## Université de Montréal

# Colombian Adolescents' Autonomy to Access Sexual & Reproductive Health Services: An Empirical Bioethics Study

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# Colombian Adolescents' Autonomy to Access Sexual & Reproductive Health Services: An Empirical Bioethics Study

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## Résumé

Contexte: L'Organisation mondiale de la santé (OMS) demande de « promouvoir » l'autonomie des adolescents dans l'accès aux services de santé. Mais la question de l'autonomie des adolescents en matière de soins de santé soulève des questions éthiques complexes (ex. : la nécessité du consentement parental). Il est donc nécessaire d'étudier empiriquement les questions éthiques liées à la promotion de l'autonomie des adolescents dans l'accès aux services de santé sexuelle et reproductive (SSSR). En raison de son contexte particulier (ex. : l'accès légal pour les adolescents aux SSSR), la Colombie a été choisie pour cette étude.

**Objectifs:** 1) comprendre comment les adolescents interprètent le concept d'autonomie; 2) explorer les préférences et les expériences des adolescents concernant leur autonomie pour accéder aux SSSR; 3) examiner comment les adolescents souhaitent que leur autonomie soit promue; 4) identifier et répondre aux questions éthiques reliées à l'appel de l'OMS à promouvoir l'autonomie des adolescents.

**Méthodologie :** Une approche mixte fut utilisée avec des entretiens semi-structurés et des questionnaires. La recherche a eu lieu dans les départements colombiens d'Antioquia et du Valle del Cauca. Les adolescents qui se présentèrent dans deux cliniques Profamilia ont été invités à répondre à un questionnaire. En parallèle, les entretiens ont permis aux participants de présenter et de partager leurs opinions et expériences concernant leur autonomie pour accéder aux SSSR.

**Résultats**: Au total, 812 adolescents de 11 à 24 ans ont répondu au questionnaire et 45 participants (de 14 à 23 ans) ont participé à un entretien individuel. Les entretiens démontrèrent que la compréhension de l'autonomie par les participants dépendait de leurs expériences personnelles, ce qui influence leur capacité d'accès aux SSSR. Selon un cadre de justice reproductive, les résultats soulignent des inégalités en termes d'autonomie pour accéder à des SSSR. Parallèlement, le questionnaire a démontré que les adolescents colombiens ont des préférences diverses en matière d'accès aux SSSR. Les études antérieures rapportent que les adolescents préfèrent la confidentialité et l'indépendance en lien aux SSSR, s'alignant ainsi sur la

tendance d'encadrer le principe d'autonomie selon une perspective individualiste et d'autosuffisance. Cependant, la plupart des participants exprimèrent le souhait de pouvoir parler ouvertement avec leurs parents de leur santé sexuelle et reproductive et plusieurs voulaient aussi être accompagnés dans leur accès au SSSR.

Conclusions: Les recommandations suivantes sont présentées en faveur d'un accès plus éthique aux SSSR en Colombie: 1) enseigner aux adolescents les fondements de l'autonomie pour que tous disposent des mêmes bases pour exercer leurs droits d'accès aux SSSR; 2) investir dans la recherche avec les parents pour déterminer si leur fournir une éducation sexuelle aiderait les adolescents à accéder aux SSSR; 3) adopter une approche « d'autonomie relationnelle » pour respecter les préférences des adolescents colombiens en matière d'accès aux SSSR. Lorsque les adolescents commencent à développer leur autonomie et avoir des relations sexuelles, il est essentiel de leur fournir les outils et les ressources nécessaires pour accéder aux SSSR dont ils ont besoin.

**Mots-clés** : adolescent, accès, autonomie, bioéthique, Colombie, méthodes mixtes, santé sexuelle, santé reproductive, santé mondiale.

# **Abstract**

**Background:** The World Health Organization (WHO) advocates "fostering" the autonomy of adolescents to access health services. But the question of adolescents' autonomy in healthcare raises complex ethical questions (e.g., necessity of parental consent). Hence, there is a need to investigate empirically the ethical questions around fostering adolescents' autonomy to access sexual and reproductive health services (SRHS). Because of its particular context (e.g., adolescents' legal access to SRHS), Colombia was chosen for this study.

**Objectives:** The objectives of this project were to 1) understand how adolescents comprehend the concept of autonomy, 2) explore the preferences and experiences of adolescents regarding their autonomy to access SRHS, 3) examine how adolescents wish for their autonomy to be fostered, and 4) identify the ethical issues and provide ethically informed solutions in line with the WHO's call to foster adolescents' autonomy.

**Methodology:** A mixed-method approach was used with semi-structured interviews and surveys for cross-sectional analysis. The research took place in the Colombian departments of Antioquia and Valle del Cauca. Adolescents who presented themselves at two Profamilia clinics were invited to answer a survey. In parallel, the interviews offered an opportunity for participants to present and share their opinions and experiences concerning their autonomy to access SRHS.

**Results:** A total of 812 participants aged 11-24 completed a survey, and 45 participants (aged 14-23) participated in an individual interview. The interviews demonstrated that participants' understanding of autonomy was highly dependent on personal experiences, which influenced their choice and ability to access SRHS. Seen through the ethical lens of a reproductive justice framework, the results highlight the unequal opportunities of adolescents in terms of autonomy to access SRHS. In parallel, the survey showed that Colombian adolescents have a variety of preferences regarding how to access SRHS. Previous research has shown that adolescents prefer privacy and independence where SRHS are concerned, findings that align with the longstanding tendency to frame the ethical principle of autonomy from the perspective of individuality and

self-reliance. However, most participants in this study expressed a strong wish to be able to talk openly with their parents about sexual and reproductive health, and many also wanted to be accompanied when they access SRHS.

**Conclusions:** Based on the study findings, the following recommendations are put forward in support of a more ethical access to SRHS in Colombia: 1) teach adolescents the basis of autonomy, so they can equally benefit from the necessary knowledge and skills to exercise their rights to access SRHS; 2) invest in research with parents to determine if providing them with comprehensive sex education could help adolescents access SRHS; 3) adopt a nuanced "relational autonomy" approach to respect the myriad of preferences that Colombian adolescents have regarding access to SRHS. As adolescents start developing their autonomy and engaging in sexual relations, it is critical to provide them with the necessary tools and resources to access needed SRHS.

**Keywords**: access to health, adolescent, autonomy, bioethics, consent, Colombia, global health, mixed method, sexual health, reproductive health

# Resumen

Contexto: La Organización Mundial de la Salud (OMS) llama a "fomentar" la autonomía de los adolescentes en el acceso a los servicios de salud. Sin embargo, la cuestión de la autonomía de los adolescentes en la atención de salud plantea complejas cuestiones éticas (por ejemplo, la necesidad del consentimiento de los padres). Por lo tanto, es necesario estudiar empíricamente las cuestiones éticas relacionadas con la promoción de la autonomía de los adolescentes en el acceso a los servicios de salud sexual y reproductiva (SSSR). Debido a su contexto particular (por ejemplo, el acceso legal de los adolescentes a los SSSR), se eligió a Colombia para este estudio.

**Objetivos:** (1) entender cómo los adolescentes comprenden el concepto de autonomía; (2) explorar las preferencias y experiencias de los adolescentes con respecto a su autonomía para acceder a los SSSR; (3) examinar cómo los adolescentes desean que se fomente su autonomía para acceder a los SSSR; (4) identificar las cuestiones éticas y proponer soluciones éticamente informadas en línea con el llamamiento de la OMS para fomentar la autonomía de los adolescentes.

