5	31.2
25	Communication issues: more effective strategies and training, socio-cultural issues	4	25.0
26	Satisfaction with healthcare	3	18.7
27	Complementary therapies: type and efficacy	2	12.5
28	Research methodologies	1	6.2
28	Conflicts in palliative care	1	6.2
28	Complexity in PC	1	6.2
28	Implementation research	1	6.2
28	Cultural issues, migration	1	6.2

^aHigh agreement.

^bModerate agreement.

study,²³ with 18 experts, was conducted to define key components of home PC and also had a low participation rate (36%). In our study, the Delphi method proved to be feasible, with a participation acceptance rate of 72% (18 of 25 invitations) and a minimum response rate per round of 83.3% (15 of 18 in round two).

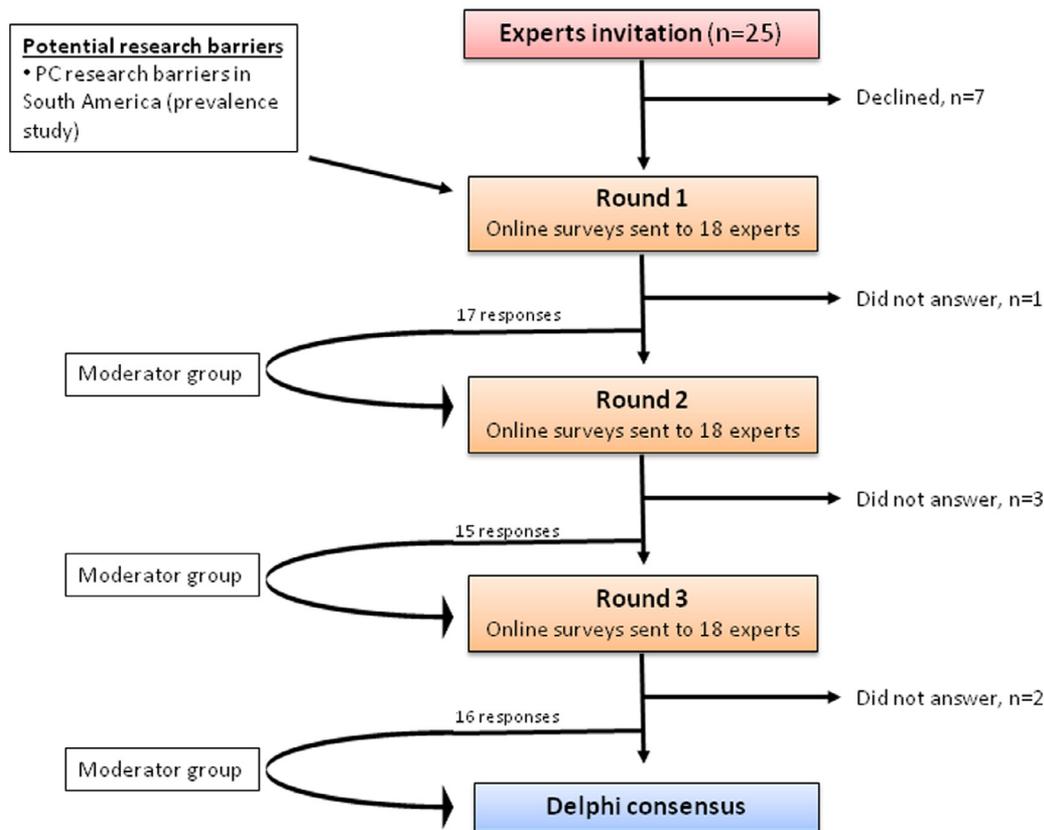


Fig. 1. Flowchart to illustrate the Delphi methodology process.

The gross national product per capita and expenditure on research and development are the main factors related to the number of biomedical publications.²⁴ In the field of oncology, for example, scientific production from high-income countries from Europe and the United States together represent more than 90% of the publications.²⁵ Similarly, in PC, most publications come from the United States and the UK;^{26,27} from the 10 most productive institutions, nine were from North America or UK.²⁷ Even in high-income countries, the proportion of research funding allocated to PC is historically small.^{28–30} The creation of research networks was the main recommendation of the Los PamPAS Research Group. Research networks are key to establishing multicenter studies, with greater potential for inclusion of participants, and greater power of generalization of results. In fact, studies with international collaboration tend to have more citations and have study designs with greater potential scientific impact (systematic reviews, clinical trials and cohort studies), compared to studies without international collaboration.¹¹ Given that funding resources are limited, the importance of research collaboration is growing. Indeed, the present study is an example of a research network initiative, evidenced by the creation of the Los PamPAS Research Group. Other very promising initiatives are underway in SA, such as Red-InPal,³¹ organized by the

Instituto Pallium Latino America. In a secondary analysis of a scoping review about PC development in Africa, Rhee et al.³² demonstrated that the number of African publications on PC development and the number of publications with international collaboration with high-income countries were strongly correlated with the levels of development on the PC World Map. Thus, the authors suggest that such measures can be considered as indicators of PC development and reinforce the importance of our Delphi study findings in SA.

