

### Institutional care in four Latin American countries: the importance of fostering public information and evaluation strategies

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#### **ABSTRACT**

More than 8 million older people in Latin America depend on long-term care (LTC), accounting for 12% of people aged ≥ 60 years and almost 27% of those aged ≥ 80. It is crucial to develop sustainable strategies for providing LTC in the area, including institutional care. This special report aims to characterize institutional LTC in four countries (Brazil, Chile, Costa Rica and Mexico), using available information systems, and to identify the strategies adopted to support institutional care in these countries. This narrative review used nationwide, open-access, public data sources to gather demographic estimates and information about institutional LTC coverage and the availability of open-access data for the proportion of people with LTC needs, the number of LTC facilities and the number of residents living in them. These countries have a larger share of older people than the average in Latin America but fewer LTC facilities than required by the demand. National surveys lack standardization in defining disability, LTC and dependency on care. Information about institutional care is mainly fragmented and does not regularly include LTC facilities, their residents and workers. Data are crucial to inform evidence-based decisions to favor prioritization and to support advances in promoting policies around institutional LTC in Latin America. Although information about institutional care in the region is fragmented and insufficient, this paper profiles the four selected countries. It highlights the need for a better structure for datadriven LTC information systems. The lack of information emphasizes the urgency of the need to focus on and encourage research into this topic.

#### **Keywords**

Long-term care; aging; Latin America.

Although the population in Latin America is younger than the world average, the area is aging swiftly (1): by 2050, it is estimated that one of every four inhabitants in the area will be aged  $\geq$  60 years (2). More importantly, more than 8 million older adults in Latin America already depend on long-term care (LTC). Although there is no standard definition for LTC, it includes a set of health, social and personal care services aiming to support people with, or at risk of, a significant loss of intrinsic capacity (i.e. the composite of mental and physical capacities) to maintain a level of functional ability consistent with their basic rights and human dignity (3). These services can be delivered in different settings, including institutional contexts or at home.



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It is important to point out that the great majority of LTC is provided by unpaid caregivers, mainly family members (1-4).

A cross-national study of six countries in Latin America compared the percentages of older adults who needed help performing activities of daily living (ADL), a measure traditionally used to identify people with LTC needs. In Argentina, rates were 5.6% for men and 6.5% for women; in Brazil, the rates were 8.6% for men and 12.8% for women; in Chile, they were 7.1% for men and 9.9% for women; in Colombia, they were 6.2% for men and 8.4% for women; in Mexico, 7.5% for men and 12.4% for women; and in Uruguay, the rates were 5.5% and 9.4% (5).

In Latin America, Argentina, Chile, Costa Rica and Uruguay have implemented LTC initiatives following the recommendations of international organizations and in line with global initiatives, such as the Sustainable Development Goals and the United Nations Decade of Healthy Ageing (2021–2030) (6, 7). In the coming decades, the aging population in Latin America will challenge health and social security systems, pressuring governments to meet the population's needs, including by providing LTC and institutional LTC, as families will not be able to meet all of these needs.

Although institutional care accounts for a lower proportion of LTC needs in Latin America (8), the increased demand will pressure current LTC facilities, some of which are underfunded and insufficiently or inefficiently regulated and supervised (9-11). Even though cross-national information about institutional LTC in the area is scarce, we aim to present comparable information about it and characterize it in four countries (Brazil, Chile, Costa Rica and Mexico), using available information systems to identify strategies that support LTC. This information may help foster the development of the LTC sector according to each country's needs and capacities.

#### **METHODS**

For this narrative review, we used secondary databases as a source of information for Brazil, Chile, Costa Rica and Mexico. These countries were selected based on the availability of data and information about their current strategies implemented to address LTC; we aimed to include countries representative of most parts of Latin America. We searched for nationwide, open-access, public data sources, including demographic estimates (i.e. the percentage and absolute population aged  $\geq 60$ years and the percentage of the total population aged ≥ 80 years), information about coverage of institutional care and the share of older people with LTC needs living in LTC facilities. In addition, we evaluated the availability of data for the main indicators used for this research, including the overall proportion of the population with LTC needs and, for older populations, the number of LTC facilities in the country, and the number of older residents living in these facilities.

