

This is the accepted version of the article by R. Mertenoff, C. Vindrola-Padros, M. Jacobs, and X. Gomez-Batiste, The Development of Palliative Care in Argentina: A Mapping Study using ALCP Indicators, *Journal of Palliative Medicine*, 2017, doi:10.1089/jpm.2016.0312.

The Development of Palliative Care in Argentina: A Mapping Study using ALCP Indicators

Rosa Mertenoff^{1,2}, Cecilia Vindrola-Padros³, Mariana Jacobs^{2,4}, and Xavier Gómez-Batiste^{5,6}

¹ British Hospital Buenos Aires, Argentina - Paliativa Asociación Civil

² Asociación Argentina de Medicina y Cuidados Paliativos, Red Federal de Cuidados Paliativos Argentina

³ Department of Applied Health Research, University College London (UCL), London, United Kingdom

⁴ Department of Psychooncology, Hospital Aleman, Buenos Aires, Argentina

⁵ WHO Collaborating center for Palliative Care Public Health Programs, Catalan Institute of Oncology, Spain

⁶ Chair of Palliative Care, University of Vic, Barcelona, Spain.

Corresponding author

Dr Cecilia Vindrola-Padros

Research Associate

Department of Applied Health Research

University College London (UCL)

1-19 Torrington Place

London

WC1E 7HB

United Kingdom

c.vindrola@ucl.ac.uk

Tel: +44 (0)20 3108 3232

The Development of Palliative Care in Argentina: A Mapping Study using ALCP Indicators

ABSTRACT

Background: The Latin American Association for Palliative Care (ALCP) developed 10 indicators to monitor the development of palliative care. The indicators have been applied across Latin American countries, but have not been used internally.

Objective: The aims of this study were to document the development of palliative care in Argentina at the national and provincial levels by using a selection of the indicators developed by the ALCP and identify the difficulties and needs of healthcare professionals working in palliative care. This is the first study to apply the indicators intra-nationally.

Design: This was a cross-sectional pilot study based on two questionnaires with representatives from each province, one workshop, and telephone conversations to corroborate the collected data. These data were used to calculate a preselection of eight ALCP indicators covering four main areas of development: education, policy, service delivery, and medication.

Subjects: A total of 30 participants took part in the study.

Results: The application of the ALCP indicators at the province level led to the identification of inequalities in the development and distribution of services across the country. The provinces in the north-west were identified as the region with the greatest need for development. The main difficulties for healthcare professionals were lack of national service registries, certified palliative care specialties, and opportunities for continuous training.

Conclusions: The ALCP indicators are useful tools for mapping palliative care development within countries. Further work needs to be carried out to increase their specificity and integrate them in policy design and service delivery.

Background

Palliative care (PC) began in Latin America in the eighties, but its development has been slow compared to other regions (1-4). Most countries in this region do not deliver PC consistently across their populations (5-8). The Atlas of Palliative Care, published in 2013, provides a regional report as well as a description of the status of palliative care in each country in Latin America, showing considerable heterogeneity in the level of development of policy, service delivery, education, professional activities and availability of opioids (6). It also shows variability within countries, with a better provision of PC in large urban centers (6).

Previous studies have advocated the need for standardized tools to measure palliative care development and address these inequalities in service delivery (5, 7, 9, 10).

The Latin American Association for Palliative Care (ALCP) developed 10 indicators to monitor the development of palliative care and promote the establishment of regional and national strategies (7, 11). These indicators were organized in 4 categories: policy, education, service provision, and opioids.

The aims of the ALCP were to compare the status of palliative care development across Latin American countries using these indicators, and provide national governments with a tool for monitoring palliative care development in their countries. Previous studies have already used the indicators to compare the delivery of palliative care across Latin American countries (7). The indicators have not been used to look at the development of palliative care within countries. In this article, we present the findings of a study that focused on mapping the development of PC in Argentina at national and provincial levels,

using a pre-selection of eight indicators of PC development established by the ALCP. This is the first study to apply the indicators intra-nationally.

