

Challenging Outlook of Caring for Adolescents and Young Adults With Cancer in Brazil: Results of a Nationwide Survey

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ABSTRACT

PURPOSE The global burden of cancer in adolescents and young adults (AYAs) emerges as a major public health issue, in which remarkable challenges and unmet needs are evident. Because of sociodemographic inequalities, initiatives to change this scenario need to be expanded globally, particularly to low-middle-income countries (LMICs). This study aimed to gain information about the standards of AYA cancer care in Brazil from the physician's perspective.

METHODS Physicians involved in AYA cancer care were invited to answer a national online survey. The questions covered several aspects from health care's demographics to specialized services availability, such as fertility and genetic counseling. The availability of a specialized AYA cancer care facility was the primary study end point, and the findings were stratified by region and treatment setting (public v private).

RESULTS Among the physicians who responded (N = 249), 90% reported no access to a specialized AYA service. Only 20% had access to a fertility specialist, and 30% to a survivorship program in their institutions. Even external referrals to medical specialties were challenging, with 24% of the physicians reporting challenges. Despite the potential cardiotoxicity related to treatments, 43% of the respondents reported to refer patients for cardio-oncologists hardly ever. Furthermore, 36% of physicians had never enrolled AYA patients into clinical trials and 42% had never ordered a genetic test. Lack of specialized human resources was particularly evident in Northern Brazil, and delays in cancer diagnoses were frequent.

CONCLUSION This first study addresses standards of AYA cancer care across Brazil. Importantly, the data disclose significant infrastructural gaps, implying that major investments in training and infrastructure are urgently needed. These data may mirror other LMICs reality.

ACCOMPANYING CONTENT

 Appendix

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INTRODUCTION

Although cancer in adolescents and young adults (AYAs) corresponds to only 2%–4% of all malignancies, it represents the leading cause of death among this population, excluding external causes, and its incidence rate has been rising.^{1–7} There are several particularities in AYA cancer, beginning from the definition of the group itself. Even after the National Cancer Institute Progress Review Group Recommendations, which defines the age frame from 15 to 39 years as AYA, it usually differs according to the country.^{8,9} In Brazil, for instance, the Instituto Nacional do Cancer adopted a distinct age range, 15–29 years, impairing statistical comparisons with international data.¹⁰

Access to an age-specific care service is globally limited, even in high-income countries (HICs). According to a survey conducted by the European Society for Medical Oncology among their members, over two thirds of physicians did not have access to centers specialized in AYA patients.¹¹ An increase in the effort to improve AYA cancer care has been observed recently albeit it has been concentrated in HICs.¹² These initiatives need to be expanded globally, particularly to low-middle-income countries (LMICs), which harbor disproportionate AYA premature deaths.¹³

As in most LMICs, little is known about the scenario of AYA cancer in Brazil. This study aimed to gain information about the standards of AYA cancer care in Brazil from the

CONTEXT

Key Objective

To map out care for adolescents and young adults (AYAs) in Brazil in private and public settings.

Knowledge Generated

This study raised concerns regarding inadequacies in fundamental assistance for this population, such as managing treatment late effects and transition of care. It also showed fragilities in specialized services such as fertility preservation and oncogenetic counseling facilities.

Relevance

This survey revealed important underprovision and inequity of AYA cancer care across Brazil, pointing to the need for strategies such as adapted resource-based guidelines for low- and middle-income countries.

perspective of the physicians, addressing aspects such as access to specialized facilities and other specialists, sources of support to transitional care, and patient journey, among others, across different treatment settings (ie, public v private) and geographic regions.

METHODS

From January to November 2022, an online survey was sent to members of the Brazilian Society of Medical Oncology (SBOC) and other partner societies (Appendix 1). The survey was also promoted at national conferences, such as the XXIII Brazilian Oncology Congress and the 10° Symposium Oncoclínicas. Therefore, participation was not restricted to oncologists, but reached out different medical specialties involved in cancer care. After instructions (Appendix 1), the participant was invited to answer the online questionnaire.

The research instrument was the closed and structured online questionnaire, elaborated and validated in phases. The first phase was based on the theoretical foundation for defining the construct and its dimensionality. The second phase included the elaboration of the content, performed through closed items with multiple choice options. The third phase involved the selection and organization of items aiming at objectivity, simplicity, clarity, precision, relevance, and interpretability. The fourth phase was the pretest, in which the questionnaire was applied individually and in person to 20 participants, seeking to assess clarity, pertinence, relevance, and dimension.

The primary end point of the study was the availability of a specialized AYA cancer care facility. Further information was collected for exploratory analyses such as sources of support to transitional care, patient journey, demographic characteristics of the respondents, AYA patient's epidemiologic profile, multidisciplinary team composition, referral pathways, access to and time spent in fertility preservation procedures, and access to genetic testing and clinical trials. Human investigations were performed after approval by a

local Human Investigations Committee and in accordance with an assurance filed with and approved by the Department of Health and Human Services on November 30, 2021 (Approval No.: 51540321.0.0000.5149). Informed consent was obtained from all the participants.

The physician's work institution was stratified according to the geographic region¹⁴ and treatment setting (public v private). Regarding the private setting, it was further classified as a large network cancer group (ie, a health care company that aggregates several treatment units) or an independent clinic.