When necessary, researchers contacted governmental or nongovernmental statistical agencies or institutes to access data with support from the Pan American Health Organization's country offices. Data were compiled into individual reports for each country. When official sources of information could not be found, researchers looked for open-access data in peerreviewed literature and sources in which data collection methods were sufficiently transparent to allow for reproducibility. Data are presented using descriptive statistics through crossnational comparisons. For this study, we considered older people to be those aged  $\geq$  60 years.

#### **RESULTS**

#### Search results

We searched for official, publicly available, open-access data sources about institutional care in the four selected countries. In Mexico and Chile (12-14) access to institutional information about LTC was facilitated by the availability of solid and reproducible data from national surveys and statistics institutes; in Brazil, data from the Unified Social Assistance System (Sistema Unico de Assistência Social, or SUAS) censuses cover only notfor-profit facilities, and the only official census conducted in the LTC sector that included private institutions dates back almost 15 years (15). Despite solid official sources in Costa Rica, some institutions (such as the Costa Rican Social Security Fund [Caja Costarricense de Seguro Social and the Ministry of Health) limited access to their data due to an institutional cyberattack that occurred on May 30, 2022.

To assess the comparability of data from the countries evaluated, Table 1 briefly describes the demographic characteristics of the older adult populations in each country in 2021 and their projections for 2050. For all countries, the population aged ≥60 years represented more than 10% of the population and is projected to increase to 25-30% by 2050. Notably, Mexico has a younger population structure compared with Brazil, Chile

TABLE 1. Demographic characteristics in the four selected Latin American countries and Latin America overall, 2021 and projections for 2050

Country or area					Population aged ≥ 80 years (thousands)			Percentage of total population aged ≥ 80 years				
	2021	2050	Growth rate 2021–2050 <sup>a</sup>	2021	2050	Growth rate 2021–2050 <sup>b</sup>	2021	2050	Growth rate 2021–2050ª	2021	2050	Growth rate 2021–2050 <sup>b</sup>
Latin America	86 121	188 111	118.43	13.1	25.1	12.0	11 374	37 497	118.43	1.7	5.0	3.3
Brazil	30 483	68 871	125.93	14.2	29.6	15.4	3 492	12 973	271.5	1.6	5.6	4.0
Chile	3 477	6 338	82.28	17.8	30.6	12.8	580	1 846	218.3	2.9	8.9	6.0
Costa Rica	793	1 759	121.82	15.3	30.5	15.2	108	420	288.9	2.1	7.3	5.2
Mexico	15 088	40 384	167.66	11.9	24.6	12.7	2 167	7 125	228.8	1.7	4.9	3.2

a Values are percentages

b Values are percentage points.

Source: Table developed by the authors based on data from (16).

and Costa Rica; nevertheless, the rate of growth expected for the population of older adults in the coming years is similar. All countries currently have a larger share of their population defined as being older (aged ≥ 60) than the average in Latin America, and their populations are expected to age faster than the average in the area (i.e. higher growth rates), particularly when looking at the oldest among the old (i.e. those aged  $\geq 80$ ).

#### Comparison of long-term care needs and facilities

A brief overview of LTC in the four countries is presented in Table 2, including information about the availability of LTC facilities (16). All countries have a higher demand for LTC among older adults than can be cared for by the number of LTC facilities available, in addition to generally insufficient support for care provided in the community. Table 3 presents information about how long-term institutional care is implemented in these countries.

In Brazil, up to 9.5% of older adults need LTC, and more than 3.3 million older adults live with functional limitations in ADL; this proportion increases with age, reaching 18.5% among people aged ≥ 75 years (data not shown) (17). The institutional LTC sector in Brazil was influenced for years by the stigma of its origins (i.e. services were provided by charitable religious organizations to people in situations of extreme vulnerability), which limited investment in research and advances in the sector (21). The last Brazilian census on the LTC sector occurred in 2010 (15). New findings in 2021 estimated there had been a significant increase in the number and geospatial distribution of Brazilian LTC facilities: compared with the 2010 census, there has been 146% growth in the number of facilities (from 3 548 to 7 029). Nonetheless, 64% of the 5 570 Brazilian municipalities do not have any LTC facility for older people (22).