Palliative care in Argentina

Argentina is the second largest Latin American country with regards to territorial extension, after Brazil. Argentina is divided in 23 provinces and the autonomous city of Buenos Aires. Sixty percent of its population lives in the provinces of Buenos Aires, Córdoba and Santa Fé. With 40 million inhabitants, 10.2% of the population with 65 or more years of age and 14.3%, with 60 years or more(12), Argentina ranks third in Latin America with regards to the size of its aging population, after Uruguay and Cuba(13). The health system is divided in three main types of providers: public services (covering approximately 50% of the population), mutuals or social plans (45%), and the private sector (5%)(14, 15). Each province has its own provincial health program and autonomous Health Ministry, which reports to the National Health Ministry. Health care delivery varies considerably across and within provinces(16).

Palliative care in Argentina has a history of 30 years (17-20). The Argentine Association of Medicine and Palliative Care (AAMYCP) was established in 1994. In 2015, the National Health Ministry promulgated the medical specialty in palliative care (Resolution 1814/15), yet it is still not regulated equally across the country. There are only two provinces with an accredited palliative care specialty: Santa Fé and Neuquén. The variability in palliative care delivery and training opportunities for professionals across provinces is evident, but has not been fully documented (for the mapping of pediatric palliative care services see

(21)). Previous studies have ranked Argentina fourth in Latin America with regards to palliative care development, but these rankings do not take into account the uneven internal development and distributions of services (5, 7).

Aims

The aims of this study were: 1) document the development of palliative care in Argentina at the national and provincial levels by using a selected number of the indicators developed by the ALCP and local experiences of service delivery, 2) identify the difficulties and more frequent needs of healthcare professionals working in palliative care, and 3) identify the areas that require development at a national level taking into consideration differences among provinces.

The indicators we used are presented in Table 1. This selection of indicators was informed by our knowledge of the available data on palliative care as well as previous published studies that used ALCP indicators (6,7).

INSERT TABLE 1 HERE

Design

This is a cross-sectional pilot study (22).

Data collection

Data were collected through two questionnaires and one workshop with study participants.

First questionnaire

We distributed the first questionnaire via email to all participants. This questionnaire was designed in collaboration with [blinded], adapting the methodology (quantitative and qualitative) used to map and evaluate the Catalonia WHO Demonstration Project (23, 24). This questionnaire requested general information on the province (population, disease incidence, etc.), general information on palliative care service delivery, the main difficulties encountered by palliative care staff, and the resources they need to further develop palliative care services in their regions. A description of the items included in the questionnaire can be found in Appendix 1.

Second questionnaire

After carrying out preliminary analysis of the first questionnaire, a second questionnaire was developed to collect targeted information aimed at calculating the ALCP indicators. The participants were asked about the existence of palliative care plans or programs, educational programs on palliative care for doctors and nurses, the availability of medical teams and specialized physicians, and the availability of opioids in pharmaceutical establishments. Detailed definitions of the indicators were provided to ensure the standardized collection of information and participants were provided with instructions on how the numerators and denominators needed to be built. A description of the questionnaire can be found in Appendix 1. The participants were contacted via telephone to corroborate our interpretation of the data, identify the data sources that were used, and address issues of missing data.

Workshop

All participants were invited to a workshop with the aim of discussing preliminary findings in greater detail. The participants were asked to share their experiences of the development of palliative care services in their provinces. The discussion was facilitated through the use of participatory methods such as graffiti wall and problem trees (25). The discussions that took place during the workshop were recorded in the form of fieldnotes.

Recruitment and sample

Participants were recruited from February 2015 to March 2016. The identification of potential participants was based on the screening of institutional lists (hospitals and hospices) for renowned professionals in the field and referrals from other professionals (snowball sampling). We sought to recruit at least one participant from each province and asked them to act as a representative for their province. This recruitment method has been used in previous palliative care mapping studies (26, 27). The inclusion criteria were healthcare professionals who play a key role in the delivery of palliative care and acted as directors or coordinators of palliative care teams in public or private hospitals or hospices. The participants also needed to have access to relevant data sources in their provinces. Potential participants were identified using institutional records such as hospital directories. The potential participants were contacted via email and provided information about the study and what their participation would entail. They were then asked if they would like to take part.

