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Views of Non-Physician Stakeholders on Barriers & Facilitators to AYA Cancer Care in Latin America

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Introduction

- Cancer is the fourth leading cause of death in adolescent and young adults (AYA: ages 15-39) worldwide.¹
- Over 90% of AYAs with cancer live in low-and-middle-income countries (LMIC).¹
- Little is known about the current landscape of AYA oncology care in these settings.
- Guidelines for the care of this unique population in LMIC in Latin America are lacking.

Objective

To investigate the needs of AYAs with cancer in Latin America through the perspectives of non-physician health care providers and stakeholders.

Design/Sample

Study Design:

Semi-structured interviews were conducted with 30 non-physician stakeholders from Mexico, Peru, Central America, and the Caribbean over Zoom.

Eligibility Criteria:

Clinical (non-physician), allied health and social care professionals.

Study Participants:

- Oncology nurses, social workers, nutritionists, psychologists, and non-governmental organization (NGO) personnel caring for with AYA patients with cancer
- Recruited by invitation via email through previously identified physician liaisons in each country

Analysis:

- Researchers developed an initial codebook, which was used to perform line by line coding of transcripts
- Key themes identified until thematic saturation was reached using Atlas.ti in parallel

Results

Table: Codebook of themes and subthemes

Barriers that impact at...	
Themes	Subthemes
The patient level	AYA specific barriers
	Financial barriers ^a
	Language barriers
	Poor access to technology
	Traveling to receive treatment
	Religious barriers
The parent level	Working with parents
	Limited medical literacy
	Caring for other children besides patient
The hospital level	Difficulty in providing psychosocial support
	Continuing education for staff
	Financial costs of treating patients with cancer
	Structural barriers
	Limited treatment options ^b

a. "For example, I have young patients who have the financial power to buy a cellphone, a computer, pay for Internet connection, food, and other necessary things. They can even get medications that the public health system doesn't have [...] There's a difference between those patients who have resources and the ones who don't, right?" (15)

b. "[...] there are treatment methods and medications that haven't been updated in 20 years." (34)

Facilitators that impact at...	
Themes	Subthemes
The patient level	Existing support groups
	Space designated for young people ^c
	Supporting survivors ^d
	Providing resources
	Continuing education
	Educating patients and families
The parent level	Multidisciplinary services
	Comprehensive Intake Assessment

c. "For example, we had a camp where we took the kids from Friday to Sunday, without their families, on their own. This is something that changed their lives and it made them realize that they could still do things." (6)

d. "Through this support group, adolescents like to be with other people their own age. They feel that they can identify with each other. They feel free to talk and express their fears and questions." (3)

Strategies to improve care that impact at...	
Themes	Subthemes
The patient level	Need more AYA specific treatment sites ^e
	Providing education for patients
	Providing more services for patients
The parent and community level	Advocacy
	Increase social support
The hospital level	Increasing funding and volunteers
	Need more medical resources within the hospital for providers
	Need more staff and support for staff ^f