For Chile, data on dependency come from the national socioeconomic characterization survey (known as Encuesta Nacional de Caracterización Socioeconómica), which has been carried out periodically since 1990. According to this survey, 14.2% (488990) of those aged ≥ 60 and 39.2% (1 349 880) of those aged > 80 had some degree of dependency in 2017 (12). These figures are

unequally distributed across the population, and the greatest differences are based on socioeconomic conditions, with more vulnerable groups being disproportionately affected (lower socioeconomic group, 28.4% versus higher socioeconomic group, 8.4%). However, data provided by the National Service for Older Adults (Servicio Nacional del Adulto Mayor, or SEN-AMA) show that in 2022 there were 17 913 residents in LTC facilities (18). Despite this information, an unknown number of LTC facilities operate without authorization from the Chilean Ministry of Health.

The prevalence of disability in Costa Rica increases with age and is higher among women than men (23). According to the 2018 National Survey on Disability (Encuesta Nacional sobre Discapacidad) 35.1% of those aged ≥ 65 years (216 884 people) had a disability (24), and 47.7% (148 524) of people aged > 65 years received assistance for ADL (19). The population with LTC needs is concentrated in the Brunca, Central Pacific and Chorotega regions (24). Interestingly, this survey did not include residents in LTC facilities. The exact number of people residing in these facilities in Costa Rica has yet to be investigated, as there is no established profile for admission to institutional care. In the 2011 census, 4 000 people (0.9% of the older population) were living in such institutions. If these proportions are maintained, then around 7 000 residents would have been expected by 2018 (23), with 54.3% of them living with some degree of dependency, but no data are available to confirm this estimate (25).

The 2018 Mexican Health and Aging Study (Estudio Nacional de Salud y Envejecimiento en México) found that 11.23% of all adults ≥ 50 years had LTC needs; notably, this proportion increased to 21.25% when considering the population aged  $\geq$  70 years compared with 6.79% for adults aged 50–69 years (13). LTC facilities for older adults are unequally distributed across Mexico, with 32.9% of such facilities concentrated in the states of Jalisco, Mexico City and Nuevo León and 36.2% of older adults living in such facilities. Notably, the prevalence of older adults living in LTC facilities is only 0.19% in contrast with the estimated need for LTC for up to 20% of the population aged  $\geq$  70 years (14).

TABLE 2. Coverage of institutional long-term care in four Latin American countries, 2010–2022

Country	% (no.) of population with LTC needs (1)	% (no.) of people aged ≥ 60 with LTC needs according to national definition (2)	% (no.) of people aged ≥ 65 with LTC needs according to 2020 standardized definition (3)	No. of LTC facilities (4)	No. of people aged ≥ 60 living in LTC facilities (5)	% of older people with LTC needs living in a LTC facility (5)/(1)
Brazil	8.4% <sup>a</sup> (17.3 million)	9.5% <sup>a</sup> (3.3 million)	10.5% (2.1 million)	3549 <sup>b</sup>	103 000 <sup>b</sup>	3.12%
Chile	16.7%° (2.8 million)	14.2%° (488 990)	12.1% (282 587)	1125 <sup>d</sup>	17 913 <sup>d</sup>	3.66%
Costa Rica	18.2% <sup>e</sup> (670 640)	35.1%° (216 884)	16.4% (85 451)	96 <sup>f</sup>	ND	ND
Mexico	11.23% <sup>g</sup> (15.4 million)	21.25% <sup>9</sup> (1.72 million)	25.2% (2.5 million)	1504h	27 590 <sup>h</sup>	0.18%

LTC: long-term care; ND: no data.

a Data from reference (17), 2019.
b Data from reference (15), 2010.