Another recommendation of this study is to facilitate the international exchange of clinicians with interest in research between South American countries and high-income countries outside SA. This exchange of researchers has proven essential for training researchers and, subsequently, maintaining research linkages in future studies. USA, Spain, UK, Canada were in 2012 the countries with much collaboration in the Region.³³

A further important recommendation is regarding clinical researcher's career. High-level research centers generally have established research teams with adequate infrastructure and researchers of various levels of experience (Master's and PhD students, junior and senior researchers). Research centers in SA, not only those associated with universities, need to identify clinicians with the greatest interest and aptitude for research and support them, both with awards and

protected time. Unfortunately, it is common for centers to pay clinicians only for their clinical activities, leaving research activities to be performed at off-work times. We believe that it is essential to provide protected time for clinicians to do research, with the percentage provided depending on their academic experience or (preferably) their scientific productivity and success in obtaining funding.

A key recommendation from this study is the establishment of centers of excellence in PC research in SA. These centers should act as catalysts for research networks and also provide research-oriented courses and workshops, such as focusing on research methods, scientific writing, and obtaining funding. In addition, such South American centers of excellence could act as consultants in the initial design of clinical trials and provide support for data analysis and training of research teams from other PC centers. In order to reduce research resources, it would even be feasible that data analyses could be performed by the centers of excellence, by trained staff, following ethical recommendations, with transparency, and a competent Research Ethics Committee. It is important to emphasize that most South American countries speak Spanish or Portuguese, which are languages of Latin origin and high lexical similarity. Thus, such proximity may be a facilitator in the teaching activities of the centers of excellence. In situations of reduced financial resources, the research infrastructure of some centers could be shared by smaller centers interested in conducting research, provided that there is involvement from health institutions, government, and research support foundations. We believe that research in SA needs not only funding, but also organization, planning, and genuine collaborations.

A systematic review identified 10 studies that analyzed research priorities in PC, with a focus on North America, Europe, and Oceania. None of them specifically evaluated SA, revealing a gap in the scientific knowledge.³⁴ Our study has defined symptom control, PC in primary care, public policies, education and prognosis as the top five research gaps. Recently, we investigated the most researched topics by South American authors in the last 20 years. Ethical issues (14%) and experience of caring in PC (10%) were the most commonly investigated topics.¹⁰ Among our five priority themes, public policy, symptom control and education were found in just over 5% of the articles. Interaction of PC and primary care seems to us a theme of extreme importance in SA, yet it has rarely been investigated. These priority themes can be used by foundations that promote research to direct resources by including them in priority calls for proposals.

Study Limitations

One limitation of this study was that it did not include experts covering all the South American

countries. For example, no representatives from Uruguay, Peru and Bolivia participated in the study. Moreover, most SA publications in palliative care are from researchers from Brazil, Argentina, Chile and Colombia,¹⁰ and we believe that the group is well represented. From other countries, it was difficult to include experts caused by the underdevelopment of PC clinically and academically and lack of experts in the field who meet the inclusion requirements. Three experts are native to SA who currently live outside the region (EB, TP, LL) but continue to maintain strong professional ties with the region, including important publications on research in SA. Concerning academic background, most of them were physicians with only one nurse and one clinical psychologist. Thus, the lack of researchers with other backgrounds can be interpreted as a limitation of the study. Another limitation of the study is the definition of priority research areas in the view of PC experts, without including opinions of patients and their caregivers.

Practical Implications

The findings of the present study may be disseminated among South American countries, their PC associations, and discussed with governmental and nongovernmental organizations that foster research. The creation and definition of Centers of Excellence in Research in SA should be the next step to follow, with wide dissemination and possibility of collaborations for teaching and research.

Conclusions

Using a Delphi methodology, potential strategies to improve scientific research on PC in SA were defined, including stimulating the formation of collaborative research networks, offering courses and workshops on research, structuring centers with infrastructure resources and trained researchers, and lobbying governmental organizations regarding the importance of palliative care. In addition, priority research topics were identified in the region.

