

Cancer Survivorship in Latin America: Current Status and Opportunities

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PURPOSE The number of cancer survivors is increasing globally although the status of cancer survivorship care provision and research in developing countries is limited. This study aimed to review published literature and available guidelines and/or recommendations to inform cancer survivorship care in Latin America.

METHODS Embase, Web of Science, Scopus, PubMed, and SciELO were systematically searched for articles and guidelines and/or recommendations published through December 31, 2020. Our search terms included cancer, survivors, neoplasm, cancer, survivorship, survivor, follow-up studies, and the name of the countries. We categorized the articles by country, year, cancer type(s), language, and domain of cancer survivorship care. We also searched governmental health agencies websites in all Latin American countries.

RESULTS Our literature review found 664 articles for inclusion. The number of publications increased over time. Brazil had most of the survivorship research (n = 483, 72.7%). The most common topics included surveillance and management of psychosocial effects (n = 237, 35.7%) and physical effects (n = 230, 34.6%). Prevention and surveillance for recurrences and health promotion and disease prevention were each addressed by about 10% (n = 71) of the publications. Although close to half of the publications included more than one cancer, 28.9% (n = 192) focused solely on breast cancer. We found no guidelines and/or recommendations explicitly focusing on Latin America in the reviews of the literature or the national governmental institutions' websites.

CONCLUSION We found a growing body of cancer survivorship publications, mainly focusing on psychosocial and physical effects, although no cancer survivorship guidance and/or recommendations focused on Latin America were identified. Expanding research across Latin American countries and covering a broader spectrum of cancer survivorship care is needed. Development of guidelines may further promote provision of quality care for this growing population of cancer survivors.

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INTRODUCTION

Cancer is a worldwide health problem with a rising incidence¹; however, the number of cancer survivors (or individuals from the time of diagnosis until the end of life) has steadily increased.² The consistent growth of this population has gained recognition as a distinct phase of cancer care over the past few decades. In the United States, the number of survivors has increased from 3 to 17 million, with the expectation of reaching 22 million in 2030.^{2,3} In 2006, the US Institute of Medicine (IOM; now the National Academy of Medicine) established a set of recommendations to help patients transition from active treatment to life post-treatment care and improve their health care and quality of life.⁴ Over the years since the IOM report, much progress has been made, particularly in gaining full recognition for this phase of cancer care, guideline development, funding opportunities, and health care

policy.⁵ Similar to the advances made in the United States, significant strides have been made in developed countries, particularly Europe, Canada, and Australia.⁶ However, less focus has been placed on cancer survivorship in developing countries, including Latin America.^{6,7}

According to GLOBOCAN, of more than 18 million new cancer cases estimated for 2018, 7.8% were in Latin America and the Caribbean (1.4 million cases).^{1,8} Although there are no formal estimates specifically for cancer survivors (the 5-year cancer prevalence in this region is close to 4 million), this number is also likely to increase, given cancer mortality rates in this region are predicted to decline.^{9,10} As survivorship has become a distinct phase of care in North America, Europe, and Australia, with resultant development of evidence-based guidelines, a focus on survivorship in Latin America is needed. Our study aimed to

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CONTEXT

Key Objective

What are the published literature and available guidelines and/or recommendations to inform cancer survivorship care in Latin America?

Knowledge Generated

Although we found no formal cancer survivorship guidelines or recommendations, there is a steady growth in the number of studies focusing on cancer survivorship care published in Latin America. There are no sufficient data to be used to translate into guidelines. The science of survivorship care delivery in Latin American must evolve to meet this need.

Relevance

Developing guidelines for or adapted to Latin America and translating existing cancer survivorship research into care delivery would improve cancer survivorship care throughout Latin America.

systematically identify and characterize the available published literature and guidelines and/or recommendations available to inform cancer survivorship care in Latin America. In this article, we present the current status and offer opportunities to promote cancer survivorship in the region.

METHODS

Scoping Literature Review

We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement for scoping review.^{11,12} We developed a review process including the following steps: (1) We defined guidelines or recommendations as any paper in which the abstract specified how to follow a cancer survivor. (2) To identify and characterize survivorship research in Latin America more broadly, we then searched EMBASE, PubMed, SciELO, Scopus, and Web of Science for published articles through December 31, 2020. We did not restrict to a starting date; the first article that met the criteria was in 1999. We included articles written in English, Portuguese, or Spanish. We used MESH (Medical Subject Headings) terms as they are universally used in indexing journal articles and books in the life sciences. The combinations of the terms used are listed in [Table 1](#).