Data analysis

Data from the first questionnaire were used to create a profile for each province and identify the most frequent difficulties and needs reported by the province representatives. Data from the second questionnaire were used to calculate the indicators at the national level and at the level of each province. The process for calculating each indicator is outlined in Table 2. Additional data sources were consulted for some of the provinces. The full list can be found in Supplementary File 1.

INSERT TABLE 2 HERE

1. Atlas Federal de Legislación Sanitaria de la República Argentina (Federal Atlas of Health Legislation of the Argentine Republic), Ministry of Health (28).
2. University Career Guide, Sistema de Información Universitaria (System of University Information) (29).
3. Accreditation of Graduate and Postgraduate Courses, Comisión Nacional de Evaluación y Acreditación Universitaria (National Commission of University Evaluation and Accreditation) (30).
4. 2010 National Census carried out by the Instituto Nacional de Estadística y Censos (National Institute of Census and Statistics of Argentina) (12).

The fieldnotes from the workshop were analysed using content analysis and were mainly used to expand our understanding of the difficulties faced by staff delivering palliative care services. The workshop and telephone conversations with the participants were fundamental components of the study and ensured our accurate interpretation of the data.

Ethical approval

The study protocol was reviewed and approved by the Independent Ethical Committee of the Foundation Huesped. An informed consent process was followed with the research participants where they were informed that their participation in the study was voluntary; they could withdraw at any time; and the information they provided would remain confidential.

Results

A total of 30 participants took part in the study. Nobody refused to participate. Participants acted as representatives for their provinces. We were able to recruit representatives for all provinces except for two (Salta and Jujuy). Data for the missing provinces were obtained through other data sources (see Table 2) and representatives from other provinces. We were able to collect data on the rest of the provinces, with the exception of some missing data for Buenos Aires province, the city of Buenos Aires, and Tierra del Fuego (see Table 4).

18 of the participants were women and 12 were men. Almost all of the participants were doctors (28), with the exception of two psychologists. All of the participants worked full-time in the delivery of palliative care services. Their experiences in this field ranged from 1 to 10 years. Most participants (21) worked in the public sector, eight worked in the private sector, and one participant worked in both the public and private sector. The details of the data sources each participant was able to access can be found in Supplementary File 1.

Indicators at the national level

The indicators at the national level have been summarized in Table 3. Argentina does not have a national palliative care plan or program. There are guidelines for specific diseases (i.e. the Programa Nacional de Cuidados Paliativos developed by the National Cancer Institute for cancer patients) and populations (i.e. pediatric patients), but there are no plans with clear policies and budget aimed at the delivery of palliative care for all patients at the national level. In

terms of the training of medical professionals, 19% of the medical schools and 8% of the nursing schools include palliative care in their curricula, and there are nine palliative care educational programs for doctors accredited by a wide range of universities.

Palliative care is included in the primary care list of services in 12 provinces.

There are approximately 73 palliative care services in the country and 166 accredited doctors. Approximately 316 pharmaceutical establishments dispense opioids, including public and private facilities.

INSERT TABLE 3 HERE

*Not at the national level, but two provinces have palliative care programs (see Table 4).

** Based on census data from INDEC (12).

Indicators at the province level

Table 4 presents a breakdown of the data by province. There is great variability in the development of palliative care across the country. The province with the highest level of development is Neuquén. This province has a palliative care program, it provides undergraduate training for doctors and nurses in all schools and has one accredited specialty in palliative medicine. As we were finishing this article, the first palliative care doctor gained accreditation. It includes palliative care in the delivery of services at the primary care level and has an adequate distribution of services, specialized doctors, and opioids in relation to its population size. In contrast, other provinces such as Salta and Jujuy do not have any development of palliative care services.

INSERT TABLE 4 HERE

- Missing data

*The program only exists in Rosario, the capital of the province.