Disclosures and Acknowledgments

CEP received funding from the São Paulo Research Foundation (FAPESP grant no. 2018/09836-8). The authors had no conflict of interest to declare.

The authors would like to acknowledge the participation of the following Palliative Care associations: Academia Nacional de Cuidados Paliativos (ANCP); Asociación Latinoamericana de Cuidados Paliativos (ALCP); Sociedad Médica de Cuidados Paliativos de Chile; Asociación Cuidados Paliativos de Colombia (ASOCUPAC); Asociación Argentina de Medicina y Cuidados Paliativos (AAMyCP); Asociación Paraguaya

de Medicina y Cuidados Paliativos (APMCP); and Instituto Pallium Latinoamerica. The authors would also like to thank Crislaine de Lima (MSc, PhD student) for her assistance during the conduct of this study.

Supplementary materials

Supplementary material associated with this article can be found in the online version at [doi:10.1016/j.jpainsymman.2022.11.020](https://doi.org/10.1016/j.jpainsymman.2022.11.020).

REFERENCES

- Brooksbank M. Palliative care: where have we come from and where are we going? *Pain* 2009;144:233–235. <https://doi.org/10.1016/j.pain.2009.06.010>.
- Clark D. From margins to centre: a review of the history of palliative care in cancer. *Lancet Oncol* 2007;8:430–438. [https://doi.org/10.1016/S1470-2045\(07\)70138-9](https://doi.org/10.1016/S1470-2045(07)70138-9).
- Connor SR. Development of hospice and palliative care in the United States. *Omega* 56:89–99. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/18051022>. Accessed April 20, 2018.
- Wenk R. The development of palliative medicine in Latin America. In: Bruera E, Higginson I, Ripamont C, Von Gunten C, eds. *Textbook of Palliative Medicine*, London: Hodder Arnold; 2006:36–41.
- Pastrana T, Eisenclas J, Centeno C, De Lima L. Status of palliative care in Latin America. *Curr Opin Support Palliat Care* 2013;7:411–416. <https://doi.org/10.1097/SPC.0000000000000008>.
- Pastrana T, De Lima L, Sánchez-Cárdenas M VSD, Garralda E, Pons JJ CC. *Atlas de Cuidados Paliativos en Latinoamérica 2020*. 2nd ed Houston: IAHPAC Press; 2021.
- The 2015 Quality of Death Index. Ranking palliative care across the world. 2015. Available at: <http://www.eiuperspectives.economist.com/healthcare/2015-quality-death-index>. Accessed September 24, 2022.
- Finkelstein EA, Bhadelia A, Goh C, et al. Cross country comparison of expert assessments of the quality of death and dying 2021. *J Pain Symptom Manage* 2022;63:e419–e429. <https://doi.org/10.1016/j.jpainsymman.2021.12.015>.
- De Lima L, Harding R, Higginson I. Palliative care research in the developing world: how can we move forward? In: *Abstracts of the 9th Congress of the European Association for Palliative Care*, Aachen, Germany: EAPC; 2005.
- de Lima C, dos Santos Neto MF, Costa RFA, et al. Characteristics of palliative care publications by South American Authors in the Last 20 Years: systematic literature review with bibliometric analysis. *J Pain Symptom Manage* 2021;62:e177–e185.
- De Lima C, Paiva BSR, Neto MFDS, et al. The impact of international research collaborations on the citation metrics and the scientific potential of South American palliative care research: bibliometric analysis. *Ann Glob Health* 2021;87. <https://doi.org/10.5334/AOGH.3158>.
- C Gattini, P Ruiz. *Health in South America, 2012 Edition: Health Situation, Policies and Systems Overview*. Washington DC: Pan American Health Organization, 2012.
- Death Rate by Country 2022. Available at: <https://world-populationreview.com/country-rankings/death-rate-by-country>. Accessed August 7, 2022.
- Murtagh FEM, Bausewein C, Verne J, Iris Groeneveld E, Kaloki YE, Higginson IJ. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliat Med* 2014;28:49–58. <https://doi.org/10.1177/0269216313489367>.
- Hasson F, Keeney S, McKenna H. Research guidelines for the Delphi survey technique. *J Adv Nurs* 2000;32:1008–10015. <https://doi.org/10.1046/j.1365-2648.2000.t01-1-01567.x>.
- Jünger S, Payne SA, Brine J, Radbruch L, Brearley SG. Guidance on Conducting and REporting DELphi Studies (CREDES) in palliative care: recommendations based on a methodological systematic review. *Palliat Med* 2017;31:684–706. <https://doi.org/10.1177/0269216317690685>.
- Hsu C-C, Sandford BA. The delphi technique: making sense of consensus. *Pract Assessment Res Eval* 2007;12:10.
- Biswanger J, Inauen R, Strasser F. Barriers to palliative care (PC) research. *Palliat Med* 2006;20:229–379.
- Rhondali W, Berthiller J, Hui D, et al. Barriers to research in palliative care in France. *BMJ Support Palliat Care* 2014;4:182–189. <https://doi.org/10.1136/bmjspcare-2012-000360>.
- Rhee JY, Garralda E, Namisango E, et al. Developing macroindicators of palliative care development in Africa: a process with in-country and international experts. *J Palliat Med* 2018;21:342–353. <https://doi.org/10.1089/jpm.2017.0207>.
- Sánchez-Cárdenas M, Garralda E, van Steijn D, et al. Eastern mediterranean regional expert network on palliative care. region-specific macro-indicators for palliative care development in the Eastern Mediterranean Region: a Delphi study. *East Mediterr Health J* 2022;27:560–568. <https://doi.org/10.26719/emhj.22.036>.
- Krause R, Barnard A, Burger H, et al. A Delphi study to guide the development of a clinical indicator tool for palliative care in South Africa. *Afr J Prim Health Care Fam Med* 2022;14:e1–e7. <https://doi.org/10.4102/phcfm.v14i1.3351>.
- Chan HY, Chan CN, Man CW, et al. Key components for the delivery of palliative and end-of-life care in care homes in Hong Kong: a modified delphi study. *Int J Environ Res Public Health* 2022;19:667. <https://doi.org/10.3390/ijerph19020667>.
- Rahman M, Fukui T. Biomedical research productivity: factors across the countries. *Int J Technol Assess Health Care* 2003;19:249–252. <https://doi.org/10.1017/S0266462303000229>.
- Tas F. The contribution of countries and world regions in productivity of oncological publication. *Ann Oncol Off J Eur Soc Med Oncol* 2008;19:1962–1968. <https://doi.org/10.1093/ANNONC/MDN378>.
- Abu-Odah H, Molassiotis A, Liu JYW. Global palliative care research (2002-2020): bibliometric review and mapping analysis. *BMJ Support Palliat Care* 2021. <https://doi.org/10.1136/BMJSPCARE-2021-002982>.
- Liu C-J, Yeh T-C, Hsu S-H, et al. Bibliometric analysis of palliative care-related publication trends during 2001 to 2016. *Am J Hosp Palliat Care* 2018;35:1280–1286. <https://doi.org/10.1177/1049909118773751>.