We found a total of 4,908 articles (315 from EMBASE, 782 from CINAHL, 2,424 from PubMed, 298 from SciELO, and 1,089 Web of Science). A total of 1,566 articles were duplicates and were removed. Articles were excluded if they were primarily editorials and solely described study protocols, letters, abstracts of congresses, or books. The article abstracts were reviewed for eligibility, and full papers were reviewed if eligibility was not clear from the abstract review alone. [Figure 1](#) shows the flow diagram according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement.¹¹

We categorized the articles on the basis of the country, cancer type(s), year, and language. We also categorized the topics of focus according to the Quality of Cancer Survivorship Care Framework,¹³ specifically *prevention and*

surveillance for recurrence and new cancers, including assessment of risk predisposition, referral to genetics evaluation, recommendations for adjuvant and risk-reducing strategies, assessment of adherence, and cancer surveillance strategies; *surveillance and management of physical effects*, including assessment and management of physical symptoms and conditions according to cancer and treatment exposures; *surveillance and management of psychosocial effects*, including assessment and management of psychological, financial, employment, and interpersonal symptoms and conditions according to cancer and treatment exposures; *surveillance and management of chronic medical conditions*, including evaluation and treatment of noncancer medical conditions using disease-specific indicators and medication reconciliation; and *health promotion and disease prevention*, including prevention-focused visits, age- and gender-appropriate cancer screening, assessment of lifestyle behaviors, vaccination, and others.

We also categorized health care delivery focused domains, including *clinical structure*, such as the type of health care delivery environment, the status of cancer survivorship providers' education and training, availability of needed specialty care and health care professionals, access to care enabled, availability of health information systems, and opportunities for research participation offered; *communication and decision making*, including information provided and understanding assessed while considering health literacy, assessment of self-management skills and support provided, advanced care planning, and shared decision making, among others; *care coordination*, including discussion with the patients and health care providers; and *patient and caregiver experience*, including satisfaction with provider and health care delivery setting.

One author (A.A.-G.) reviewed all articles. To check for potential error or bias, another researcher (L.N.) reviewed a random 10% selection. There was 90% initial consistency in the results, with the inconsistency because of a mismatch in the designation of quality care domains; this was

TABLE 1. Search Terms

EMBASE (Latin America OR Central America OR South America OR Argentina OR Brazil OR Bolivia OR Chile OR Colombia OR Costa Rica OR Cuba OR Dominican Republic OR Ecuador OR El Salvador OR Guatemala OR Haiti OR Honduras OR Mexico OR Nicaragua OR Panama OR Paraguay OR Peru OR Puerto Rico OR Uruguay OR Venezuela) AND (cancer survivors OR ((neoplasm OR cancer) AND (survivorship OR survivor OR follow-up studies)))
CINAHL (Latin America OR Central America OR South America OR Argentina OR Brazil OR Bolivia OR Chile OR Colombia OR Costa Rica OR Cuba OR Dominican Republic OR Ecuador OR El Salvador OR Guatemala OR Haiti OR Honduras OR Mexico OR Nicaragua OR Panama OR Paraguay OR Peru OR Puerto Rico OR Uruguay OR Venezuela) AND (cancer survivors OR ((neoplasm OR cancer) AND (survivorship OR survivor OR follow-up studies)))
PubMed ("Latin America"[All Fields] OR "Central America"[All Fields] OR "South America"[All Fields] OR "Argentina"[All Fields] OR "Brazil"[All Fields] OR "Bolivia"[All Fields] OR "Chile"[All Fields] OR "Colombia"[All Fields] OR "Costa Rica"[All Fields] OR "Cuba"[All Fields] OR "Dominican Republic"[All Fields] OR "Ecuador"[All Fields] OR "El Salvador"[All Fields] OR "Guatemala"[All Fields] OR "Haiti"[All Fields] OR "Honduras"[All Fields] OR "Mexico"[All Fields] OR "Nicaragua"[All Fields] OR "Panama"[All Fields] OR "Paraguay"[All Fields] OR "Peru"[All Fields] OR "Puerto Rico"[All Fields] OR "Uruguay"[All Fields] OR "Venezuela"[All Fields]) AND ("cancer survivors"[All Fields] OR ((neoplasm"[All Fields] OR "cancer"[All Fields]) AND ("survivorship"[All Fields] OR "survivor"[All Fields] OR "follow-up studies"[All Fields])))
SciELO (Latin America OR Central America OR South America OR Argentina OR Brazil OR Bolivia OR Chile OR Colombia OR Costa Rica OR Cuba OR Dominican Republic OR Ecuador OR El Salvador OR Guatemala OR Haiti OR Honduras OR Mexico OR Nicaragua OR Panama OR Paraguay OR Peru OR Puerto Rico OR Uruguay OR Venezuela) AND (cancer survivors OR ((neoplasm OR cancer) AND (survivorship OR survivor OR follow-up studies)))
Web of Science (Latin America OR Central America OR South America OR Argentina OR Brazil OR Bolivia OR Chile OR Colombia OR Costa Rica OR Cuba OR Dominican Republic OR Ecuador OR El Salvador OR Guatemala OR Haiti OR Honduras OR Mexico OR Nicaragua OR Panama OR Paraguay OR Peru OR Puerto Rico OR Uruguay OR Venezuela) AND (cancer survivors OR ((neoplasm OR cancer) AND (survivorship OR survivor OR follow-up studies)))