The study sample was calculated on the basis of SBOC database, in which a total of 2,500 clinical oncologists had active registration in the year 2021.¹⁵ Thus, for a statistical power of 95%, assuming a significance level of 0.05, and considering a difference of 20% between those who are part of a dedicated AYA cancer care and those who are not, 224 responses would be required.

Descriptive statistics were used to summarize the data. A normality test (Shapiro-Wilk) was performed for each continuous variable. Categorical data are presented as frequency and percentages, and continuous data are expressed as medians and IQR or mean and standard deviation, as appropriate. For comparison between groups, the chi-square (adjusted by the Monte Carlo Simulation according to small proportion frequencies) or the Fisher's exact tests were applied as appropriate, if categorical variables, and the Mann-Whitney *U* test or Kruskal-Wallis test, if continuous data. In multiple comparisons, Bonferroni correction was applied. Statistical analysis was performed using SPSS software, version 25 (SPSS, Chicago, IL), and significance was assumed at $P < .05$.

RESULTS

Characteristics of Respondents

The questionnaire was completely responded by 249 physicians. Of them, 51% were men and 48.8% were in the age

group of 31–40 years. Among the respondents, 73% were medical oncologists, followed by other professionals, as detailed in Table 1. Almost half (49%) worked exclusively in the private setting, and 76% were affiliated to a large network cancer group. One third of the participants reported practicing general oncology, and among those who considered themselves as specialists, breast cancer was the predominant specialty (25.6%). The survey had a nationwide representation as depicted in Figure 1.

Dedicated AYA Cancer Care According to Brazilian Regions and Treatment Settings (private v public)

Regarding the primary study end point, 90% of the respondents informed that their services did not have a dedicated AYA cancer care. Among Brazilian geographic regions, there was a significant difference concerning the composition of the institutional body of specialists, as summarized in Table 2. The availability of fertility specialist was higher in the Southeast (34.6%) and South (22.5%); medical geneticist in the Midwest (88.9%), South (80.7%), and Northeast (79.4%); cardio-oncologists in the Northeast (55.9%) and Southeast (50.3%); and social workers in the Southeast (69.9%).

A lack of human resources was observed in the Northern region, where 100% of physicians reported no fertility preservation specialist as part as their clinical staff and only 28% reported cardio-oncologist or a medical geneticist in their institutions. When comparing the private and public settings (Table 3), the availability of specialists did not differ significantly.

Concerning the feasibility of external referral to specialists, there was a higher proportion of the category easy for physician and patients (ie, referral without major barriers) in the North (42.8%) and Midwest (44.4%), especially in the private setting (47.1%). Answers such as difficult for the physician and patient were more frequent in the regions Northeast (55.9%), South (53.8%), and Southeast (40.4%) and in the public setting (41.1%). All these comparisons reached statistical significance ($P < .05$). Among the external specialties, only psychology and social workers were more easily available in the private than in the public setting.

The average waiting time for a first consultation with external specialists was different according to geographic regions ($P = .035$). The proportion of patients who spent <10 days were higher in the Northeast (67.6%) and South (61.5%), while a waiting time of more than 15 days was more common in the North (85.7%). Considering the specialty which the patients take longer to obtain a first appointment, the medical geneticist ranks first (37.7%). Nevertheless, when stratified by region ($P = .469$) and treatment setting ($P = .617$), there were no significant differences.

TABLE 1. Survey Respondent's Baseline Characteristics

Characteristic	No. (%)
Age, years, %	
31-40	48.8
41-50	28.6
51-60	12.3
61-70	6.7
>70	3.6
Sex	
Male	127 (51)
Female	122 (49)
Service setting	
Private	122 (49)
Large network cancer group	93 (76)
Independent groups	29 (24)
Public	15 (6)
Both (public and private)	112 (45)
AYA-dedicated service	
No	224 (90)
Yes	25 (10)
Region	
North	7 (2.8)
Northeast	34 (13.7)
Midwest	9 (3.6)
Southeast	173 (69.5)
South	26 (10.4)
Specialty	
Oncol	182 (73)
Hematol	15 (5.6)
Surgeon	15 (5.6)
Urol	9 (4)
RT	9 (3.6)
Mastologist	7 (2.8)
Gynecol	2 (1.2)
Palliative	2 (0.8)
Others	8 (3.4)
Subspecialty	
None	82 (33.2)
Breast	65 (25.6)
GI	22 (8.8)
GU	17 (6.8)
Gynecol	12 (5.2)
Chest	12 (4.8)
Hematol	12 (4.8)
HNC	10 (4)
Sarcoma/skin	10 (3.6)
Others	7 (3.2)

Abbreviations: AYA, adolescent and young adult; GU, genitourinary; Gynecol, gynecologist; Hematol, hematologist; HNC, head and neck cancer; Oncol, oncologist; RT, radio-oncologist; Urol, urologist.



FIG 1. Brazilian survey respondents by region. Region respondents, No. (%): North, 7 (2.8); Northeast, 34 (13.7); Midwest, 9 (3.6); Southeast, 173 (69.5); South, 26 (10.4); and total, 249 (100).