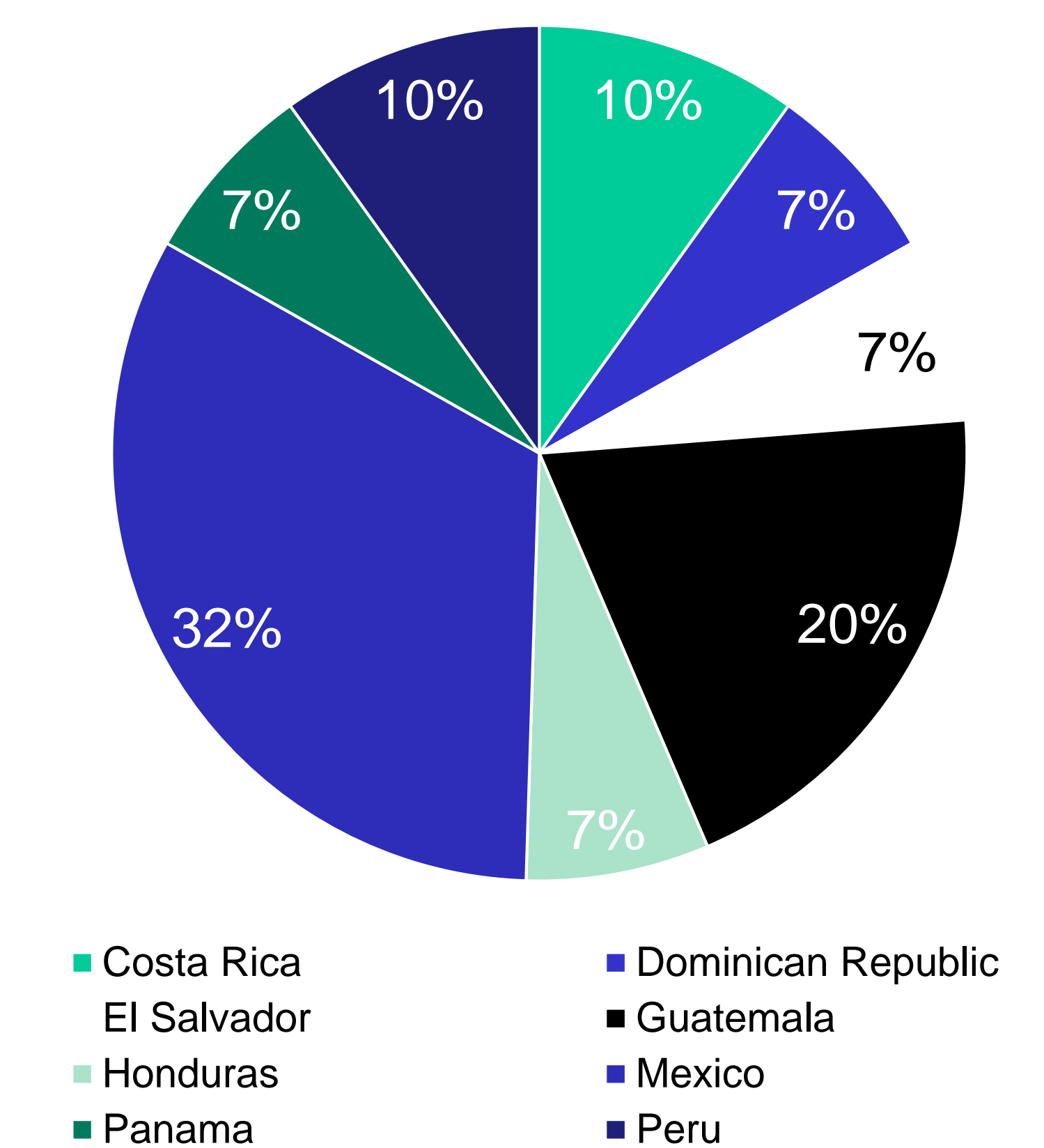
e. "[...] we're the only organization that sees children with cancer, and we only have one pediatric hospital nationally." (18)

f. "I think that we should have more staff to spend more time caring for the emotional side of patients. Sometimes we don't have enough time to talk or provide psychological attention." (24)