Abbreviation: CINAHL, Cumulative Index to Nursing and Allied Health Literature; SciELO, Scientific Electronic Library Online.

amended by adding an option to include more than one domain for each paper.

Governmental Health Agencies

We aimed to identify any recommendations and/or guidelines for cancer survivorship issued by each of the countries' governmental health agencies, specifically the Ministry of Health and National Cancer Institutes. We searched the websites for each of these sources in all countries listed earlier, including the survivorship and cancer survivor terminology. The initial search was conducted in 2019, updated in the spring of 2020 and again in April 2021.

RESULTS

Literature Review

We found 664 articles focused on cancer survivorship in Latin America. No guidelines or recommendations focused

on the Latin America were found. Most (86.4%) of the papers were in English, 9.9% in Spanish, and 3.1% in Portuguese. Table 2 shows the characteristics of the articles. The most common topics were surveillance and management of psychosocial effects (35.7%) and physical effects (34.6%). The domains of prevention and surveillance for recurrences and health promotion and disease prevention were each addressed by about 10% of the publications. Table 3 shows the frequency of cancer types among the published literature. Around 28.9% of the studies were focused on survivors of breast cancer, and 48.6% were on more than one type of cancer. Figure 2 shows the number of articles by year of publication. Almost half (48.0%) of the articles were published in the last 5 years. Brazil had the majority of studies of survivorship (72.7%; Fig 3).

Governmental Health Agencies

Among 38 sites searched, we found no guidelines on survivorship developed in Latin America. However, we did find guidelines that focused on the treatment phase of cancer care. Only a general patient-directed survivor educational guide made by the Mexican National Cancer Institute was found.¹⁴