Data from reference (12), 2017, based on the prevalence of people with moderate to high disability

d Data from reference (18), 2022 Data from reference (19), 2019

Data from reference (20), 2020

**Source:** Table prepared by the authors based on the sources cited in the footnotes.

TABLE 3. How long-term institutional care is implemented in the four selected Latin American countries, 2023

Characteristic	Country							
	Brazil	Chile	Costa Rica	Mexico				
Scope and access to institutional LTC	SUAS, public prosecutors and local governments usually mediate access to public and private not-for-profit facilities, but there is no transparency about how this access is regulated. In private for-profit facilities, access occurs according to the ability of residents or their family to pay the fees, the availability of beds and factors such as the location and quality of care.	SENAMA and local governments prioritize access to public LTC facilities based on social vulnerability criteria. There is no centralized system for prioritization for private for-profit and not-for-profit facilities, and access is based on the user's ability to pay and personal preferences. However, not-for-profit establishments can receive payment subsidies.	There is no established profile for admission to institutional care. Older people are institutionalized due to abandonment, health conditions (dependency) or family decisions	The number of LTC facilities in Mexico is low and unequally distributed. States with large metropolitan areas have the highest concentration of LTC facilities for older adults. According to census data, in 2020 the overall proportion of adults aged ≥ 60 years living in these facilities was 0.19%. Most older adults in Mexico live at home, either alone or under the informal care of family members.				
Statutory inspection bodies	ANVISA; SUAS; Municipal Councils of Older Adults; public prosecutors	SENAMA; Ministry of Health	Ministry of Health; CONAPAM	DIF; INAPAM				
Information systems	LTC facilities should report to local inspection bodies the occurrence of events such as a fall with injury, suicide attempt, and incidences of acute diarrheal disease, scabies and dehydration among residents, but there are no regulations about collecting and publicizing this information.	LTC facilities are overseen by the Ministry of Health, which reviews quality regulations, including those for infrastructure and staffing ratios. Additionally, since the beginning of the COVID-19 pandemic, SENAMA has maintained an internal registry that contains information about the number and characteristics of LTC facilities.	The indicators and procedures for authorizing and evaluating LTC facilities, whether public or private, for-profit or not-for-profit, are the responsibility of the Ministry of Health.  Outbreaks and mandatory reporting of diseases are notified to the Ministry of Health.  CONAPAM keeps an updated registry, accredited by the Ministry of Health, of citizens and legal immigrants, but this includes only those who receive a subsidy from CONAPAM.	Information on LTC facilities is registered using a component of the 2020 national census conducted by INEGI, which evaluated Social Assistance Accommodation ( <i>Alojamento de Assistência Social</i> ). Data about LTC facilities include the number of beds, available spaces and facilities and equipment; civil protection services; number and type of toilets; number of showers; adaptations for people with disabilities; and overall capacity. Public LTC facilities register their data directly with DIF and INAPAM.				
Financing of institutional LTC	No regulation defines the amount or percentage of financing that the government must transfer to fund public and not-for-profit LTC facilities. Most not-for-profit facilities rely on their legal prerogative to use up to 70% of residents' income to support their funding; donations and local public—private partnership funding cover the remainder of their costs. Residents' and their family's incomes pay for care in for-profit facilities, without tax reimbursement or financial compensation.	Multiple financing mechanisms are provided by SENAMA to subsidize private LTC facilities, including funds through FONASA for infrastructure improvement, operation, and payment for bed-days. However, there is no regulation about how facilities can use income from each resident.	For public LTC facilities, CONAPAM determines the technical criteria for distributing public financial resources for programs and services provided to older adults. The Social Protection Board (Junta de Protección Social) is empowered by law to transfer money to support programs for the management of organizations financing the basic needs of residents in LTC facilities. Pensions for older adults complement other sources of financing. In the case of private LTC facilities, costs are covered by the older person's family.	INAPAM and DIF concentrate on the 107 public LTC facilities receiving federal financing, which represent only 7.1% (107/1 504) of such facilities. The rest are privately operated (i.e. registered as civil associations, private assistance institutions, civil societies, religious associations, market associations or in an unspecified category).  For all privately operated LTC facilities, costs are usually covered by residents, their families or donations provided directly to the facility.				

ANVISA: Agência Nacional de Vigilância Sanitária (Brazilian National Health Surveillance Agency); CONAPAM: Consejo Nacional de la Persona Adulta Mayor (National Council for Older Adults); DIF: Sistema Nacional para el Desarrollo Integral de las Familias (National System for the Integral Development of the Family); FONASA: Fondo Nacional de Salud (public health insurance system); INAPAM: Instituto Nacional de Ias Personas Adultas Mayores (National Institute for Older Adults); INEC: Instituto Nacional de Isadistica, Geografia y Informatica (National Institute for Statistics, Geography and Information); LTC: long-term care; SENAMA: Servicio Nacional del Adulto Mayor (National Service for Older Adults); SIStem Minica de Assistência Social (Unified Social Assistance System).