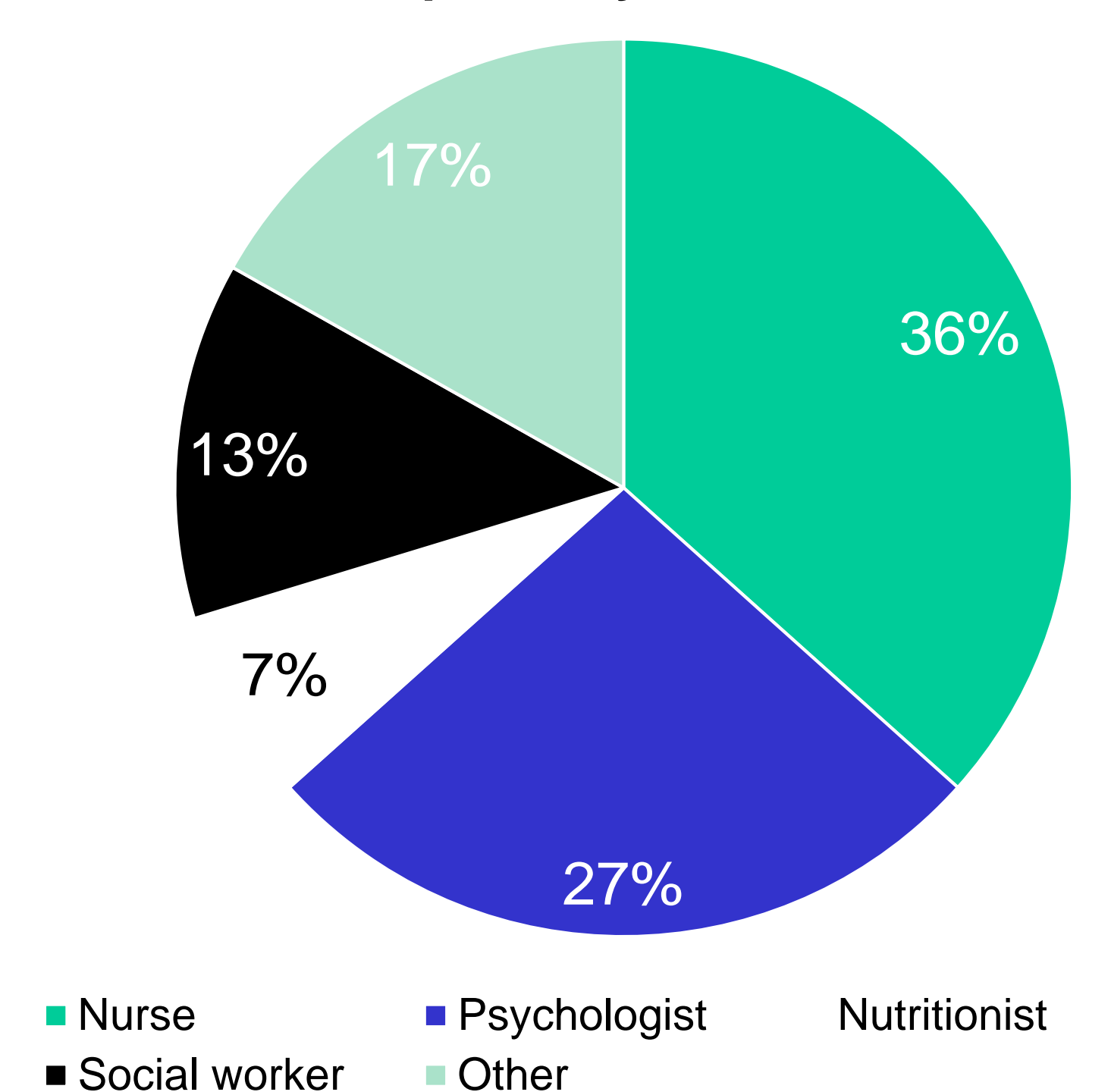
Results

30 participants, representing 8 countries, provided 1202 minutes of transcript data

Participants by Countries of Practice



Participants by Profession



Conclusions

- We assessed barriers and facilitators to care for AYAs with cancer in LMIC from the perspectives of non-physician stakeholders in Latin America.
- Similar to high-income countries, AYAs with cancer in Latin America face challenges due to their age, difficulty with access to care, and lack of an exclusive space for AYA care.
- Further, AYA patients could benefit from multidisciplinary teamwork.
- As LMIC build their cancer control programs, it is essential to consider these items when building AYA programs.

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Resources

GBD 2019 Adolescent Young Adult Cancer Collaborators. The global burden of adolescent and young adult cancer in 2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet Oncol* 2021 Dec 3;23(11):27-52. doi: 10.1016/S1470-2045(21)00581-7.