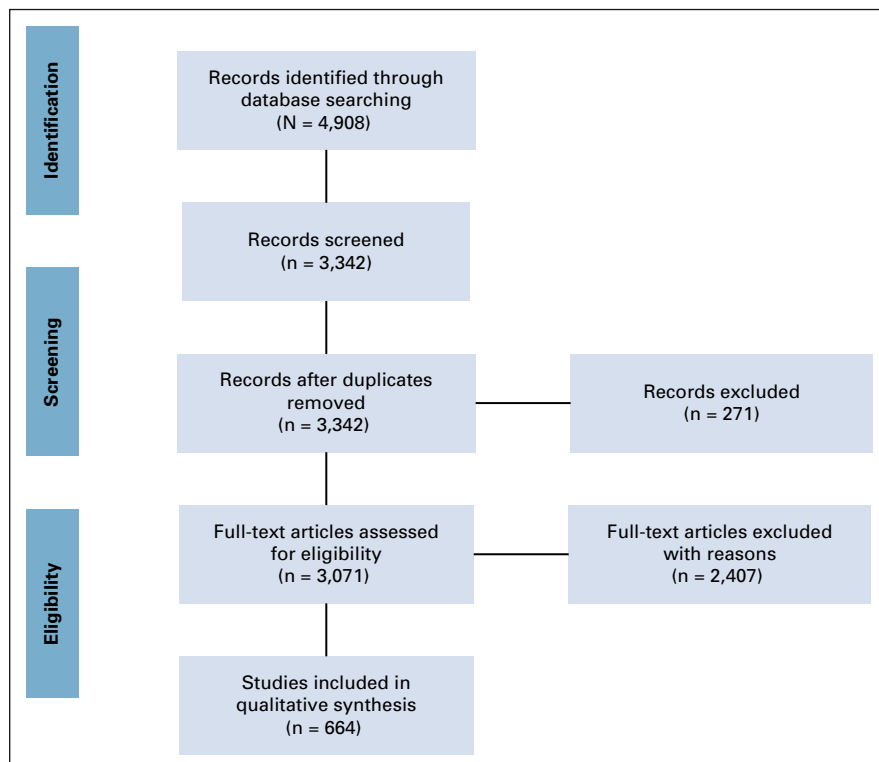
DISCUSSION

The high prevalence of cancer and the reduction of mortality rates have resulted in the emergence of a new population of cancer survivors whose number is increasing worldwide, including in developing countries such as those in Latin America.^{2,6} Our scoping review of published articles revealed a steady growth in research studies focused on cancer survivorship issues in Latin America, with the most common domains of the studies being surveillance and management of psychosocial and physical effects. Most of the research was conducted in Brazil. No specific survivorship guidelines and/or recommendations for follow-up care explicitly focusing on Latin America were found in our literature review or in the review of governmental agencies.

Our findings regarding the focus of cancer survivorship research are consistent with those from the United States.¹⁵ As in our study, breast cancer has been the predominant cancer type in American survivorship literature, and most research has focused on the psychosocial domain of cancer care. The most common cancers in Latin American and the Caribbean are breast, prostate, colorectal, lung, and stomach cancers.¹⁶ As emphasized in the US literature, although additional effort is needed across all prevalent cancers, Latin American studies should expand focus on other cancer types and domains of survivorship care.¹⁷

We found the largest number of studies in Brazil. Brazilian health care is heterogeneous; structured and well-equipped cancer centers are located mostly in the southeast and southern states. Brazil has pioneered cancer survivorship programs and offers multidisciplinary long-term follow-up.⁷ Although we did not find that Brazil to

FIG 1. Flow diagram of database search.



have a guideline focusing on adult cancer survivors, we found a guideline focusing on cardiac effects of pediatric cancer treatment.¹⁸ Furthermore, Brazil is part of a Breast Health Global Initiative consensus statement for resource allocations in low- and middle-income countries. This initiative recommends health professional education that focuses on the management of physical and psychosocial long-term treatment complications.¹⁹ This initiative also emphasizes the importance of patient education. Community awareness of survivorship issues was also identified as an essential part of supportive care programs. Other recommendations include screening and managing psychosocial distress, long-term treatment-related complications, and monitoring survivors for recurrences or development of second primary malignancies.

Although the recent growth in survivorship research literature in Latin America is encouraging, progress in advancing cancer survivorship care has been limited.^{6,17} Efforts must focus on translating this research into care and policies that support and drive routine, widespread quality care delivery. We propose that Latin American countries consider the 10 IOM recommendations and take appropriate steps to promote cancer survivorship in the region.⁴ First, raising awareness of the needs of the survivors and establishing survivorship as a distinct phase of cancer care is needed (Recommendation 1). By searching Google, one can find many survivorship-focused events and news articles in Latin American countries. Continuing advocacy strategies and education of health care providers

are essential steps in promoting awareness. The second IOM recommendation focused on the provision of a survivorship care plan (SCP), a summary of their cancer and treatment, and with follow-up recommendations. Our search did not find literature addressing SCPs. On the basis of the challenges in their implementation in the United States²⁰ and the move away from SCPs by the United States Commission on Cancer, Latin American countries may continue to strive toward providing SCPs but focus attention on cancer survivors through programmatic development.²¹

The third IOM recommendation advised the development of guidelines for cancer survivorship care. Such guidelines have already been published in North America and Europe.²² Our search revealed only one such guideline in Latin America that focused on childhood cancers.²³ Although countries in Latin America may choose to develop their guidelines, it may be more useful to adapt guidelines that have been developed by organizations in other countries, such as the American Society of Clinical Oncology, American Cancer Society, National Comprehensive Cancer Network, and the European Society for Medical Oncology, among others. The American Society for Clinical Oncology has previously released the Resource-Stratified Guideline; however, this has mainly focused on prevention and treatment.²⁴ A similar guideline for survivorship care may be developed. Quality in cancer survivorship care delivery should be measured (Recommendation 4). This is a critical element in promoting cancer survivorship care although the selection of measures that are clinically