**Métodos:** Se utilizó un enfoque de método mixto: entrevistas semiestructuradas y encuestas. La investigación tuvo lugar en los departamentos colombianos de Antioquia y Valle del Cauca. Los adolescentes que se presentaron en dos clínicas de Profamilia fueron invitados a responder una encuesta. Paralelamente, las entrevistas permitieron a los participantes presentar y compartir sus puntos de vista y experiencias sobre su autonomía en el acceso a la salud sexual y reproductiva.

**Resultados:** Un total de 45 participantes de 14 a 23 años participaron en una entrevista, y 812 participantes de 11 a 24 años completaron una encuesta. Las entrevistas demostraron que la comprensión de la autonomía de los participantes dependía en gran medida de sus experiencias personales, lo que influyó en su elección y capacidad para acceder a los SSSR. Visto a través de la lente ética de un marco teórico de justicia reproductiva, los resultados ponen de manifiesto la desigualdad de oportunidades de los adolescentes en términos de autonomía para acceder a los

SSSR. Paralelamente, las encuestas mostraron que los participantes tienen una variedad de preferencias para acceder a los SSSR. Las investigaciones anteriores muestran que los adolescentes prefieren la privacidad y la independencia en lo que respecta a los SSSR. Dichos hallazgos se alinean con la tendencia a enmarcar el principio ético de la autonomía sobre la base de una perspectiva individualista y de autosuficiencia. Sin embargo, la mayoría de los participantes expresaron su deseo de poder hablar abiertamente con sus padres sobre su salud sexual y reproductiva y muchos también querían recibir apoyo para acceder a los SSSR.

Conclusión: Según los resultados de la investigación, se proponen las siguientes recomendaciones: (1) enseñar a los adolescentes las bases de la autonomía, con el objetivo de que todos los adolescentes tengan las mismas bases para ejercer sus derechos de acceso a los SSSR; (2) invertir en estudios con los padres para determinar si proporcionarles una educación sexual integral ayuda a los adolescentes a acceder a los SSSR; (3) adoptar un enfoque de "autonomía relacional" para respetar la miríada de preferencias que tienen los adolescentes colombianos para acceder a los SSSR. A medida que los adolescentes comienzan a desarrollar su autonomía y a tener relaciones sexuales, es fundamental proporcionarles las herramientas y los recursos necesarios para acceder a los SSSR que necesitan.

**Palabras clave:** adolescente, acceso, autonomía, bioética, Colombia, método mixto, salud sexual, salud reproductiva, salud mundial

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# **List of Abbreviations**

AA-HA! Global Accelerated Action for the Health of Adolescents

CDC Centers for Disease Control and Prevention

EPS Entidad Promotora de Salud (subsidized health promoting entities in Colombia)

HIC High-income countries

LMIC Low- and middle-income countries

MRI Magnetic resonance imaging
SDG Sustainable Developmental Goals
STI Sexually transmitted infections

SRHS Sexual and reproductive health services

UN United Nations

UNESCO United Nations Educational, Scientific and Cultural Organization

UNICEF United Nations International Children's Emergency Fund

WHO World Health Organization

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I would like to thank the Canadian Institutes of Health Research (CIHR) for their financial support, which allowed me to accomplish this doctoral thesis. I would also like to thank CIHR for having awarded me the Canada Graduate Scholarships — Michael Smith Foreign Study Supplements, which allowed me to go write a manuscript for my thesis in Los Angeles, California. That said, I would like to thank Mellissa Withers for hosting me at the Keck School of Medicine at the University of Southern California and help me write our manuscript for this thesis. I would additionally like to express my gratitude to CIHR for awarding me the Canadian Doctoral Award to Honour Nelson Mandela. This award is given to graduate students whose research align with Mandela's legacy. In the case of my doctoral research: youth's health. I sincerely hope that the product of this thesis does justice to this award.

I need to thank Profamilia for having helped tremendously with the accomplishment of this research. Without Profamilia's help, especially Claudia Patricia Pérez, it would not have been possible to complete a doctoral thesis of this quality. Finally, I would like to thank every single participant for having volunteered to participate in my research. I genuinely hope that the findings of this research will be able to bring positive change to young people and their access to the health services they need and want.

#### **Foreword**

It is common in the culture of science to see a strong push for objectivity that often translates into the erasure of the researcher's person and history, as if these must be separated from the development of the research project itself. In this view, the goal of science is to produce knowledge through "neutral" processes, and so the inclusion of the researcher's story and influences within the project may be interpreted as a source of bias, something to be eliminated. As a researcher trained in anthropology, I reject this positivist view of science and recognize that research — and thus the researcher — are always embedded in larger socio-cultural, historical, and political contexts. We can never be neutral, and so it is best that as researchers we recognize this and be explicit and transparent about our normative positionality. Thus, in the case of this PhD thesis, an important question to answer is: why, as someone trained in medical anthropology, did I decide to do a PhD in bioethics on the topic of adolescents, especially considering that I had no background on this subject?

Initially, in 2016, I had enrolled in the Bioethics PhD program at the Université de Montréal to explore the ethical issues related to women's reproductive health in the context of the Zika epidemic in Latin America. As I was taking my courses in bioethics, the World Health Organization declared the Zika epidemic over. At the time, I was still interested in studying the topic, so in the summer of 2018 I did an internship in Panama City at UNICEF's Latin America and Caribbean Regional Office — the goal was to develop contacts and get an initial sense of the local interpretation of the Zika epidemic. I worked in the adolescent section of UNICEF's HIV/AIDS Department and so became familiar with global health issues related to adolescents.

One specific event triggered my decision to change research topics and dedicate my PhD to adolescents' autonomy to access sexual and reproductive health services (SRHS). As someone whose research focused on HIV and pre-exposure prophylaxis (PrEP), I was invited to join a conference call with a sexual health clinic in Guatemala to discuss PrEP. During the call, a clinic worker explained that one of their biggest challenges was with adolescent populations.

Adolescents younger than 18 years old would frequently present themselves at the clinic asking for HIV testing. But since they were unaccompanied by their parents, the clinic was legally obligated to decline these requests and tell adolescents to return accompanied by their parents to give consent for HIV testing. As a result of this requirement, the worker explained, adolescents would not return to the clinic and there were strong indications that they had been (or would be) infected with HIV. Evidently, having to turn away a vulnerable patient asking for an HIV test was demoralizing for the healthcare workers in the clinic.

I found the description of the situation ethically unacceptable. Having had completed my bioethics courses in a school of public health, I started enumerating in my head all the ethical issues involving adolescent autonomy to access SRHS, which ranged from issues of respect for basic human dignity (deontology) to public health problems often analyzed from a consequentialist perspective. That day, a quick online search led me to conclude that 1) there was no consensus in the bioethics literature concerning adolescents' autonomy in healthcare, and 2) that there are significant and important differences between countries in their parental consent laws for adolescents to independently access health services. It was at that moment that I decided to dedicate my PhD to the topic of adolescents' autonomy to access health services.

## PART 1: BACKGROUND

**Summary:** The first part of the thesis introduces the research problem (e.g., the emergence of the adolescent subject in global health and the lack of consensus in bioethics on questions of autonomy for adolescents), the research objectives, and the methodological approach. The theoretical framework used in the thesis to approach the ethical question of adolescents' autonomy is then presented. This section concludes by explaining the overall structure of the thesis, i.e., written in article format and with articles divided between those based on empirical results and those of a conceptual nature.

# Introduction

The ethical principle of autonomy is undisputedly the most widely accepted (and contested) concept in contemporary bioethics (Beauchamp & Childress 2019; O'Neil 2002). There is general unanimity in North American bioethics – as well as in national laws and regulatory frameworks – that patients should have their autonomy respected in healthcare, a notion that is grounded in respect for individual human dignity. In practice, this liberty is articulated through the respect of patient preferences, ensuring that patients have the right to make their own choices, and requiring free and informed consent prior to accessing or receiving health services.