Source: Table developed by the authors based on the results of their research.

It is important to emphasize the lack of data about and standardized information to describe LTC, which hinder the ability to make comparisons across countries. Instead of considering these as caveats, it is helpful to see them as representing an opportunity for international standardization. Some specific

challenges must be considered. The first is the use of different definitions for disability, particularly for older adult populations with LTC needs. Second, there is no universal definition of an LTC facility: different types of facilities offer different types of services in each country.

#### Long-term care policies and institutional care

Brazil. The Brazilian National Health Surveillance Agency (Agência Nacional de Vigilância Sanitária, or ANVISA) establishes minimum criteria for LTC facilities and has regulatory and inspection powers. In many Brazilian municipalities, facilities must also be registered with the Municipal Councils of Older Adults (Conselhos Municipais da Pessoa Idosa), and in some states, public prosecutors also exercise supervisory authority. Where these types of supervision exist, facilities are registered, and most indicators are based on deficits and diseases (26). LTC facilities are defined as "governmental or nongovernmental institutions, of a residential nature, intended for the collective residence of older persons" (27). In not-for-profit public and private LTC facilities, the processes for admitting residents and caring for them over the long term are not always clear and often depend on legal demands (i.e. sometimes legal processes are required to obtain a bed), social vulnerabilities or determining that a person's family is unable to care for them or they have no family to care for them. Entry into for-profit private facilities is regulated by the ability of residents and their families to afford their stay, without any kind of subsidy or tax compensation (28). There is no requirement that the staff at these facilities include health care personnel. Brazil is starting to develop a national care policy that includes LTC and is based on interministerial and intersectoral actions. There is no official curriculum for education or training, or support for formal or informal caregivers: families and LTC facilities are usually the primary sources of LTC for older adults living with impaired functional abilities. The private LTC facility sector, however, has grown exponentially during the past decade, and the lack of regulations has increased the number of unregistered LTC facilities across the country (22).

**Chile.** In Chile, the current public offering partially responds to LTC needs through a home-based program for people with severe dependency provided by primary care centers and a local support and care network (Red Local de Apoyo y Cuidados) (29). Although these programs include a variety of LTC services, a significant care gap remains. As a result, the government has pledged to implement a nationwide strategy to address the LTC gap (30); however, to date, no progress has been made on its design and implementation. However, institutional LTC services are provided by a mix of public, private not-for-profit, and private for-profit facilities. Although there are only 19 public facilities, the main policy to increase access has been to provide subsidies to private not-for-profit facilities (31). These institutions require authorization from the Ministry of Health and must have a technical director acting as the facility manager and trained personnel to assist residents with activities such as eating and toileting. The standard of staff required for each facility (i.e. ratio of caregivers to residents) varies depending on the residents' characteristics (i.e. mainly based on their level of functionality) (32).

Costa Rica. In Costa Rica, older people are institutionalized when they are abandoned, are dependent or as a result of a family decision. The economic resources needed to fund LTC needs come from the National Council for Older Adults (Consejo Nacional de la Persona Adulta Mayor, or CONAPAM) through Law no. 7972, for the Creation of Tax Charges on Liquors, Beers and Cigarettes (Ley para la creación de cargas tributarias sobre licores, cervezas y cigarrillos), and Law no. 8783, the amendment to the Law on Social Development and Family Allowances (Ley

de Desarrollo Social y Asignaciones Familiares) (33). In other cases, the Social Protection Board (Junta de Protección Social), a decentralized public sector entity that oversees the administration, sale and commercialization of all lotteries) transfers money, under Law no. 8718, to support programs for the management of organizations to finance the basic needs of residents in LTC facilities. In public facilities, older adults' pensions complement other sources of financing. In the case of private LTC facilities, the costs are covered by the older person's family (34). In 2012, the government regulated the indicators and procedures for the qualification and evaluation of LTC facilities (34). According to the Health Services Unit (Unidad de Servicios en Salud) of the Ministry of Health, 96 facilities are authorized to operate, of which 72 are not-for-profit and 24 are for-profit. In 2021, 74 facilities were registered with CONAPAM (33). This indicator, however, does not include all of the facilities authorized by the Ministry of Health. The National Household Survey (Encuesta Nacional de Hogares) (35) and the Disability Survey (19), which include data up to 2018 and 2022, respectively, do not include people living in LTC facilities, thus creating an information vacuum. It is the same for workers in these facilities.