Fifty-one percent of physicians reported that the time spent for fertility preservation was superior to 15 days. However, the average time between egg/sperm collection and the beginning of cancer treatment did not show statistically significant differences between the macroregions ($P = .108$) or treatment settings ($P = .054$) as demonstrated in [Figure 2](#). Although many physicians reported patients under fertility preservation, <30% of these patients were able to use their preserved eggs or sperm.

Regarding patient's referral to clinical trials, 40%, 23%, and 36% of the physicians reported that routinely, occasionally, and never considered it, respectively. When stratified by subspecialty, oncologists dedicated to the treatment of gynecologic (83.3%) and head and neck (80%) cancers were the top referrers ($P = .038$; [Fig 3](#)).

Among the respondents, 91% reported to routinely ask patients about their cancer family history and 58% had already ordered a germline genetic panel to screen hereditary syndromes. The rates of genetic test ordering were higher among clinical oncologists (91.2%) and mastologists

(85.7%) compared with other specialists ($P = .019$) ([Appendix Table A1](#)). Physicians dedicated to the treatment of breast (95.3%) and gastrointestinal (90.9%) cancers were the most likely to order a germline panel ($P < .001$), as seen in [Appendix Table A2](#).

The other important aspect in AYA cancer care is the possibility of delays in the diagnosis of the malignancy. Nationwide, from the perspective of the physicians, 60% and 35% admitted the existence of delays in 10%-50% and over 50% of the patients, respectively.

Forty-three percent of physicians were not aware of the potential cardiotoxicity of the interventions and did not routinely refer their patients for a cardio-oncologist. Among those who indeed refer, only 20% do so in the pretreatment phase. In addition, only 30% had access to a cancer survivorship program in their institution. No statistically significant differences were observed between subspecialties ($P > .05$).

In 59% of the cases, AYA patients undergo any form of transitional care, which may be to palliative care,

TABLE 2. Characteristics of Support for AYA Patients According to Brazilian Regions

Variable	Brazilian Regions, No. (%)					P ^a
	North (n = 7)	Northeast (n = 34)	Midwest (n = 9)	Southeast (n = 173)	South (n = 26)	
Institutional clinical staff						
Fertility specialist	0 (0.0)	1 (2.9)	1 (11.1)	39 (22.5)	9 (34.6)	.018*
Oncogeneticist	2 (28.6)	27 (79.4)	8 (88.9)	109 (63.0)	21 (80.7)	.012*
Cardio-oncologist	2 (28.6)	19 (55.9)	1 (11.1)	87 (50.3)	7 (26.9)	.017*
Palliative care	7 (100.0)	33 (97.0)	9 (100.0)	156 (90.1)	21 (80.8)	.150
Survivorship	1 (14.3)	17 (50.0)	2 (22.2)	58 (33.5)	5 (19.2)	.077
Psychologist	7 (100.0)	32 (94.1)	8 (88.9)	162 (93.6)	23 (88.5)	.800
Social worker	4 (57.1)	13 (32.2)	4 (44.4)	121 (69.9)	13 (50.0)	.003*
External specialists availability						
Fertility specialist	5 (71.4)	28 (82.3)	9 (100.0)	109 (63.0)	22 (84.6)	.012*
Oncogeneticist	4 (55.1)	15 (44.1)	5 (55.6)	94 (54.3)	18 (69.2)	.453
Cardio-oncologist	4 (57.1)	18 (52.9)	5 (55.6)	75 (43.3)	16 (61.5)	.392
Palliative care	3 (42.9)	9 (26.5)	2 (22.2)	84 (48.5)	12 (46.1)	.111
Psychologist	1 (14.3)	10 (29.4)	4 (44.4)	95 (54.9)	16 (61.5)	.012*
Social worker	1 (14.3)	9 (26.5)	3 (33.3)	71 (41.0)	10 (38.5)	.368
External referral pathways						
Easy (physician and patient)	3 (42.8)	3 (8.8)	4 (44.4)	42 (24.3)	6 (23.1)	.045*
Difficult (physician)	0 (0.0)	2 (5.9)	0 (0.0)	2 (1.2)	1 (3.8)	
Difficult (patient)	3 (42.8)	10 (29.4)	4 (44.4)	38 (22.0)	4 (15.4)	
Difficult (physician and patient)	0 (0.0)	19 (55.9)	1 (11.1)	70 (40.4)	14 (53.8)	
Absent	1 (14.3)	0 (0.0)	0 (0.0)	21 (12.1)	1 (3.8)	
Average time for first evaluation with external specialists						
<10 days	0 (0.0)	23 (67.6)	2 (22.2)	70 (40.7)	16 (61.5)	.035*
10-15 days	0 (0.0)	6 (17.7)	3 (33.3)	37 (21.5)	5 (19.2)	
15-30 days	5 (71.4)	1 (2.9)	2 (22.2)	22 (12.8)	3 (11.5)	
>30 days	1 (14.3)	4 (11.8)	2 (22.2)	22 (12.8)	0 (0.0)	
Absent	1 (14.3)	0 (0.0)	0 (0.0)	21 (12.2)	2 (7.7)	
Specialists who take longer to schedule a first assessment						
Fertility specialist	2 (33.3)	14 (51.8)	3 (33.3)	46 (34.3)	4 (19.0)	.469
Oncogeneticist	4 (66.7)	8 (29.6)	3 (33.3)	64 (47.7)	12 (57.1)	
Cardio-oncologist	0 (0.0)	3 (11.1)	2 (22.2)	12 (8.9)	2 (9.5)	
Palliative care	0 (0.0)	1 (3.7)	0 (0.0)	5 (3.7)	2 (9.5)	
Psychologist	0 (0.0)	1 (3.7)	0 (0.0)	5 (3.7)	1 (4.7)	
Social worker	0 (0.0)	0 (0.0)	1 (11.1)	2 (1.5)	0 (0.0)	