TABLE 2. Characteristics of Articles (n = 664)

Characteristic	n (%)
Domain	
Surveillance and management of psychosocial effects	237 (35.7)
Surveillance and management of physical effects	230 (34.6)
Prevention and surveillance for recurrence and new cancers	71 (10.7)
Health promotion and disease prevention	67 (10.1)
Clinical structure	58 (8.7)
Communication and decision making	43 (6.5)
Patient and caregiver experience	21 (3.2)
Surveillance and management of chronic medical conditions	10 (1.5)
Care coordination	10 (1.5)
Country	
Brazil	483 (72.7)
Mexico	71 (10.7)
Colombia	35 (5.3)
Puerto Rico	27 (4.1)
Argentina	24 (3.6)
Chile	18 (2.7)
Peru	7 (1.1)
Costa Rica	6 (0.9)
Venezuela	6 (0.9)
Uruguay	4 (0.6)
Cuba	4 (0.6)
Panama	4 (0.6)
Guatemala	3 (0.4)
Bolivia	2 (0.3)
Ecuador	2 (0.3)
Haiti	2 (0.3)
Honduras	2 (0.3)
El Salvador	1 (0.2)
Nicaragua	1 (0.2)
Paraguay	1 (0.2)
Martinique	1 (0.2)

relevant and not burdensome has been challenging in the United States. A recent framework for measuring the quality of cancer survivorship care has been developed¹³ and can serve as a model for the evaluation of programs in Latin America. Governments and governmental agencies in Latin America must support the implementation of cancer programs considering survivorship care (IOM Recommendations 5 and 6). Coordinated government policies provide an opportunity to accelerate progress against cancer.²⁵

There is an urgent need to train and prepare the oncology and primary care professionals to care for the growing population of cancer survivors (IOM Recommendation 7) in Latin America. Currently, medical oncology, radiation oncology, and pathology are not commonly pursued specialties among graduating medical students and residents

TABLE 3. Frequency of Cancer Types Across Articles

Type of Cancer	n (%)
Mixed	323 (48.6)
Breast	192 (28.9)
Cervical	25 (3.8)
Leukemia or lymphoma	23 (3.5)
Colorectal	19 (2.8)
Thyroid	16 (2.4)
Prostate	13 (2.0)
Gastric	12 (1.8)
Head and neck	8 (1.2)
Oral	7 (1.1)
Lung	6 (0.9)
Skin	4 (0.6)
Liver	3 (0.5)
Ovarian	3 (0.5)
Others ^a	8 (1.2)

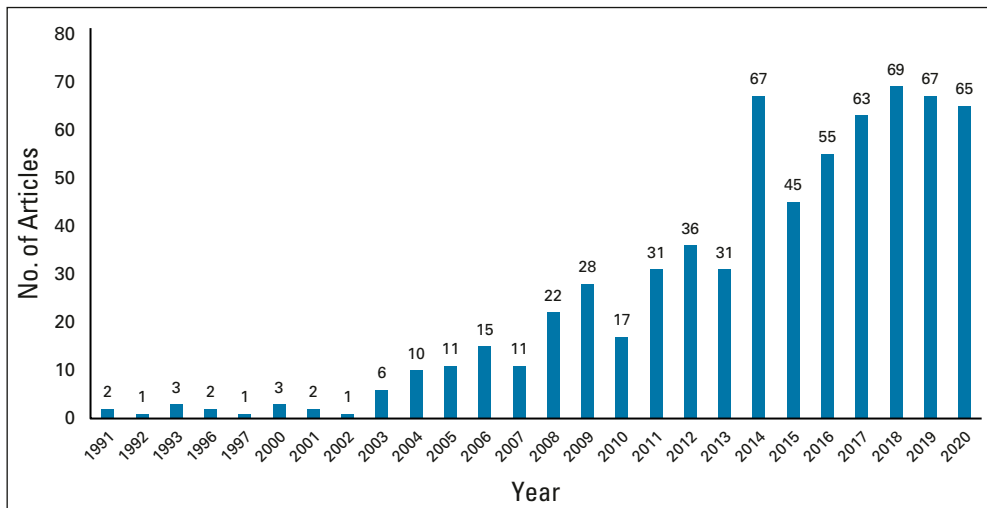
^aOther categories include endometrial, gallbladder, bladder, esophageal, multiple myeloma, pancreatic, testicular, vulvar, and Wilms tumor.

from Latin America. The training varies a lot depending on the country and tends to be centralized in the capital city.^{26,27} In our search for online resources, we found one conference focusing on oncology survivorship in Argentina²⁸; this may serve as an example for other Latin American countries. There must be a coordinated effort to promote education and training in oncology across Latin America.