Historically, medical practice had been highly paternalistic, and it was usually difficult (if not impossible) for patients to contest medical professionals, and especially physicians, who were in a position of authority (Jonsen 2003; Weinstock et al. 1990). With the emergence of the field of bioethics in the 1970s, which was concurrent with civil liberty groups contesting the conservative social structures of the time (e.g., anti-racism, anti-war, women's rights, gay rights), many scholars and clinicians questioned and challenged these existing power relations. They advocated for a change in clinician-patient relations so that respect for patients' autonomy should be privileged, and all decisions should be made collaboratively between patients and their clinicians (Boas et al. 2018). While this view is now commonly accepted for adult patients, at least in countries of the global North (Mahowald 2006: 140), there is much less agreement regarding adolescents' autonomy in healthcare (Michaud et al. 2015). No longer children who are subject to parental authority but not yet autonomous adults, adolescents are in a contested space, as can be observed, for example, in debates over parental consent for adolescents to access health services (e.g., contraception), or trans youth's ability to make healthcare decisions such as transitioning (Ashley 2022).

Adolescents constitute a vulnerable population which undoubtedly justifies limiting their autonomy in specific contexts in order to protect them from harm, e.g., prohibiting access to alcohol and cigarettes, setting an age for being able to drive unaccompanied, or requiring

parental consent for adolescents to participate in high-risk clinical trials (Santelli et al. 2015). However, adolescents are entitled to have their autonomy and human dignity respected (Brierley & Larcher 2016), and as articulated in different international codes – e.g., the *UN Convention on the Rights of the Child* (UN 1989) and the General Comment 7 of the *Office of the United Nations High Commissioner for Human Rights* (UN 2005) – adolescents (and children) should be consulted in matters that affect them, including health-related decisions (Dockett & Perry 2011). Further, the *International Ethical Guidelines for Health-Related Research Involving Humans* (2017) advocates for the integration of young people in low-risk research without requiring parental consent, when appropriate, based on a principle of justice (i.e., if they are not allowed to participate in research then they can never benefit from the results of research).

To complicate matters, there is no consensus in the scientific literature (whether in psychology, the biomedical and health sciences, or bioethics) nor in national health laws regarding when adolescents can (e.g., age, competency) or should (e.g., ethics, law) be able to start making autonomous health-related decisions without parental consent. For example, in Canada, there are differences across provinces regarding the minimum age after which children or adolescents can access health services without parental consent. In Manitoba (2022), the *Health Care Directives Act* states that at the age of 16, an individual can autonomously consent to healthcare, whereas in Quebec (2022) the *Civil Code* sets 14 as the minimum age for consent to medical decisions, although one needs to be 18 years old to obtain medical aid in dying. In Ontario (2022), there is no minimum age of consent for treatment – it is the responsibility of the healthcare professional to ensure that the patient is competent to make informed decisions.

In Canada, and internationally, respect for adolescent autonomy in healthcare can rely either on chronological age or be based on competency, and it can vary depending on age and the type of intervention or service. Further, while there may be different arguments to justify and explain why one age and not another should be used "to draw the line," there is no consensus. In addition, as the literature on competency development shows (Drobac 2011), individuals – whether adult, adolescent, or child – may be more or less competent (i.e., able to understand

and decide) depending on a variety of personal, social and cultural factors. As such, policies governing adolescent access to healthcare can be inconsistent (even incoherent) with regions and between different countries; and these will likely create or exacerbate inequalities in access to needed care. This lack of consensus regarding how and when to respect adolescents' autonomy in healthcare is a critical ethical issue, and one in which the field of bioethics can and should contribute.

#### **Research Objectives**

The aforementioned ethical questions (e.g., determining when one can start to have their full autonomy respected in healthcare) are highly complex and arguably too vast to be addressed in the context of a single PhD thesis. Instead, a more modest entry point will be used to begin exploring some of the ethical challenges arising with adolescent access to healthcare services. Using an empirical bioethics approach (Ives et al. 2016; Kon 2009) and the World Health Organization's call to "foster" adolescents' autonomy to access health services as the setting, this project focused on Colombian adolescents and their access to sexual and reproductive health services (SRHS). There were four specific objectives:

- 1) Understand how adolescents comprehend the concept of autonomy;
- 2) Examine the preferences and experiences of adolescents regarding their autonomy to access SRHS;
- 3) Explore how adolescents wish for their autonomy to be fostered to access SRHS; and
- 4) Identify the ethical issues and propose ethically informed solutions in line with the WHO's call to foster adolescents' autonomy to access health services.

While it would certainly be possible to investigate the questions associated with adolescents' autonomy to access SRHS strictly through conceptual analysis or via a systematic literature review, it is also important to talk directly with adolescents themselves in order to document their experiences and understandings of their autonomy, especially as it concerns their access to health services. Such empirical information can then be used to lay the groundwork for a more nuanced analysis of the issues or challenges faced by adolescents, and subsequently, to inform

the development of policies that are better aligned with adolescents' particular lived realities and preferences. As such, the present doctoral research project implemented an empirical bioethics approach, broadly aligned with three of the four hierarchical categories presented by Kon (2009), i.e., Lay of the Land, Ideal vs Reality, and Improving Care (see **Table 1**); the fourth and ultimate category, Changing Ethical Norms, was beyond the scope of this thesis but the hope is the work presented here will nonetheless support such future research and normative change to promote more just access to healthcare for adolescents, both in Colombia and internationally.

#### Table 1. Research Objectives

#### LAY OF THE LAND (describe)

**Objective 1:** Clarify how adolescents understand the concept of autonomy.

The first objective was to document the opinions and experiences of Colombian adolescents to see how they understood their autonomy to access SRSH. This first step enabled the creation of an initial portrait of the issues at stake, which then oriented the subsequent ethical analysis.

#### Questions:

- How do Colombian adolescents understand the concept of autonomy (broadly) and how do they comprehend their own autonomy?
- What are Colombian adolescents' preferences and experiences regarding their autonomy to access SRHS? (e.g., do they want to go alone or accompanied to the clinic?)

#### **IDEAL VERSUS REALITY (analyze)**

**Objective 2:** Examine the preferences and experiences of adolescents.

**Objective 3:** Explore how adolescents wish their autonomy to be fostered.

These two objectives build on the results of the first objective. With a description of the reality of Colombian adolescents, it was then possible to determine if there were discrepancies between what these adolescents experienced and the measures they would appreciate to be implemented regarding access to SRHS.

#### Questions:

- What are Colombian adolescents' perspectives on the WHO's call to foster adolescents' autonomy to access SRHS? (e.g., do they reject or endorse the initiative?)
- What are the challenges experienced by Colombian adolescents regarding their autonomy to access SRHS?
- How and by which measures do Colombian adolescents want their autonomy fostered?

#### IMPROVING CARE (recommend)

**Objective 4:** Identify the ethical issues and propose ethically informed solutions.

The last objective consisted of presenting ethically informed recommendations based upon the results of the research.

- How can the autonomy of adolescents be fostered to access SRHS in Colombia?
- What are the ethical implications of such measures? What are the ethical justifications to foster the autonomy of Colombian adolescents?
- What lessons can be learned for other contexts outside Colombia?

# Methodology

For the present empirical bioethics project, a mixed-method approach was used involving both qualitative and quantitative methods: semi-structured interviews and surveys for cross-sectional analysis. The results of the surveys were useful to paint a descriptive portrait of the preferences of adolescent patients as it concerns their access to a sexual and reproductive health clinic (e.g., if they prefer to go alone or accompanied). In parallel, the semi-structured interviews allowed the participants to develop in greater detail their opinions and experiences on the subject (e.g., explain why it would be important for them to be accompanied by a parent to go to a clinic).