Abbreviation: AYA, adolescent and young adult.

^aMonte Carlo simulation.

*Significant *P* value.

survivorship programs, and from pediatric to adult oncology. In this process, 40% of the physicians reported an active role, whereas 60% reported engagement of the institution.

DISCUSSION

In the present study, in which the status of AYA cancer care across Brazil was mapped out, we identified fragilities concerning the support in different geographic Brazilian

regions and treatment settings. This survey demonstrated that 90% of the participating physicians did not have access to a specialized AYA center. As a result, one expects harmful consequences to patient care, such as delays in diagnoses of cancer and barriers to a comprehensive multidisciplinary approach, potentially affecting AYA morbidity and mortality.

It is known, from retrospective studies, that AYA cancer care conducted from age-specific reference centers is

TABLE 3. Characteristics of Support for AYA Patients According to Treatment Settings

Variable	Treatment Settings, No. (%)			P
	Public (n = 17)	Private (n = 123)	Public and Private (n = 108)	
Clinical staff				
Fertility specialist	3 (17.6)	30 (24.4)	17 (15.7)	.254 ^a
Oncogeneticist	11 (64.7)	80 (65.0)	76 (70.4)	.670 ^a
Cardio-oncologist	9 (52.9)	54 (43.9)	53 (49.0)	.639 ^a
Palliative care	14 (82.3)	112 (91.1)	99 (91.7)	.462 ^a
Survivorship	2 (11.8)	38 (30.9)	43 (39.8)	.052 ^a
Psychologist	17 (100.0)	117 (95.1)	97 (89.9)	.144 ^a
Social worker	12 (70.6)	74 (60.1)	68 (62.9)	.687 ^a
External specialists availability				
Fertility specialist	12 (70.6)	82 (66.6)	79 (73.1)	.562 ^b
Oncogeneticist	9 (52.9)	69 (56.1)	58 (53.7)	.923 ^b
Cardio-oncologist	9 (52.9)	65 (52.8)	44 (40.7)	.166 ^b
Palliative care	5 (29.4)	61 (49.6)	44 (40.7)	.176 ^b
Psychology	7 (41.2)	73 (59.3)	46 (42.6)	.028 ^{b,*}
Social worker	4 (23.5)	56 (45.5)	34 (31.5)	.040 ^{b,*}
External referral pathways				
Easy (physician and patient)	4 (23.5)	58 (47.1)	42 (38.9)	.035 ^{a,*}
Difficult (physician)	0 (0.0)	0 (0.0)	5 (4.6)	
Difficult (patient)	7 (41.1)	23 (18.7)	29 (26.8)	
Difficult (physician and patient)	3 (17.7)	28 (22.7)	26 (24.1)	
Absent	3 (17.7)	14 (11.5)	6 (5.6)	
Average time for first evaluation with external specialists				
<10 days	5 (29.5)	60 (49.2)	46 (42.6)	.617 ^a
10-15 days	5 (29.5)	24 (19.7)	22 (20.4)	
15-30 days	2 (11.7)	12 (9.8)	19 (17.6)	
>30 days	2 (11.7)	13 (10.7)	13 (12.0)	
Absent	3 (17.6)	13 (10.7)	8 (7.4)	
Specialists who take longer to schedule a first assessment				
Fertility specialist	3 (23.1)	35 (35.0)	30 (36.1)	.834 ^a
Oncogeneticist	6 (46.1)	47 (47.0)	38 (45.8)	
Cardio-oncologist	1 (7.7)	10 (10.0)	8 (9.6)	
Palliative care	2 (15.4)	4 (4.0)	2 (2.4)	
Psychologist	1 (7.7)	3 (3.0)	3 (3.6)	
Social worker	0 (0.0)	1 (1.0)	2 (2.4)	

Abbreviation: AYA, adolescent and young adult.

^aChi-squared test.

^bMonte Carlo simulation.

*Significant P value.

associated with better clinical outcomes and survival rates are directly correlated with the number of AYAs seen annually in each center. Thus, it is strongly recommended that AYA patients with cancer be treated by skilled personnel under an appropriate infrastructure.¹⁶ On the basis of that, efforts are required to tailor the care of AYA patients with cancer, with the immediate unmet need of implementing specialized AYA cancer care in Brazil.