28. McIlfratrick S, Muldrew DHL, Hasson F, Payne S. Examining palliative and end of life care research in Ireland within a global context: a systematic mapping review of the evidence. *BMC Palliat Care* 2018;17. <https://doi.org/10.1186/S12904-018-0364-7>.
29. Higginson IJ. Research challenges in palliative and end of life care. *BMJ Support Palliat Care* 2016;6:3–4. <https://doi.org/10.1136/BMJSPCARE-2015-001091>.
30. Hui D, Reddy A, Parsons HA, Bruera E. Reporting of funding sources and conflict of interest in the supportive and palliative oncology literature. *J Pain Symptom Manage* 2012;44:421–430. <https://doi.org/10.1016/J.JPAINSYM-MAN.2011.09.016>.
31. Red-InPal. Available at: <https://www.pallium.com.ar/investigacion/red-inpal/>. Accessed September 24, 2022.
32. Rhee JY, Garralda E, Torrado C, et al. Publications on palliative care development can be used as an indicator of palliative care development in Africa. *J Palliat Med* 2017;20:1372–1377. <https://doi.org/10.1089/jpm.2017.0168>.
33. Pastrana T, De Lima L, Wenk R, Eisenchlas J, Monti C, Rocafort J CC. *Atlas de Cuidados Paliativos en Latinoamérica*. 1st ed Houston: IAHPC Press; 2012.
34. Hasson F, Nicholson E, Muldrew D, Bamidele O, Payne S, McIlfratrick S. International palliative care research priorities: a systematic review. *BMC Palliat Care* 2020;19. <https://doi.org/10.1186/S12904-020-0520-8>.