The research took place in the Colombian departments of Antioquia and Valle del Cauca, with the support of Profamilia, a network of Colombian clinics providing SHRS. The invited participants were adolescents aged 10-24 years old (for both surveys and semi-structured interviews). Adolescents who presented themselves at two Profamilia clinics in Cali and Medellin were invited to answer a survey. For the semi-structured interviews, participants did not need to be patients of Profamilia. There were no exclusion criteria: the goal was to have a diversity of participants with different demographic profiles. A total of 812 participants aged 11-24 completed a survey in the clinics, and 45 participants aged 14-23 participated in an individual interview. The interviews demonstrated that participants' understanding of autonomy was highly dependent on personal experiences, which influenced their choice and ability to access SRHS. Seen through the ethical lens of a reproductive justice framework, the results highlight the unequal opportunities of adolescents in terms of autonomy to access SRHS. In parallel, the survey showed that Colombian adolescents have a variety of preferences in how to access SRHS (e.g., alone or accompanied).

Previous research has shown that adolescents prefer privacy and independence where SRHS are concerned, findings that align with the longstanding tendency to frame the ethical principle of autonomy from an individualistic and independent perspective. However, as will be explored in the next chapters, most of the participants in this study expressed a strong wish to be able to talk openly with their parents about sexual and reproductive health, and many also wanted to be

accompanied in their access to SRHS. Hence, the research results present a different outlook on the ethical question of adolescents' autonomy concerning sexual and reproductive health, which underscore the relevance of empirical bioethics.

#### **Thesis Structure**

The doctoral thesis is written in article-format, that is, many of the chapters include manuscripts that have been submitted for publication, are in review or have been published in academic journals (e.g., in journals focused on sexual health, adolescent health, and bioethics). Specifically, the thesis is comprised of 9 manuscripts: two published commentaries and seven peer-reviewed articles (labelled Articles I-VII), six of which are already published, and three under review. Four of the manuscripts are specific to the Colombia case study, while the other five are more general and not specific to Colombia, either because they set the context (e.g., the two commentaries), or propose recommendations that are generalizable to other contexts. Some of the thesis content can be repetitive, such as the presentation of the methodology and the case study at the beginning of the thesis and within the articles, which are independent academic publications. As the lead researcher and doctoral candidate, I am the first author of all the publications, which are co-authored principally with my PhD supervisors Professors Bryn Williams-Jones and Vardit Ravitsky, as well as other colleagues. My contribution was substantial as I developed the research project, conducted the empirical research, came up with the original ideas of each manuscript, and wrote the first drafts, which were revised and approved by all the authors (when applicable).

The thesis is organized in three major parts: **Part 1** provides background on key concepts, as well as the research approach and methods; **Part 2** presents the empirical data and its analysis; and **Part 3** presents recommendations based upon the empirical research.

#### Part 1: Background

• **Chapter 1** introduces the research problem and provides a review of the concepts of "adolescence" and "autonomy" as developed both in the global health and bioethics literatures. This chapter also includes two commentaries: 1) "'Fostering Autonomy' for

Adolescents to Access Health Services: A Need for Clarifications", published in the *Journal* of Adolescent Health in 2021, and 2) "Dignity and Adolescents' Autonomy", published in 2022 in *Impact Ethics*.

- Chapter 2 presents the theoretical frameworks used to approach the question of adolescents' autonomy, that is, subjectivity and reproductive justice, and their interrelated theoretical influences (e.g., intersectionality).
- Chapter 3 presents the research methodology: an empirical bioethics approach using
  mixed methods (quantitative and qualitative) to explore the ethical question of
  adolescents' autonomy to access SRHS in Colombia. The chapter also presents the profile
  of the participants in the study.

#### Part 2: Results

- Chapter 4 presents Colombian adolescents' understanding of their autonomy and experiences to access SRHS, in an article entitled "Colombian Adolescents' Perceptions of Autonomy and Access to Sexual and Reproductive Health Care Services: An Ethical Analysis" published in 2021 in the *Journal of Adolescent Research*.
- Chapter 5 presents a descriptive portrait of Colombian adolescents' preferences regarding access to SRHS. This portrait is separated into two articles: the first, "Colombian adolescents' preferences for independently accessing sexual and reproductive health services: A cross-sectional and bioethics analysis" was published in 2022 in Sexual & Reproductive Healthcare, and is followed by a second article entitled "A Mixed-Methods Study Exploring Colombian Adolescents' Access to Sexual and Reproductive Health Services: The Need for a Relational Autonomy Approach" which is under review at the Journal of Bioethical Inquiry.

#### **Part 3: Recommendations**

Chapter 6 explores different solutions derived from the empirical data and ethical
analyses, presented in four articles. The first article – "Colombian Youth Express Interest
in Receiving Sex Education from their Parents" published in the journal Sexuality and

Culture — proposes offering comprehensive sex education to parents of adolescents as a potential solution for fostering Colombian adolescents' autonomy to access SRHS. Conceptual in nature, the second article entitled "Questioning the Pertinence of Parental Consent Requirements for Adolescents to Access Sexual and Reproductive Health Services" is under review at the journal Clinical Ethics and challenges parental consent requirements for adolescents to access SRHS. The third manuscript (in French) leaves the Colombian context to argue generally that one possible means to foster adolescents' autonomy is to use the offices of an ombudsperson in the health system: "Accompagner l'autonomie des adolescents par les Commissariats aux plaintes et à la qualité de services dans le réseau de la santé" (Accompanying the Autonomy of Adolescents by Commissioners in the Healthcare System) was published in the journal Éthique publique. The fourth article, entitled "How Bioethics and Sex Education Can Help Address the Question of Consent in Sex for Adolescents," is under review to the journal Sex Education, is also not specific to Colombia, and advocates for teaching bioethical concepts (i.e., free and informed consent) to adolescents to help foster their autonomy.

 The final Chapter 7 includes a Discussion of the overall thesis findings and a general Conclusion.

# **Chapter 1: The Concepts of Adolescence and Autonomy**

# The Emergence of the 'Adolescent' as a Global Health Problem

In 2015, the Global Strategy for Women's, Children's and Adolescents' Health was introduced to help achieve the United Nation's (UN) Sustainable Development Goals (SDG) related to health (Every Women Every Child 2015). The Global Strategy notably advocates for universal access to sexual and reproductive health services (UN 2015). This was the first time a global health initiative of this magnitude recognized adolescents as a distinct group different from children and adults, and one with unique health needs and challenges that must be addressed. To help reach the goals of the Global Strategy related to adolescents, in 2017 the World Health Organization (WHO) introduced the Global Accelerated Action for the Health of Adolescents (AA-HA!) (WHO 2017). Echoing the Global Strategy, AA-HA! argues that it is erroneous to frame adolescents as either "older children" or "young adults" and instead insists that adolescents be given their own specific category in medical and public health programs. In addition, a new definition of adolescence was introduced in global health research and policy – defined now as the period between 10 to 24 years old (Sawyer et al. 2018) – in order to be more inclusive and pay attention to the diverse social contexts that define youth. This broader definition can help with understanding, in more detail, methodologically speaking, the transition from child to adolescent, and adolescent to adulthood.