Moreover, the study revealed geographical and socioeconomic inequalities, which should be urgently addressed by health authorities. The United Nations ranks Brazil among the 10 most unequal countries regarding socioeconomic conditions. The other important aspect is the infrastructure heterogeneity within the country. While the South and Southeast are better developed (socioeconomic index of 0.798 and 0.794, respectively), other regions continue to experience worse quality of education, health, and life

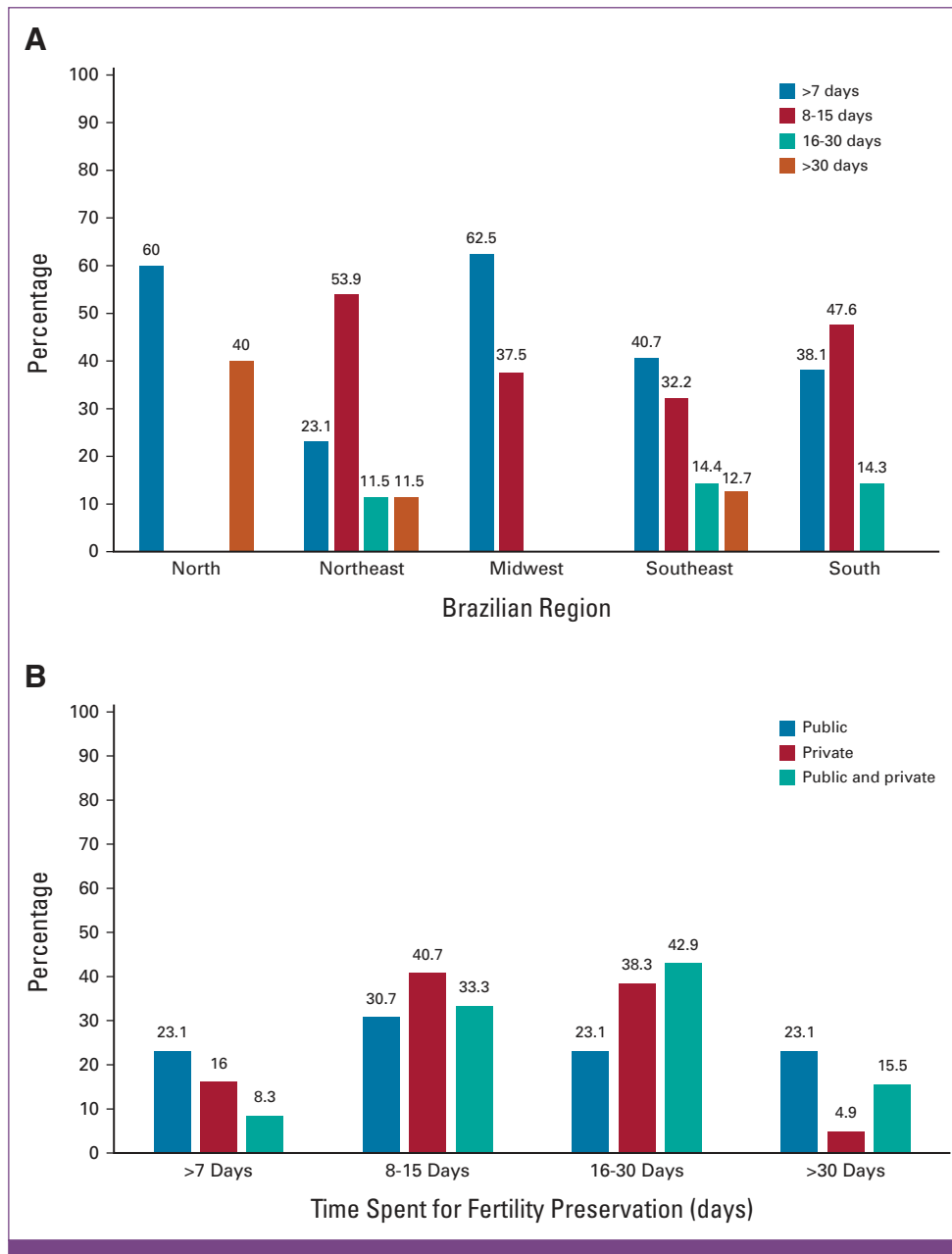


FIG 2. Time spent for fertility preservation according to (A) region and (B) treatment settings.

expectancy, such as the North and Northeast (0.730 and 0.715, respectively).¹⁷ As a result, the unequal distribution of health professionals across the country is also considered an issue. While the specialist physicians/Brazilian population ratio in the Southeast region is 46.27%, in the Midwest and North regions, this index is worse as 8.25% and 7.68%, respectively.¹⁸ In this regard, our study showed that the North region has a lack of human resources, such as specialists in fertility, genetics, and cardio-oncology, and a longer time to appointments with medical specialties is the rule—in both the private and public settings.

Among the most critical data raised by this study, fertility preservation stands out. Although many physicians had

patients under fertility preservation procedures, the preserved eggs or sperm was not often used. The American Cancer Society suggested that 18% of men and 38% of women recruited through US population-based cancer registries between 2007 and 2008 had not undergone fertility preservation because they had not been informed about these options.¹⁹ In addition, specialists in this field are not commonly available in LMICs. We advocate systematic referral of AYA patients for oncofertility counseling or, when a specialist is not immediately available, that the counseling be performed by the treating physician himself.