Recommendation 8 addresses the need to eliminate discrimination and minimize the adverse effects of cancer on employment. Evidence in the United States suggests that survivors have a significant risk of losing their jobs or receiving social security benefits for an extended period.^{29,30} In a Brazilian observational study, return-to-work rates were 30.3% and 60.4% at 12 and 24 months, respectively, after the breast cancer diagnosis, lower than those observed in developed countries.³¹ A better understanding of the factors influencing employment in Latin American countries is needed. Many patients are likely to be involved in manual work; access to rehabilitation is an essential factor to consider.³²⁻³⁴ Another important aspect of survivorship care is health coverage (IOM Recommendation 9). Many survivors in Latin America may face significant barriers to coverage because of their cancer history.³⁴

Furthermore, many health systems in Latin America only provide minimal or incomplete services, or for emergencies only, especially for poor people.^{34,35} Health systems in Latin America are particularly challenged by the lack of coverage for the population excluded from social security.³⁶ Eliminating pre-existing condition exclusions and developing a universal health system could be a potential solution to this.

FIG 2. Annual number of articles published on cancer survivorship in Latin America.



Finally, the last IOM recommendation aims to increase expenditure on research. Although research, in general, is increasing in the region,³⁷ it still needs improvement. Within the region, Brazil is the only country that spends more than 1% of its gross domestic product on research, still lower than the 2% recommended by WHO.³⁷ As our search revealed, the number of papers published in Latin America focused on cancer survivorship is still deficient.

Finally, in addition to taking into account the 10 IOM recommendations, Latin American countries may further address inequities in survivorship care.⁶ First, it is essential to better understand the current state of survivorship across countries for better use of resources. To the best of our knowledge, there are no data regarding the number and characteristics of cancer survivors in Latin America. Tracking the population of cancer survivors by cancer type and years since diagnosis, for example, as conducted in the

FIG 3. Number of articles published across Latin American countries from 2015 to 2020.



United States, is critical to assess the effect of interventions at the city, country, or regional level. Second, it is crucial to expand the number of national cancer control plans and, as already mentioned, to disseminate resource-stratified guidelines.

Finally, the cancer survivorship field relies on the formation of partnerships. There is much that may be learned from research and well-established survivorship programs in the United States and other developed countries. Collaborations should be undertaken to ensure better care for cancer survivors in Latin America. However, although international collaboration can create more opportunities to promote findings generated in Latin America, local expertise on research teams is needed to ensure that care delivery interventions are acceptable and feasible in local settings. Furthermore, when local researchers have direct ownership in the development of interventions, the dissemination potential of the findings is likely to be greater.

We acknowledge the limitations of our study. Although we conducted a rigorous, scoping review of existing cancer survivorship literature in Latin America, it was not a formal systematic review and did not assess the quality of the studies. As cancer survivorship care is comprehensive, we

may have missed published literature that was not captured using our search terms or that we excluded articles that may have been relevant. Some publications may have been misclassified by domain, cancer type, and/or country. Our review of national governmental websites was limited to materials available online rather than in print. Nevertheless, we believe that our study adds important information that will help advance the field of cancer survivorship in Latin America.

In conclusion, although we found no formal cancer survivorship guidelines or recommendations, there is a steady growth in the number of studies focusing on cancer survivorship care published in Latin America. However, there are gaps in the literature, including the country of conduct, cancer types, and domains of cancer survivorship care. There are no sufficient data to be used to translate into guidelines. The science of survivorship care delivery in Latin American must evolve to meet this need. Development of guidelines for or adapted to Latin America and efforts to translate existing cancer survivorship research into care delivery would improve cancer survivorship care throughout Latin America.

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Manuscript writing: All authors

Final approval of manuscript: All authors

Accountable for all aspects of the work: All authors

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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Open Payments is a public database containing information reported by companies about payments made to US-licensed physicians (Open Payments).

Ann H. Partridge

Patents, Royalties, Other Intellectual Property: I receive small royalty payments for co-authoring the breast cancer survivorship section of UpToDate

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