There are currently more than 1.8 billion adolescents around the world, making it the largest cohort of adolescents in human history (Gupta et al. 2014). This demographic reality embodies many challenges and opportunities as "the health and human capital of today's adolescents will be a determinant of future economic and social development in [low and middle-income] countries" (Bloom 2012 in Patton et al. 2016: 2429). In this context, it is critical to explore and address ethical issues related to adolescents' autonomy to access health services, particularly in developing countries. For example, adolescents are often stuck between pediatrics and adult medicine, without access to health services tailored to their life stage (Pettifor & Subramaniam

2018), which raises a critical justice issue given that adolescents should also – as do children and adults – have access to appropriate age- and context-adapted health services.

One of the leading global health challenges emerging from the literature on adolescent health is that adolescents have many unmet needs in healthcare, such as those related to sexual and reproductive health (Mazur et al. 2018; Nature 2018; Patton et al. 2016). In addition, adolescents as a group have had fewer health gains with international development compared to other age groups (Patton et al. 2016). This situation results from many factors, including for example, adolescents' inexperience and lack of knowledge about how to access and use healthcare services in their communities (Patton et al. 2012). This low use of health services is also due to other reasons, such as conflicting schedules with school, lack of economic resources to pay for health services, and confidentiality issues when wishing to consult healthcare providers without parental consent (Mazur et al. 2018; Santhya & Jejeebhoy 2015).

The global health problem of access to healthcare services touches upon a central ethical issue related to the autonomy of adolescents – what does autonomy involve, in practice, and how or why should it be respected? The WHO (2017: 93), in AA-HA!, has advocated for the need to find measures to "foster the autonomy" of adolescents to access healthcare services in order to address their diverse health needs. Some of the recommendations put forward include creating adolescent-friendly clinics, training health workers to be "adolescent competent," and teaching adolescents how to use the available health services in their community (Barroso 2014). However, there are important gaps in knowledge regarding the implementation of these recommendations to improve the health of adolescents through fostering their autonomy (Mazur et al. 2018; Tylee et al. 2007). Simultaneously, there is a lack of ethical discussion addressing the idea of fostering adolescents' autonomy to access health services. For example, it is worth asking whether adolescents might perceive the WHO proposal to be overly paternalistic, or if they have their own ideas about how to have their autonomy fostered to access health services.

The WHO's call to "foster" the autonomy of adolescents to access health services serves as a practical entry point to concretely examine the ethical question of adolescents' autonomy. This call signals an important global health problem by advocating to foster adolescents' autonomy to access health services. However, just as importantly, the WHO's push to foster adolescents' autonomy invites the development of a pragmatic component (e.g., reflecting on *how* to foster adolescents' autonomy to access health services, and basing the reflection on ethical arguments), which was a central aim of this doctoral research.

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"Fostering Autonomy" for Adolescents to Access Health Services: A Need for Clarifications
Brisson, Julien; Ravitsky, Vardit; Williams-Jones, Bryn. 2021. *Journal of Adolescent Health*, vol. 68, issue 6, pp. 1038-1039. https://doi.org/10.1016/j.jadohealth.2021.03.007

The global health literature studying adolescent health issues has shown that adolescents are among the groups that least use health services despite having serious health-related needs (Patton et al. 2016). To help promote adolescent health, the World Health Organization's *Global Accelerate Action for the Health of Adolescents* advocates implementing measures to "foster the autonomy" of adolescents to access health services (WHO 2017: 93). The argument is persuasive: protect the well-being of adolescents. However, there are significant challenges to understanding what is actually meant by "fostering autonomy" and the possible or necessary steps required for adolescents to be able to both choose and have access to health services. For example, fostering autonomy could entail the development of decision-making skills (e.g., knowing how, when, and where to access health services) or the implementation of enabling policies to make health services more accessible for adolescents, such as removing financial or geographic barriers that impede access.

To clarify the World Health Organization's concept of "fostering autonomy" for adolescents to access health services, we present in **Table 2** clarifications meant to help provide orientation and guide researchers, policy makers, and health professionals involved in adolescent medicine and health research. The first part is centered on education, and the second focuses on policies. In

each subsection, an explanation is provided on how to foster adolescent autonomy to access health services.

The concept of autonomy can have many different meanings that are interrelated but have different import. For example, in some contexts, autonomy is synonymous with independence, whereas in others, it represents agency (i.e., having a genuine ability to make choices) (Soenens et al. 2018). When engaging in initiatives to foster or promote adolescent autonomy to access health services, the distinction between the various meanings of autonomy should be considered. Simultaneously, consideration must be paid to the wide normal developmental variability among adolescents between the ages of 10 and 20 years to develop age-appropriate initiatives related to their autonomy.

Exploring ways to "foster autonomy" should involve adolescents by meaningfully engaging them on topics that directly impact them (Mabaso et al. 2016). They should, for example, know what initiatives are being developed and, with what means, to help foster their autonomy to access health services. Furthermore, within each initiative, it is important to consider and make explicit the articulation of different categories or views of autonomy. For example, historically, in sex education for adolescents in schools, much attention was given to prevention through health literacy (e.g., how to use condoms). However, there has not been the same attention to knowledge development regarding how to access sexual and reproductive health services, such as clearly explaining how to get an HIV test or access contraceptives in a clinic (Chandra-Mouli et al. 2014).

While education initiatives to foster adolescents' autonomy to access health services may be conducted in schools, it is crucial not to ignore the possibly highly beneficial role of adults in adolescents' life (e.g., parents, caregivers, teachers, other family members, social workers) in being well-positioned to promote and foster the development of adolescents' autonomy to access health services. For example, in Colombia, there is Profamilia, which is a network of non-profit clinics across the country which provides accessible sexual and reproductive health services

to the population. Trained health workers (e.g., psychologists, social workers, nurses) often go to underprivileged neighborhoods to present to young people, including their parents, the available services at Profamilia. The workers answer any questions adolescents and their parents might have regarding access to Profamilia's services, such as the costs of services based on the type of health insurance parents have or clarifying information (e.g., parental fear that contraceptives can harm adolescents). This example highlights the interconnection of different categories to foster adolescents' autonomy to access health services and the pertinence of involving parents of adolescents on the topic.

There is a strong ethical justification to foster the autonomy of adolescents to access health services; adolescents represent a vulnerable population, no longer children but not yet adults. Based on bioethical principles of non-maleficence and beneficence, it is unethical to withhold information or impede adolescents' access to appropriate services that can help address their health issues. While health systems can be complex to access and navigate, even for adults, adolescents should not have to wait to become adults in order to be able to understand how to access and use appropriate health services. Fostering adolescents' autonomy to access health services needs to be a comprehensive process: adolescents need knowledge about health, about how to access health services (and the limits), and these initiatives have to be complemented by the reduction of barriers and implementation of facilitating policies to improve access (policy change).

Table 2. Categories to "foster the autonomy" of adolescents to access health services

#### Fostering autonomy through education

#### 1. Education to improve health literacy

To access health services, adolescents must first have health literacy: health-related knowledge, an understanding of what constitutes health problems, and of possible remedies. As a group, adolescents have specific prevalent health-related needs (e.g., mental health). Thus, they must possess the knowledge to recognize when they are experiencing health problems, such as symptoms, and understanding what issues would require medical or other attention.

#### 2. Education about local health systems

It is crucial to educate adolescents about their local health systems and how they can access health services. Greater health literacy can enable an adolescent experiencing a health problem to first recognize the problem and then know how to navigate their local health systems to access appropriate services.

3. Education about rights and restrictions to access health services

Health literacy and knowledge of one's local health system do not automatically translate into the ability to independently access health services. Some countries have strict parental consent laws, whereas in other countries there are parental consent laws that support adolescents exercising autonomy to access health services. Hence, adolescents' autonomy can be fostered by educating them about their rights and existing local restrictions to access health services.