Another important issue for AYA patients with cancer is their representation in clinical trials. As detected in this survey, as

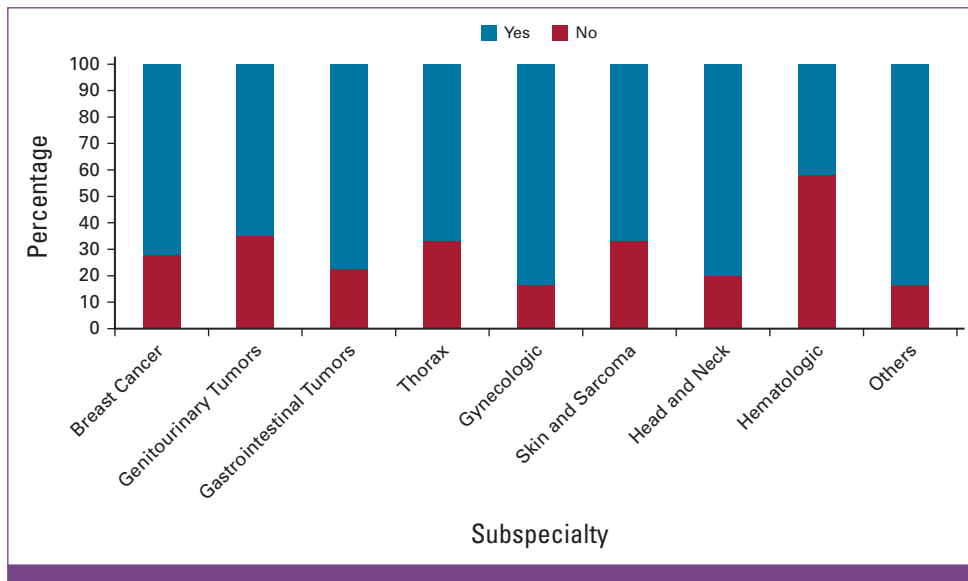


FIG 3. Referral rate for clinical trials according to subspecialty.

many as 36% of the physicians have never referred these patients to specific studies. Increasing access to clinical trials—for instance, by breaking the age 18 years dogmatic inclusion criteria of many studies and further promoting the development of innovative therapies—is a crucial step toward tackling under-representation.²⁰⁻²³ The limited number of clinical trials for this age group, especially in LMICs, is another barrier to be overcome.

A study by Knaple et al²⁴ reported that over 25% AYA cancers have a genetic predisposing condition. Therefore, these patients are likely to benefit from further evaluation.²⁴ However, our study showed that only 58% of physicians have already ordered a genetic germline panel. Barriers in testing access are probably a major issue, but lack of physician's information may also occur. Reassuringly, more than 90% of physicians in this survey reported that AYA's family cancer history evaluation is a routine for them—a first and important step to improve this reality. Despite a trend in oncology toward subspecialty, one third of Brazilian oncologists were not dedicated to a specific area of care. Analyzing the statistics related to subspecialties, physicians dedicated to the treatment of breast and GI cancers were most likely to order a genetic panel, which might have been affected by the growing number of molecularly target treatments available to these tumors. Moreover, those dedicated to gynecologic and head and neck cancers were the most inclined to refer patients to clinical trials, presumably because of more limited therapeutic options.

Another important concern raised in the present study is diagnostic delays—with some physicians in this survey estimating that this problem might affect at least 60% of their patients. As already known, the onset of new symptoms in AYA patients may not immediately trigger evaluation for malignancy, because of the low incidence of cancer in this

age group and low health care professional suspicion.²⁵ To modify this scenario, primary care practitioners must be trained to recognize cancer risks and early symptoms of cancer in AYA patients. However, the reality is that oncology teaching to medical students remains challenging in Brazil—with as many as 77 of 110 medical schools reportedly having no oncology teaching in their curriculum.²⁶ Since the production of this work, leaders of the SBOC in partnership with the Associação Médica Brasileira have been discussing strategies to include clinical oncology in the mandatory medical curriculum.

The AYA cancer survivor population has grown to over 500,000 individuals in the United States by the year 2020, with nearly one in three survivors reporting a severe or life-threatening condition 20 years after diagnosis and a sixfold increase in the risk of developing second malignancies.²⁷⁻³⁰ Considering the long-life expectancy of AYA patients and their active workforce contribution, these findings are disturbing and require continuous efforts from all parts. Cardiovascular complications are the leading nonmalignant cause of death among AYA cancer survivors, which supports the National Comprehensive Cancer Network AYA guideline recommendation of cardio-oncology evaluation before commencement of an oncology treatment.²⁵ Despite that, 43% of the physicians in our study do not routinely refer their patients to a cardio-oncology team and yet fewer refer in the pretreatment phase. These data suggest that physicians are either unaware of the cardiovascular risks or experience restricted access to such evaluations.

According to the Global Burden Disease Study 2019, AYA cancers contributed with 23.5 million disability-adjusted life years, of which 97.3% came from years of life lost.¹³ Thus, cancer remains an important contributor to premature death in AYA globally so that an optimal follow-up after treatment

must be ensured. Despite that, only 33% of the respondents reported having access to a survivorship program.