**Mexico.** In Mexico, there is no national government policy that describes minimum standards of care, institutional organization, infrastructure, operation and the human resources necessary for LTC facilities (36). The management of public LTC facilities is under the supervision of two main regulators: the National System for the Integral Development of the Family (Sistema Nacional para el Desarrollo Integral de las Familias, or DIF) and the National Institute for Older Adults (Instituto Nacional de las Personas Adultas Mayores, or INAPAM) (37, 38). INAPAM and DIF regulate 107 LTC facilities, representing only 7.1% of the 1504 such facilities in Mexico, according to data from the 2020 Social Assistance Accommodation Census (Censo de Alojamientos de Asistencia Social) (39). Individual state government offices manage policies related to the prioritization of care groups, care modalities and the services these facilities offer (40). In addition to regulation by public entities, such as DIF and INAPAM, each LTC facility has its own regulatory body, which complicates the implementation of unified approaches at the national, state and regional levels. Private LTC institutions have prices that are often out of reach for most of the population and, thus, they are inaccessible for many older adults in Mexico. Because of this, most older adults are cared for at home, resulting in major economic pressure and increasing the number of older adults whose care is provided primarily by informal caregivers. According to data from the 2019 National Survey on the Use of Time (Encuesta Nacional sobre Uso del Tiempo) (41), approximately 10.4% of adults aged ≥ 18 years are involved in providing special care for household members, regardless of their age, who have a chronic or temporary illness or disability, with carers spending an average of 23.4 hours per week caring for one person in their household at home. About 12.9% of adults aged ≥18 years spend an average of 15.8 hours a week caring for a household member aged ≥ 60, including an average of 19.1 hours weekly that are devoted to passive care alone. This care is not remunerated or supported financially by any public entity.

#### Availability of data about institutional care

A 2014 survey of Brazilian LTC facilities included 1451 units and 53 643 residents (42). These are the most up-to-date

national data in Brazil, but the results are not publicly available. The last federal census of the sector was published in 2010 (15). Although there are national surveys of dependence on care in the general population, it is unclear whether people living in LTC facilities were included (17). In addition, there is a lack of robust and open-access longitudinal databases relevant to the institutional care sector in Brazil.

In Chile, the National Service for Older Adults (SENAMA) keeps an updated nationwide registry of formal and informal facilities (i.e. those without authorization from the Ministry of Health). During the first year of the COVID-19 pandemic, SENAMA hired new professionals to work in the field to improve the completeness and quality of data by actively searching for unregistered facilities and developing an electronic platform, with the support of the company Unholster (Santiago, Chile). Although these data are not publicly available, a SENAMA website that aims to guide people in making decisions about choosing facilities contains data on the number and location of the registered facilities (https://www.eleamchile.cl/).

The cyberattack on May 30, 2022, in Costa Rica disabled access to several public websites (such as those of the Costa Rican Social Security Fund, the Ministry of Health and CONAPAM) and had delayed the digital recording of data by institutions at the time this article was written. Before each affected government institution disabled its official web pages, most of the information was extracted from the institutional websites; however, it was necessary to contact representatives at each institution to ask them to provide public information.

In Mexico, the National Institute for Statistics, Geography, and Information (Instituto Nacional de Estadística, Geografía y Informatica, or INEGI) conducts a Social Assistance Accommodation Census that includes characteristics of LTC facilities for older adults; this census is conducted along with the national census and is available for 2015 and updated for 2020 (https:// www.inegi.org.mx/programas/caas/2015; https://www.inegi. org.mx/programas/ccpv/2020/#Microdatos). The census provides a holistic characterization of LTC facilities and residents' needs. These data are publicly available in aggregated form for LTC residents, staff members and facilities all over Mexico. No individual- or facility-level data are available. These data are expected to be updated in the upcoming midterm census in 2025. Furthermore, the Ministry of Health keeps a directory of all LTC facilities registered in Mexico (http://dnias.dif. gob.mx/).