#### Fostering autonomy through policies

#### 4. Development of enabling policies for adolescents

The best educational and health literacy program will be insufficient if it is not complemented by policies that enable adolescents to actualize their knowledge and autonomy. Structural factors may prevent adolescents from accessing health services (e.g., stringent parental consent laws, high cost for services, restricted hours for clinics). Policy change is needed to remove these barriers and allow adolescents to access health services.

#### 5. Training healthcare professionals

As adolescents constitute a unique group of patients (e.g., emerging autonomy, distinctive health needs), healthcare workers should have specific training to interact appropriately with adolescent patients. Within such training, healthcare workers need to develop the skills to foster adolescents' autonomy in accessing and using health services and to make health-related decisions (e.g., ask them suitable questions so that they can make an informed decision regarding a particular form of treatment). Training must also be provided regarding adolescents' evolving capacities. Healthcare professionals need to learn developmentally appropriate strategies to involve parents in supporting adolescent health and their emerging autonomy.

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# Adolescence as a Concept

Adolescence is a recent invention in human history (Bedin 2009; Huerre 2009: 14; Moran 2000). In the fifteenth century, the term "adolescence" first appeared with the Latin *adolescere*, which means to grow into maturity (Muuss 1990 in Lerner & Steinberg 2009: 3; Sawyer et al. 2018: 223). However, it was only in the nineteenth century that adolescence became understood as a distinct life stage (Bedin 2009; Rozzi 2014: 41). This distinction was first made within the bourgeois and aristocratic classes before transitioning to the working class in the twentieth century. As explained by historians, before the nineteenth century, European populations did not have a concept for adolescence; individuals transitioned directly from the status of child to adult (Ariès 1960; Rozzi 2014: 40). Adolescence emerged as a distinct life stage in the twentieth century because of industrialization, progress in medicine, improvements in nutrition, advances in public health, and, most importantly, greater access to education, which allowed for the period of "childhood" to be extended for a longer period by having children dependent on their parents for additional years of support (Catalano et al. 2012: 1653; Frota 2007).

Adolescence is now recognized as a distinct category of human development; however, not all academic disciplines (e.g., anthropology, bioethics, psychology, neurology, sociology, medicine) understand adolescence the same way (Bedin 2009: 7; Lansford & Banati 2018: 464). There is a general agreement that puberty defines the start of adolescence – a biological process – which usually starts with menarche for girls (Sawyer & Patton 2018: 30). Biology provides some objective markers for the start of adolescence (Worthman & Trang 2018), but specific indicators do not exist to define when adolescence ends and adulthood begins (Arnett & Taber 1994: 532; Dahl et al. 2018: 441-2; Feuillet-Liger 2012: 325). Generally speaking, socio-cultural elements, like social role transitions – e.g., marriage and childbearing – determine when adolescence (or childhood) ends, and one becomes an adult (Ledford 2018: 431; Sawyer et al. 2018: 22).

In Ethiopia and Eritrea, for example, the period of adolescence for girls is not associated with chronological age but with a social status of being unmarried and without children (Grabska, de Regt & Del Franco 2019: 11). In other words, the social age does not reflect the chronological age like in the West (Clark-Kazak 2009: 1310). In other contexts, such as in the Hmong culture in southeast Asia, the chronological age of 12-13 years old simultaneously represents the end of childhood and the start of adulthood, with no existence of an adolescence period in between (Patel et al. 2007: 1302). The scientific understanding of adolescence has a very Eurocentric origin, which can involve different ethical issues when using this scientific framework for different cultural contexts in global health and international development. Notably, this can be the case with India, where there is no concept of adolescence, nor is there a linguistic word equivalent to "adolescence" in Indian languages (Burra 2014).

From a purely evolutionary perspective, puberty simply represents sexual maturation for humans to become capable of reproducing (Ellis 2012: 40; Suleiman et al. 2017). Such a basic representation of adolescence does not exist today when discussing adolescents in science (Peper & Dahl 2013; Kleinert & Horton 2016: 2355). For many decades, science characterized adolescence as a period of "stress and storm," which led to some form of a "pathologization" of adolescents (Aggleton 2014: x; Alderman, Rieder & Cohen 2003: 138; Arnett 2006; Grabska, de Regt & Del Franco 2019: 8). This idea was first put forward in 1904 by the father of adolescent psychology, Stanley Hall (1904), who understood adolescence as a disordered stage of human development. This perspective characterizing adolescence as a problematic period filled with chaos became the popular approach to frame adolescent health, particularly within the field of public health. This is the case, for example, with the United States Centers of Disease Control and Prevention's (CDC) "Youth Risk Behavior Survey" that presents adolescence primarily in terms of risks (Drobac 2016: 57). This idea of risks saturates the adolescent's existence: they are presented as being at high risk of various illnesses, such as eating disorders (e.g., anorexia, obesity), mental health problems (e.g., suicide, depression), alcohol and drug use, cigarette smoking (and now electronic cigarettes), and at risk of peer pressure, bullying, reckless driving, violence, dropping out of school, being homeless, having unwanted pregnancies, etc.

As it relates to the topic of sex, which is also intimately tied to the notion of risk, adolescents' sexuality has long been a central preoccupation, not just for the field of public health but also society in general, from politicians to religious institutions and parents (Aruda & Burke 2013: 558; Chilman 1990 in Averett, Benson & Vaillancourt 2008; Shanner 2012: 119). This phenomenon is not new; even in Ancient Greece, adolescents' sexuality was seen as a problem. Hippocrates and Aristotle believed that masturbation and uncontrollable sexual impulses were an important problem among Greek adolescents (Bettman 1962; Greydanus 1982 in Greydanus & Strasburger 2006: xiii). Today, adolescents' sexuality continues to be a significant worry, especially as framed by international development and global health. For example, adolescents are the only age group for whom AIDS-related deaths have been rising, as opposed to diminishing like other age groups (Bekker et al. 2015; Bekker et al. 2018), and the leading cause of death for adolescent girls aged 15-19 are related to complications in pregnancy and childbirth (Dillon & Cherry 2014; Chandra-Mouli et al. 2014; UNICEF 2012). To help with those problems, global health experts and the WHO (2017) have advocated for developing initiatives to foster adolescents' autonomy to access health services, such as sexual and reproductive health services (SRHS). However, as previously mentioned, there is a lack of consensus regarding what to make of adolescents' autonomy, particularly in healthcare.

# A Bioethical Problem: The Challenge to Define Autonomy for Adolescents

As already noted, the question of adolescents' autonomy constitutes an important bioethical problem, mainly because there is no consensus on how to address autonomy in this group, which is in transition between childhood (considered incompetent) and adulthood (considered competent). The main tension centres on defining the balance between respecting individual (adolescent) liberty and (paternalistically) protecting them from making choices that they may not yet be ready to make, and which could be harmful. On the one hand, from a principle of respecting human dignity, adolescents should have their autonomy respected in some (many) instances (e.g., the right to refuse to participate in a study). On the other hand, since adolescents constitute a potentially vulnerable population, it is just as ethically acceptable from a paternalistic stance to limit their autonomy in other contexts (e.g., parents choosing between

high-risk oncology treatment options for adolescents). Hence, it is necessary to explore the ethical issues surrounding adolescents' autonomy in specific contexts, such as in their access to health services. And as mentioned above, this is important because adolescents do not access to needed health services, and given the significant size of this age group, this constitutes a critical global health problem. Further, since there is a lack of concrete norms around adolescents' autonomy in healthcare, this raises ethical issues of justice because 1) policies can be maladjusted for adolescents, and 2) adolescents are entitled to be heard on subjects that concern them (e.g., to help with the development of adolescent-friendly services) (Mabaso et al. 2016).