**In the private healthcare system
***Based on census data from INDEC (12).

Only two provinces (Neuquén and Santa Fé) have an established palliative care plan, but more than half include palliative care in the delivery of services at the primary care level. Neuquén distributes services homogeneously across the province, while in Santa Fé, these services can only be found in the capital of the province (Rosario). Other provinces do not have established programs, but have created networks of providers to deliver community-based care. This is the case of Rio Negro, where a network of multidisciplinary teams has been developed to provide hospital-based and home-based care across five regions (Viedma, Cipolletti, Villa Regina, General Roca and San Carlos de Bariloche). At a national level, there is an unequal distribution of palliative care services (including specialized doctors) and pharmaceutical establishments that dispense opioids. As can be seen in Figure 1, there are still evident gaps in services in the northern provinces and those located in the west.

INSERT FIGURE 1 HERE

Difficulties and challenges in the development of PC

The first questionnaire asked the representatives to identify their main difficulties and challenges as well as their needs. Their responses are summarized in Table 5. It is evident that there are barriers operating in the development of palliative care services at the province level. These barriers mainly concern issues related to the design and implementation of palliative care policies, the training of healthcare professionals, the funding of palliative care development and delivery, the creation of national registries, and the equal distribution of opioids. The representatives requested assistance with all of

these issues and proposed strategies to work collaboratively with other provinces, sharing experiences and establishing bilateral training opportunities.

INSERT TABLE 5 HERE

Discussion

Our calculation of the ALCP palliative care indicators highlighted important trends in the development of palliative care in Argentina at national and provincial levels. At a national level, the results of our indicators differ from those reported in prior studies. For instance, we found a smaller quantity of services per million inhabitants (1.82) compared to the indicators published by Pastrana et al. (3.76) (7). This could be due to differences in reporting, or it could potentially be linked to the dissolution of services in some areas of the country. We are aware of two services that closed recently, one in Buenos Aires and the other one in Tierra del Fuego.

Our calculation of the number of doctors working in palliative care per million inhabitants was 4.13, compared to 2.50 reported by Pastrana et al. (7), which could suggest an increase in professional training opportunities in the PC field. We found that the number of specialized palliative care educational programs for doctors was twice the number found in previous studies (8 in our study vs. 4 in Pastrana et al. (7)), but the proportion of medical schools that include palliative care education in undergraduate curricula was 19% while Pastrana et al. (7) documented 22%.

During our study, we were able to collect data to calculate indicators that had not been calculated before for Argentina. This is the case of ED.2, the proportion of nursing schools with palliative care at undergraduate level (8%), and ME.3, the number of pharmaceutical establishments that dispense strong opioids per 1 million inhabitants (7.88).

Argentina is classified by the Worldwide Palliative Care Alliance (WPCA) as a level 3b (5) and has an ALCP index of 4.39 (7), appearing to be one of the Latin American countries with the highest development of palliative care (ranked fourth in Latin America according to the ALCP index). However, when the ALCP indicators are used at the province level, we are able to see that the development and distribution of services are unequal across the country. Services are concentrated in Neuquén, and Rio Negro, with a homogeneous distribution of services, and Buenos Aires, and Santa Fé, with a heterogeneous distribution and some areas where PC is not available. The northwest region has severe deficiencies in care delivery, training opportunities for healthcare professionals, and the availability of opioids in pharmaceutical establishments. This situation poses pressing questions regarding the type of palliative care patients are receiving (or not receiving) in these areas of the country.

The analysis of the indicators as well as the difficulties and needs reported by the province representatives pointed to the lack of standardized registries and training opportunities for healthcare professionals. Future areas of short and long term development in Argentina could be: 1) The elaboration of a service registry by province, standardized at the national level, 2) The development of

opportunities for PC training (basic and continuous training), and 3) The regulation and certification of the palliative medicine and nursing specialties (already promulgated by the Ministry of Health in resolution 1814/2015 for medicine and 199/2011 for nursing).

The findings of this study should be interpreted with their limitations in mind. The indicators measure the presence of services and professionals, but do not allow us to assess the quality of care or the degree to which services are used by the population. Some of the indicators are too general and might not reflect the ways in which services or professional activity are organized. For instance, the number of specialized doctors working in palliative care per one million inhabitants does not specify if this is full-time or part-time doctors (or both), or acknowledge that these doctors' services might be spread out over the public and private sector. The PS.1 indicator documents the inclusion of palliative care in primary care, but it does not make a distinction between different components of primary care such as GP or community practices, hospices, or home care.