#### **DISCUSSION**

Even though information about institutional care in Latin America is fragmented due to the models used in the official and continuous information registers, this paper developed a profile of LTC facilities in four countries and highlighted the need for a better structure to deliver LTC due to the projected increase in demand for such services that will arise as a result of ageing populations. Although indicators of socioeconomic status and health coverage are continually collected through household surveys, there is a lack of reliable information regarding institutional LTC in Latin America (43).

Information can be and has been used in different countries to monitor and improve care (44, 45). In some countries, national information systems have been developed to provide basic data to monitor compliance with regulations and

to assure the quality of LTC facilities. Such information is of interest to many stakeholders, including consumers, caregivers, provider organizations, facility managers, policy-makers and researchers. These data can range from those collected during inspections to reporting-based regulatory information and to data gathering, but these indicators require individual-level data collection, including information based on valid, reliable and timely data about the care provided, the recipients of care, facilities and caregivers. Publicly reported measures of institutional care should reflect the values that society, the workforce, older residents and their advocates attribute to different aspects of quality (44, 46-48).

The social relevance of acknowledging this information relies not only on providing basic information to monitor compliance with regulations but also on moving away from looking at inputs and towards looking at quality measures that reflect providers' performance as well as the outcomes of interventions adopted in LTC facilities, considering that they are a cornerstone to fostering equitable and well-thought-out public policies for developing the sector in Latin America. Therefore, providing up-to-date and open-access information about the demand for and supply of available services for LTC in each country is an essential first step towards improving the quality of care and in the evolution of the sector.

Promoting a healthy and open debate about the importance of establishing new paradigms for LTC in Latin America is essential to achieve the goals proposed in the United Nations Decade of Healthy Ageing (49). Information, monitoring and evaluation systems, as proposed by the World Health Organization (WHO) (3), are key to guaranteeing a person-centered approach to caring for older residents, their families and caregivers, and fostering better relationships among society, LTC facilities and their workforce (49). As this paper acknowledges, there is work to be done in Brazil, Chile, Costa Rica and Mexico to achieve integrated, up-to-date and reliable LTC information systems, not only to evaluate progress at the national level but also to evaluate it among countries inside and outside the area. This is an enormous challenge, and countries can start by identifying LTC facilities and their populations, creating national registries and defining the minimum data set necessary to monitor and evaluate the performance of these facilities; countries can pilot these projects in a particular region or develop a case study before scaling up these initiatives (7).

#### **Limitations**

Information about institutional LTC in Latin America is scarce and is not standardized; thus, comparisons between countries are difficult. Despite efforts to adopt transparent reporting practices for making health estimates across countries, limitations to external validity still need to be addressed. The information presented in this paper does not represent the reality in all of Latin America; information is country-specific, and it shows there are important differences between the four selected countries, which prevents results from being generalized to other contexts.

These data gaps, however, represent the innovation of this paper. This is one of the first attempts to highlight the relevance of the topic by identifying information gaps in countries and highlighting the need to move forward with a minimum set of data to be collected and systematized in countries in Latin America.

#### **Conclusions**

This paper provides information about the delivery and organization of institutional LTC in four countries in Latin America. In addition to presenting a profile of LTC in these countries, our results highlight the lack of standardized, public and openaccess data about LTC and LTC facilities, including information concerning the quality of care and facility management. Despite the relevance of LTC for the development of national health and social security systems, and for strengthening public policies for the sector, few national surveys address these issues, and there is a lack of minimum data for LTC in the countries evaluated. So far, few initiatives for improving LTC strategies have been developed, and those that exist are mostly poorly articulated and insufficiently comprehensive to meet growing demands from the population.

There is a significant need to increase LTC provision in Latin America to address the increase in demand predicted by demographic and epidemiological transitions. To make progress in policies and practices, it is crucial to fill in gaps in information about LTC by ensuring there is future research and that official information is gathered in national surveys. The WHO Framework for countries to achieve an integrated continuum of long-term care can be used as a strategy to support countries in making progress, while considering the cultural

and socioeconomic specifics of low- and middle-income countries (3).