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#### **Dignity and Adolescents' Autonomy**

Brisson, Julien. 2022. Impact Ethics.

https://impactethics.ca/2022/02/11/dignity-and-adolescents-autonomy/

In 2015, the United Nations (UN) added adolescents as their own unique category to the Sustainable Development Goals to be reached by 2030. The UN stressed that as a group, adolescents require urgent attention, especially considering that they are the group that has made the least health gains from the perspective of international development.

This new global health movement advocating for greater investments in adolescent populations is highly critical, particularly as the world currently has the largest cohort of adolescents in human history. Arguments for investing in adolescent health initiatives are predominantly consequentialist. This is particularly the case for sexual and reproductive health. Worrying statistics are often presented, such as that worldwide, pregnancy and childbirth complications are some of the leading causes of death for adolescent girls, and adolescents are the only age group for whom AIDS-related deaths are rising. In contrast, deontological arguments, such as those that support adolescents' autonomy from a deontological perspective (for example, that autonomy is an inherent aspect of human dignity) are quite absent from popular discourses, academic literature and policy justifications in global health.

There is a clear difference in the framing of the value of autonomy for adults as compared to the value of autonomy for adolescents. Adults have intrinsic and complete autonomy from a deontological perspective (e.g., in principlism), while autonomy for adolescents is commonly framed as incomplete since they are not yet adults. In the case of adults, no further arguments are needed to respect their choices to access sexual and reproductive health services, such as an adult woman's choice to use contraceptives. However, it is vital to ask the question: should adolescents' autonomy to access sexual and reproductive health services depend on consequentialist arguments or are adolescents entitled to autonomy as dignity from a deontological perspective? Is there any meaningful difference in the value of autonomy of adolescents and adults?

In the specific context of access to sexual and reproductive health services such as abortion, contraceptives, testing and treatment of sexually transmitted infections (STIs), the autonomy of adolescents should be framed as equal to the autonomy of adults. The autonomy of adolescents should be recognized as intrinsic if they request these services independently. There are no medical reasons why adolescents should be denied access to safe abortions, contraceptives, or STI treatment because they are not yet adults. Rooting adolescents' access to sexual and reproductive health services as conditional or based solely on consequentialist arguments strips adolescents of human dignity by framing them as potential public health burdens in need of intervention instead of individuals entitled to dignity to access the health services they need. For example, an adolescent's request to be tested and treated for an STI should be treated as equally valid in terms of autonomy as an adult's request.

From an ethics perspective, consequentialist arguments can have much weight in helping orient policy decisions. For example, empirical studies show that parental consent requirements and lack of respect for adolescent patients' confidentiality in healthcare can be serious barriers for adolescents to access sexual and reproductive health services. As a consequence, adolescents forego the healthcare attention they need, which then leads to public health problems like

untreated STIs. Hence, it is logical to advocate for adolescents to have their autonomy respected to access sexual and reproductive health services by using consequentialist arguments.

However, such a framing of adolescents' autonomy can be ethically problematic since framing the justification in this way makes an adolescent's ability to access the health service dependent upon potentially detrimental consequences. Yet, the same is not needed for adult patients. If an adult woman wants to use contraceptives, her full autonomy should be respected. If a woman's access to contraceptives were dependent upon consequentialist arguments, this approach would violate the woman's intrinsic autonomy (as human dignity) to respect her choices. The same ethical argument should also apply to adolescents' autonomous access to sexual and reproductive health services. Seeing adolescents as subjects entitled to access these services on the condition that a dire consequence can happen neglects to recognize adolescents as people entitled to dignity.

As conversations around adolescent health keep expanding, notably with the UN's Sustainable Development Goals, we must be careful not to limit our advocacy for adolescents' access to sexual and reproductive health services on consequentialist arguments. Discussions about adolescents' autonomy as dignity need to be further developed, particularly within the field of bioethics.

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# **Defining Adolescents' Autonomy**

The topic of autonomy has been discussed extensively by various disciplines within the scientific literature (e.g., psychology, politics, philosophy, economy, sociology) (Soenens et al. 2017: 2), and especially in bioethics (Traphagan 2013; Walter & Ross 2014: S17), which has led to understanding and framing the concept differently since there is a lack of consensus about the definition of autonomy (Soenens et al. 2017: xiii). For example, in some contexts, autonomy represents self-governance, freedom, or independence from others. In other situations, autonomy is framed as agency, cognitive maturity, or an ethical principle to be respected in

healthcare and research (Beauchamp & Childress 2008; Van Petegem et al. 2012: 76). These diverse conceptualizations of autonomy are based upon different theoretical approaches, which complicates the understanding of what exactly is being discussed when talking about autonomy (Smetana 2017: 54; Soenens et al. 2017: xiii), and even more so when it is advocated to "foster the autonomy" of adolescents in global health and international development.

The following section first presents the different broad categories of how autonomy is conceptualized and explains how these relate to adolescents (see **Table 3**). The second section discusses and analyzes the ethical implications for adolescents' autonomy, more specifically related to the ethical issues involved in "fostering the autonomy" to access SRHS.

**Table 3. Main Categories of Autonomy** 

CATEGORY	DEFINITION
Autonomy as Independence	The ability to do an action by oneself (being self-reliant).
Autonomy as Volition	Behaving based upon one's personal values, interests, desires, or preferences.
Autonomy as Maturity	Based on the neuropsychology on the person.
Autonomy as Agency	The ability to make genuine choices given the context.

#### **Autonomy as Independence**

One of the common ways to frame autonomy is in relations to independence. As it relates more precisely to adolescence, "autonomy as independence" refers to the extent that an adolescent is self-reliant and can make everyday decisions independently, without relying on others like a parent or other authority figures (Goossens 2006; Soenens et al. 2017: 1; Steinberg 2002).

An example of this type of autonomy is getting oneself from home to school. It would be unacceptable to expect a 4-year-old child to use public transportation by themselves in the morning to go to school. Granting such a level of autonomy (independence) to a young child would potentially be harmful to them (e.g., possibility of getting lost). By contrast, it is reasonable to expect a 15-year-old to autonomously (independently) take public transportation without the need for adult supervision. Within a developmental psychology framework, this transitional sense of greater autonomy (independence) from others, like parents, is considered a healthy part

of human development in learning to be self-sufficient (Kagitçibasi 2017: 194; Zimmer-Gembeck and Collins 2003). An example of "fostering autonomy" (as independence) for adolescents would be teaching them knowledge on nutrition and how to cook by themselves in order to not always depend on their parents to feed them.

This specific understanding of autonomy is much less common when discussing autonomy within healthcare ethics, as opposed to "autonomy as volition" or "autonomy as agency," which are discussed in the following sections. The respect of a patient's autonomy as independence would involve, for example, respecting the wish and ability of an in-patient adolescent to shower autonomously (independently) in a hospital without the intervention of a healthcare professional or parent, thus respecting the adolescent patient's privacy. However, this capability of being autonomous (independent) does not automatically translate into having the autonomous (mature) capability to make important choices regarding serious medical decisions (e.g., ability to choose one treatment over another).

Understanding autonomy as independence in relations to adolescents is more relevant within a public health ethics approach (e.g., everyday situations) that involves different dynamics and ethical issues than inside the clinic, with the narrow doctor-patient relationship. The greater sense of autonomy (independence) given to adolescents can potentially put them in harm's way. This is particularly the case with the initiation of risky behaviour during adolescence "enabled" by having more autonomy (independence), such as smoking, alcohol, and drug use. As such, some might intuitively believe that the answer to such problems would be to restrict, as opposed to foster, the autonomy (independence) of adolescents to protect them in their everyday activities.