In addition to the limitations of the indicators, our study is limited in the sense that it relied on data reported by the study participants, potentially leading to skewed or missing data. We were able to cross-check some of the provincial data with national databases, but this was not possible for all indicators. The study participants have provided a list of the data sources consulted in each province, but in some cases they could only rely on information obtained by consulting with local providers or pharmaceutical establishments (see Supplementary File 1). Provincial registries and databases are not standardized and the quality of the

data is not assessed routinely. This being said, we believe that the participatory approach we employed in the study led to the engagement of the study participants during all stages of research, facilitating data collection and analysis. Our sample size is small and future studies should focus on collecting data from larger groups of experts.

Conclusions

The results of this study point to evident inequalities in the development and distribution of palliative care services in Argentina. The ALCP indicators are not only useful tools for mapping palliative care development across Latin American countries, but can be used to explore service delivery and training opportunities within countries as well. Further work needs to be carried out to increase the specificity of the indicators so they can accurately represent what occurs in practice. In addition, national standards need to be set to identify quality of care targets and tailor service delivery accordingly. We are planning further research on national differences in the quality of palliative care, focusing on patients' and carers' experiences of care and staff members' experiences of care delivery. We hope to identify the factors acting as barriers in the development of palliative care in Argentina and inform the development of national and regional interventions focused on addressing them.

Acknowledgments

We would like to thank the support provided by members of Red Federal de Atención Paliativa y Cronicidad Avanzada y: Mc Garrell Daniela; Carrizo de la Fuente Virginia; Coller Maria; Cattaneo Walter; Simó Mariela; Rey Victoria; Solorzano Fabian Roberto; Pordomingo Virginia; Nespral Alejandro; Gill Mabel; Alassia Alejandro; Nieva Mariela; Barra Luis Pablo; Vargas Mariela; Perez David; Torresi Victoria; Felix Alicia Nora; Pirchi Mariangeles; Marchetti Fernanda; Colautti Norma; Jury Graciela; De Muria Mariano; Del Colle José; Leisa Julián; Besil Belén; Yori Mariana; Jozami Paula; Bunge Sofía and Junín Marta and Najún Matías. We would also like to thank Bruno Vindrola-Padros for his comments on earlier versions of this manuscript.

Funding statement or declaration of conflicting interests

RM declares no conflict of interest or funding for this study.
CVP declares no conflict of interest or funding for this study.
MJ declares no conflicts of interest or funding for this study.
XGB declares no conflicts of interest or funding for this study

References

1. Bruera E: Palliative care in Latin America. *J Pain Symptom Manage* 1993;8:365-368.
2. De Lima L, Barnard D: Advances in palliative care in Latin America and the Caribbean: Ongoing projects of the Pan American Health Organization (PAHO). *J Palliat Med* 2001;4:227-231.
3. De Lima L, Bruera E: The Pan American Health Organization: Its structure and role in the development of a palliative care program for latin america and the caribbean. *J Pain Symptom Manage* 2000;20:440-448.
4. Twycross RG: Palliative care programmes in Latin America. *Palliat Med* 1993;7:166-167.
5. Lynch T, Connor S, Clark D: Mapping levels of palliative care development: A global update. *J Pain Symptom Manage* 2013;45:1094-1106.
6. Pastrana T, Eisenclas J, Centeno C, De Lima L: Status of palliative care in Latin America: Looking through the latin america atlas of palliative care. *Curr Opin Support Palliat Care* 2013;7:411-416.
7. Pastrana T, Torres-Vigil I, De Lima L: Palliative care development in Latin America: An analysis using macro indicators. *Palliat Med* 2014;28:1231-1238.
8. Pastrana T, Centeno C, De Lima L: Palliative care in Latin America from the professional perspective: A SWOT analysis. *J Palliat Med* 2015;18:429-437.
9. Wright M, Wood J, Lynch T, Clark D: Mapping levels of palliative care development: A global view. *J Pain Symptom Manage* 2008;35:469-485.
10. Centeno C, Clark D, Lynch T, Racafort J, Praill D, De Lima L, et al: Facts and indicators on palliative care development in 52 countries of the WHO European region: Results of an EAPC task force. *Palliat Med* 2007;21:463-471.
11. DeLima L: How can we monitor palliative care? suggestions from the Latin American Association for Palliative Care. *Int J Palliat Nurs* 2013;19:160-161.
12. Insitituto Nacional de Estadistica y Censo. Censo 2010. 2010.
13. Population ageing and and international development: From generalisation to evidence. Lloyd-Sherlock P. Bristol, UK, The Policy Press, 2010.
14. Soriano E, Rosa J, Velozo J, Schpilberg E, Imamura M, Diaz P, et al: Incidence and prevalence of psoriatic arthritis in Buenos Aires, Argentina: A 6-year health management organization-based study. *Rheumatology (Oxford)* 2011;50:729-734.
15. Stolkiner A, Comes Y, Garbus P: Alcances y potencialidades de la atencion primaria de la salud en Argentina. *Saude Colectiva* 2011;16:2807-2816.