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# Atención en centros de cuidados a largo plazo en cuatro países de América Latina: importancia de fomentar la información pública y las estrategias de evaluación

#### **RESUMEN**

En América Latina, más de 8 millones de personas mayores dependen de los cuidados a largo plazo (CLP), lo que representa el 12% de las personas de 60 años o más y casi el 27% de las de 80 años o más Resulta crucial elaborar estrategias sostenibles para la prestación de CLP en la región, incluida la atención en centros de CLP. Este artículo especial tiene como finalidad determinar las características de la atención prestada en centros de CLP en cuatro países (Brasil, Chile, Costa Rica y México), utilizando los sistemas de información disponibles, así como determinar cuáles son las estrategias adoptadas en estos países para brindar apoyo a la atención en centros de CLP. En esta revisión descriptiva se utilizaron fuentes de datos públicas, de libre acceso y de ámbito nacional para recopilar estimaciones demográficas e información sobre la cobertura de la atención en centros de CLP, así como sobre la disponibilidad de datos de libre acceso acerca de la proporción de personas con necesidades de CLP, el número de centros de CLP y su correspondiente número de residentes. Estos países tienen una proporción de personas mayores superior a la media de América Latina, pero menos centros de CLP de los necesarios para cubrir la demanda. En las encuestas nacionales no hay una definición estandarizada de la discapacidad, los cuidados a largo plazo y la dependencia. La mayor parte de la información sobre la atención en centros de CLP está fragmentada y no incluye datos periódicos sobre los centros de CLP existentes, sus residentes o sus trabajadores. Estos datos son cruciales para fundamentar decisiones basadas en la evidencia destinadas a propiciar la priorización y brindar apoyo a los avances en la promoción de políticas en materia de centros de CLP en América Latina. Aunque la información sobre la atención en centros de CLP en la región es fragmentaria e insuficiente, en este artículo se presenta el perfil de los cuatro países seleccionados. Se resalta la necesidad de mejorar la estructura de los sistemas de información sobre CLP basados en datos. Esta falta de información pone de relieve la necesidad urgente de centrarse en este tema y fomentar la investigación al respecto.

Palabras clave

Cuidados a largo plazo; envejecimiento; América Latina.

## Cuidados institucionais em quatro países da América Latina: a importância de promover informações públicas e estratégias de avaliação

#### **RESUMO**

Na América Latina, mais de 8 milhões de pessoas idosas dependem de cuidados de longa duração (CLD), o que representa 12% das pessoas com mais de 60 anos e quase 27% das pessoas com mais de 80 anos. É fundamental criar estratégias sustentáveis para oferecer CLD na região, inclusive cuidados institucionais. O objetivo deste relatório especial é caracterizar CLD institucionais em quatro países (Brasil, Chile, Costa Rica e México), usando os sistemas de informação disponíveis, e identificar as estratégias adotadas para apoiar os cuidados institucionais nesses países. Esta revisão narrativa usou dados públicos de acesso aberto de âmbito nacional para coletar estimativas demográficas e informações sobre a cobertura de CLD institucionais e a disponibilidade de dados de acesso aberto sobre a porcentagem de pessoas com necessidades de CLD, o número de instituições de CLD e o número de residentes nessas instituições. Esses países têm uma parcela maior de pessoas idosas do que a média da América Latina, mas menos instituições de CLD do que a demanda exige. Falta padronização na definição de incapacidade, CLD e dependência de cuidados nas pesquisas nacionais. Em sua maior parte, as informações sobre cuidados institucionais são fragmentadas e não incluem instituições de CLD, seus residentes e trabalhadores de maneira regular. É essencial usar dados para guiar decisões baseadas em evidências a fim de favorecer a priorização e apoiar avanços que promovam políticas para CLD institucionais na América Latina. Embora as informações sobre cuidados institucionais na região sejam fragmentadas e insuficientes, este documento traça o perfil dos quatro países selecionados, destacando a necessidade de uma estrutura melhor para sistemas de informações de CLD orientados por dados. A falta de informações ressalta a urgência de aumentar o foco no tópico e encorajar pesquisas sobre o assunto.

Palavras-chave

Assistência de longa duração; envelhecimento; América Latina.