An often-overlooked particularity of the AYA population is the transitional care of childhood cancer survivors, defined by the European PanCareFollowUp Recommendations as an “active, planned, coordinated, multidisciplinary process to enable AYA survivors to effectively and harmoniously transfer from child-centered to adult-oriented healthcare systems”.³¹ In the present study, 40% of physicians reported having never transitioned patients according to these recommendations. Even when this transition occurred, 40% of the respondents reported having performed it themselves—with limited or no institutional support.

As limitations of the current study, we highlight potential selection bias—almost half (49%) of the respondents worked exclusively in the private setting, and 76% were affiliated to a large network cancer group, possibly because of the fact that physicians who work in places dedicated to research are more likely to undertake the questionnaire; the number of responses was not homogeneously distributed across Brazil; socioeconomically more vulnerable geographic regions did not have a high number of responses. As access to timely diagnosis and proper cancer treatment and

support tends to be better in the private setting in Brazil, expanding the number of doctors from the public health system would probably worsen the results. Moreover, we must acknowledge the heterogeneity of the sample; however, at the same time, the sample’s diversity reflects the reality of the care of AYA with cancer, which involves multiple specialists and multidisciplinary team professionals. Furthermore, the composition of our sample is similar to that of a previous survey performed among members of the European Society of medical Oncology.¹¹ As strengths of the study, we highlight the robust sample size, the willingness of other specialists to participate in a survey focused on cancer care, implying commitment to the cause of multidisciplinary in AYA cancer care, and the contribution of many professionals dedicated to the cancer management even across the most remote regions of the country.

In conclusion, this first survey study addressing standards of AYA cancer care across Brazil reveals significant infra-structural gaps, implying that major investments in training and infrastructure are urgently needed. As an immediate measure, the authors propose the development and implementation of a nationwide AYA cancer care guideline.

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Manuscript writing: All authors

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AUTHORS’ DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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APPENDIX 1

1. List of partner societies:
 - a. Associação Brasileira de Hematologia, Hemoterapia e Terapia Celular (ABHH)
 - b. Grupo Brasileiro de Tumores Ginecológicos (EVA)
 - c. Sociedade Brasileira de Cirurgia Oncológica (SBCO), Sociedade Brasileira de Pediatria (SBP), Sociedade Brasileira de Radioterapia (SBRT)
2. Survey invitation

"The SBOC and partner societies invite you to take part in

A survey for healthcare professionals about Adolescents and Young Adults (AYA) with Cancer.

Dear Dr, The recently published data related to AYA with cancer have called for the urgent removal of care inequalities for AYA with cancer by putting in place age-appropriate specialist services.

As a healthcare professional involved in the care of cancer patients, could you please complete our survey?

This will help us take an important step in mapping the state of development of age-specific AYA cancer across Brazil, in order to understand the challenges and design projects to address them. Results will be shared soon.

Thank you in advance for your invaluable support for young people with cancer. Sincerely, Ana Izabela Kazzi, Angélica Nogueira and Paulo Henrique Diniz."

TABLE A1. Stratification of Variables According to Physician Specialty

Variable	Physician Specialty, No. (%)									P ^a
	Oncol (n = 182)	Hematol (n = 14)	RT (n = 9)	Surg (n = 14)	Mastol (n = 7)	Gynecol (n = 3)	Urol (n = 10)	Paliative (n = 2)	Others (n = 8)	
Clinical trial referral										
No	53 (29.1)	8 (57.1)	4 (44.4)	3 (21.4)	5 (71.4)	2 (66.7)	5 (50.0)	2 (100.0)	6 (85.7)	.020*
Yes	129 (70.9)	6 (42.9)	5 (55.6)	11 (78.6)	2 (28.6)	1 (33.3)	5 (50.0)	0 (0.0)	1 (14.3)	
Late diagnosis, %										
<10	30 (1.6)	0 (0.0)	0 (0.0)	1 (7.1)	0 (0.0)	3 (100.0)	5 (50.0)	0 (0.0)	2 (28.6)	.032*
10-50	107 (59.1)	14 (100.0)	7 (77.8)	10 (71.4)	5 (71.4)	0 (0.0)	4 (40.0)	2 (100.0)	1 (14.3)	
51-90	39 (2.5)	0 (0.0)	2 (22.2)	1 (7.1)	2 (28.6)	0 (0.0)	1 (10.0)	0 (0.0)	4 (57.1)	
>90	5 (2.7)	0 (0.0)	0 (0.0)	2 (14.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
Care transition										
Pediatric to adult oncol	24 (13.2)	5 (35.7)	3 (33.3)	3 (21.4)	0 (0.0)	1 (33.3)	3 (30.0)	1 (50.0)	2 (25.0)	.137
Palliative	84 (46.2)	1 (7.4)	4 (44.4)	4 (28.6)	1 (14.3)	0 (0.0)	0 (0.0)	2 (100.0)	0 (0.0)	<.001*
Survivorship	44 (24.2)	2 (14.3)	3 (33.3)	3 (21.4)	0 (0.0)	0 (0.0)	5 (50.0)	0 (0.0)	1 (12.5)	.300
Cardio-oncology referral										
Before, during, and after	30 (16.6)	1 (7.1)	2 (22.2)	2 (14.3)	1 (14.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	.265
Before	42 (23.2)	4 (28.6)	1 (11.1)	4 (28.6)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (12.5)	
During	43 (23.8)	0 (0.0)	1 (11.1)	0 (0.0)	0 (0.0)	0 (0.0)	2 (20.0)	1 (50.0)	0 (0.0)	
After	6 (3.3)	0 (0.0)	1 (11.1)	1 (7.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
No routine	60 (33.1)	9 (64.3)	4 (44.4)	7 (50.0)	6 (85.7)	3 (100.0)	8 (80.0)	1 (50.0)	7 (87.5)	
Germline genetic panel request										
No	16 (8.8)	6 (42.9)	4 (44.4)	7 (50.0)	1 (14.3)	2 (66.7)	3 (30.0)	2 (100.0)	8 (100.0)	.019*
Yes	165 (91.2)	8 (57.1)	5 (55.6)	7 (50.0)	6 (85.7)	1 (33.3)	7 (70.0)	0 (0.0)	0 (0.0)	