16. Descentralización y equidad en el sistema de salud Argentino. Maceira D. Buenos Aires, Argentina, CEDES, 2003.
17. Bruera E, Sweeney C: Palliative care models: International perspective. *J Palliat Med* 2002;5:319-327.
18. Wenk R, Bertolino M: Argentina: Palliative care status 2002. *J Pain Symptom Manage* 2002;24:166-169.
19. Wenk R, Bertolino M: Palliative care development in South America: A focus on Argentina. *J Pain Symptom Manage* 2007;33:645-650.
20. Wenk R, De Lima L, Eisenchlas J: Palliative care research in Latin America: Results of a survey within the scope of the Declaration of Venice. *J Palliat Med* 2008;11:717-722.
21. Dussel V, Bevilacqua M, Brage E, Requena M, Bravo A, Jerez C, et al. Prácticas y recursos utilizados en la provisión de cuidados paliativos a niños con cáncer en la Argentina. Mapeo nacional Cuidados Paliativos Pediátricos. 2014.
22. STROBE Statement—Checklist of items that should be included in reports of cross-sectional studies. Available from: http://www.strobe-statement.org/fileadmin/Strobe/uploads/checklists/STROBE_checklist_v4_cross-sectional.pdf. Accessed October 2016.
23. Gomez-Batiste X, Caja C, Espinosa J, Bullich I, Martinez-Munoz M, Porta-Sales J, et al: The Catalonia WHO demonstration project for palliative care implementation: Quantitative and qualitative results at 20 years. *J of Pain and Symptom Manage* 2012;43:783-794.
24. Espinosa J, Ela S, Beas E, Lasmarias C, Martinez-Munoz M, Gomez-Batiste X: Mapping service provision – a snapshot of palliative care in catalonia- what is the best methodology for mapping palliative care service provision? *European Journal of Palliative Care* 2013;20:182-187.
25. Participatory action research: Theory and methods for engaged inquiry. Chevalier J, Buckles D. UK, Routledge, 2013.
26. De Lima L, Pastrana T, Radbruch L, Wenk R: Cross-sectional pilot study to monitor the availability, dispenses prices, and affordability of opioids around the globe. *Journal of pain and symptom management* 2014;48:649-659.
27. Wenk R, Bertolino M, De Lima L: Analgesicos opioides en Latinoamerica: La barrera de accesibilidad supera la de disponibilidad. *Medicina Paliativa* 2004;11:148-151.
28. Ministerio de Salud. Atlas Federal de Legislación Sanitaria de la Republica Argentina. Available from: <http://www.legislaud.gov.ar/atlas/categorias/cuidados.html>. Accessed October 2016.

29. Sistema de Informacion Universitaria. Guia de Carreras Universitarias. Available from: <http://guiadecarreras.siu.edu.ar/>. Accessed October 2016.

30. Comision Nacional de Evaluacion y Acreditacion Universitaria. Buscador de carreras acreditadas. Available from: <http://www.coneau.gov.ar/CONEAU/>. Accessed October 2016.