Abbreviations: Gynecol, gynecologist; Hematol, hematologist; Mastol, mastologist; Oncol, oncologist; RT, radio-oncologist; Surg, surgeon; Urol, urologist.

^aMonte Carlo simulation.

*Significant P value

TABLE A2. Stratification of Variables According to Physician Subspecialty

Variable	Breast (n = 64), No. (%)	GU (n = 17), No. (%)	GI (n = 22), No. (%)	Lung (n = 12), No. (%)	Gynecol (n = 12), No. (%)	Skin and Sarcoma (n = 9), No. (%)	HNC (n = 10), No. (%)	Hematol (n = 12), No. (%)	Others (n = 7), No. (%)	P ^a
Clinical trial referral										
No	18 (28.1)	6 (35.3)	5 (22.7)	4 (33.3)	2 (16.7)	3 (33.3)	2 (20.0)	7 (58.3)	1 (16.7)	.038*
Yes	46 (71.9)	11 (64.7)	17 (77.3)	8 (66.7)	10 (83.3)	6 (66.7)	8 (80.0)	5 (41.7)	5 (83.3)	
Late diagnosis, %										
<10	8 (12.7)	6 (35.3)	5 (22.7)	0 (0.0)	2 (16.7)	0 (0.0)	3 (30.0)	0 (0.0)	1 (16.7)	.065
10-50	46 (73.0)	8 (47.1)	11 (50.0)	6 (50.0)	7 (58.3)	7 (77.8)	4 (40.0)	12 (100.0)	4 (66.7)	
51-90	8 (12.7)	3 (17.7)	4 (18.2)	5 (41.7)	3 (25.0)	1 (11.1)	3 (30.0)	0 (0.0)	1 (16.7)	
>90	1 (1.6)	0 (0.0)	2 (9.1)	1 (8.3)	0 (0.0)	1 (11.1)	0 (0.0)	0 (0.0)	0 (0.0)	
Care transition										
Pediatric to adult oncol	4 (6.2)	3 (17.6)	3 (13.6)	2 (16.7)	2 (16.7)	3 (33.3)	2 (20.0)	5 (41.7)	1 (14.3)	.100
Palliative	18 (28.1)	6 (35.3)	13 (59.1)	5 (41.7)	3 (25.0)	5 (55.6)	6 (60.0)	1 (8.3)	3 (42.9)	.292
Survivorship	18 (28.1)	7 (41.2)	2 (9.1)	1 (8.3)	0 (0.0)	4 (44.4)	2 (20.0)	2 (16.7)	2 (28.6)	.334
Cardio-oncology referral										
Before, during and after	10 (15.6)	3 (17.6)	5 (22.7)	1 (8.3)	2 (16.7)	4 (44.4)	0 (0.0)	1 (8.3)	1 (16.7)	.149
Before	12 (18.7)	3 (17.6)	4 (18.2)	2 (16.7)	0 (0.0)	2 (22.2)	3 (30.0)	3 (25.0)	1 (16.7)	
During	13 (20.3)	2 (11.8)	7 (31.8)	3 (25.0)	3 (25.0)	0 (0.0)	1 (10.0)	0 (0.0)	0 (0.0)	
After	3 (4.7)	1 (5.9)	1 (4.6)	1 (8.3)	0 (0.0)	0 (0.0)	1 (10.0)	0 (0.0)	0 (0.0)	
No routine	26 (40.6)	8 (47.1)	5 (22.7)	5 (41.7)	7 (58.3)	3 (33.3)	5 (50.0)	8 (66.7)	4 (66.7)	
Germline genetic panel request										
No	3 (4.7)	4 (23.5)	2 (9.1)	3 (25.0)	2 (16.7)	4 (44.4)	2 (20.0)	5 (41.7)	2 (33.3)	<.001*
Yes	61 (95.3)	13 (76.5)	20 (90.9)	9 (75.0)	10 (83.3)	5 (55.6)	8 (80.0)	7 (58.3)	4 (66.7)	

Abbreviations: GU, genitourinary; Hematol, hematologist; HNC, head and neck cancers.

^aMonte Carlo simulation.

*Significant P value.