#### **Autonomy as Volition**

A different way to understand autonomy is through a self-determination theory that frames autonomy as self-endorsed functioning, or in other words, behaving based upon one's personal values, interests, desires or preferences (Ryan & Deci 2000 in Van Petegem et al. 2012; Soenens et al. 2017: 1). An example could be choosing to become a vegetarian. An adolescent who has

parents who eat meat could decide by herself to become vegetarian and make this decision based upon her own unique personal values or preference, e.g., for ethical reasons or because she dislikes the taste of meat. In this example, the choice was not taught or coerced by the parents, making this behaviour a genuine autonomous choice.

Such a conceptualization of autonomy resonates with the popular approach to understanding autonomy in bioethics (e.g., a principlism approach). For example, respecting a woman's autonomy to choose the method of contraception she prefers to control her reproductive health. The ethical importance of respecting a patient's autonomy (as volition) is quite straightforward: a patient should have the ability to make health decisions that directly affect them instead of having someone else (e.g., doctor) decide on their behalf. However, when it comes to adolescent patients and their autonomy (as volition) in healthcare settings, it is more ethically complicated, notably as there is great variability in contexts and different laws and norms between countries that can limit the adolescents' autonomy (as volition). This would be the case, for example, of a 15-year-old girl in Guatemala wishing to use the contraceptive pill. Without her parents' consent, the adolescent girl's autonomy (as volition) cannot be respected (or fostered) by the healthcare professional in this specific legal context.

#### **Contrasting the Two Types of Autonomy**

It is important to acknowledge the overlapping aspects of "autonomy as independence" and "autonomy as volition." The two understandings of autonomy are not mutually exclusive since an adolescent engaging in autonomous (independent) behaviour may also choose that behaviour autonomously (volition). For example, in the case of a 14-year-old student smoking cigarettes on school grounds, this may be an act independence since no authoritative figure forces the student to smoke. Simultaneously, smoking can represent autonomy as volition, such as when the friends of the student are smokers, which created a sincere desire for the student to start smoking to gain peer acceptance. The act of smoking can also be a rebellious act in response to restrictive parents or school authorities, which would involve a mixture of autonomy as independence and volition — in this case, smoking as means of expressing bodily autonomy (independence) from

adult control and autonomy (as volition) from parents' or teachers' values. These elements of peer-pressure and rebellion from authority figures are pertinent for discussions of the neuropsychology of the adolescent brain, which invites one to critically reflect upon the nature of "autonomous" decision-making.

#### Neuropsychology and the Science of "Autonomy as Maturity"

The previous two conceptualizations of autonomy (as independence and volition) embody a more abstract understanding of autonomy. By contrast, studies using empirical approaches to understand adolescents' autonomy, such as those in psychology and neurology, may help "map out" or locate autonomy (as maturity) within the brain, for example through magnetic resonance imaging (MRI). In the last decade, remarkable progress in neuroimaging technologies resulted in the development of radical new understanding of the operation and structures of the adolescent brain (Arain et al. 2013; Blakemore 2012; Griffin 2017), overturning previously held assumptions about the adolescent brain as being, for example, "biologically deficient" compared to adults (Lerner et al. 2018: 69-70).

One of the strengths of such an empirical approach is that it provides rigorous and tangible evidence to help influence and orient policies that directly affect adolescents' wellbeing and health. For example, neurological studies have demonstrated that the adolescent brain is capable of complex problem solving equal to that of adults (Steinberg et al. 2009; Steinberg 2014) — adolescents can, in fact, display high levels of maturity in some areas and situations. Nonetheless, empirical studies also demonstrate that adolescents have sections of the brain that are much less mature than those of adults, resulting in adolescents being less capable to "maturely" calculate some risks (such as assessing long-term consequences), more easily influenced by peers and more likely to be impulsive in their behaviour (ibid.). Recent neurological studies have also shown that the brain continues to mature well into the mid-twenties, which challenges the popular notion in law (and often in bioethics) that one is a fully cognitively mature adult starting at 18 years old (Drobac 2011).

This framing of adolescents' behaviour has important ethical implications, specifically as it relates to decision making in healthcare settings or public health contexts. To return to the previous example of the 14-year-old student smoking cigarettes, it may be that the friends did not coerce the 14-year-old and it was the student who actively asked their friends for a cigarette. So it is possible that the act of smoking is an autonomous (volitional) choice. However, it is also highly likely that the student chose to smoke, not from a genuine desire but to have a sense of belonging with their friends or from indirect peer pressure of wanting "to fit in" (or perhaps a mixture of both reasons) (Hoffman et al. 2007). Hence, in the latter case, smoking is not a genuine autonomous (as volition) choice but rather a passively coerced decision "caused" by the student's "adolescent brain" being more susceptible to the influence of their peers.

Fostering "autonomy as maturity" is a more complex initiative, methodologically speaking, and involves paying attention to the neurology/psychology of the adolescent brain – which does not apply for this research project. The thresholds for defining maturity are also difficult to measure, since "age is no longer necessarily an indication of maturity" (Le Breton 2012: 45) and some adolescents can be just as psychologically mature as adults, whereas some adults can be less mature than adolescents in some contexts (Mahowald 2006: 140). This raises, then, the following question: should adults who reject the science of global warming be automatically considered more mature (cognitively) than young adolescents because of their older age, even though these adolescents can maturely grasp the science and seriousness of the threats of global warming? That said, an essential element to help develop (foster) autonomy as maturity is through education. If an adolescent is not provided the necessary knowledge and skills (e.g., comprehensive sexual health education), they may not have the opportunity to actualize their autonomy (as maturity) and access SRHS if needed.

When discussing adolescents' autonomy, it is vital to acknowledge the neurological and psychological elements capable of influencing behaviour and ability to making choices (autonomy as maturity) that are different from an adult's brain, such as the case of susceptibility to peer influence (although adults, too, are subject to peer-pressure). However, there are evident

dangers to framing a group of people's behaviour as essentially biologically determined. One of the issues in reducing or interpreting an individual's choices and/or behaviours as a biological response is that it invalidates the personhood (agency) of the individual and their capacity to make genuine and meaningful decisions in their life.

#### **Autonomy as Agency**

The concept of agency can have different meanings depending on discipline and theoretical approach (e.g., feminism, sociology, political science) and be conceptualized in different ways (e.g., relational vs. individualist autonomy, empowerment); in the interests of concision, these definitions are not explored (but see, for example, Abrams 1999; Davies 1991; Emirbayer & Mische 1998). For the purposes of the present discussion, agency means having the "real possibility" to make choices within diverse contexts that can enable or disable the ability to make choices. A good example is access to contraceptives. A country could pride itself in making it legal for women to choose whichever contraceptive technology they wish to use, thus making it possible for women to make autonomous (volition) choices. However, if some or all contraceptive options have to be paid for by women themselves, and these are expensive, then women of poorer economic status will have their agency (real autonomy to execute choices) restricted because they do not have the genuine opportunity or ability to choose the contraceptive option they desire, only that which they can afford.

In parallel to all the previous conceptualizations of autonomy, the uniqueness and theoretical strength of understanding autonomy as agency is that it pays considerable attention to the wider social context of the individual. As such, it is of great importance with regard to adolescents and their access to SRHS, which will be discussed in the next chapter. As argued by Bundy et al. (2018), the concept of adolescents' agency in their navigation of healthcare is particularly underdeveloped in the literature, especially as it relates to adolescents living in low and middle-income countries. The barriers of access to SRHS for adolescents are foremost structural, that is, parental consent laws, the costs of health services, the location and operating hours of clinics, etc. Yet, even though barriers to access SRHS by adolescents could be removed, such as in a

country like Colombia, this will not automatically translate into adolescents being able to access and use SRHS. So, while adolescents in Colombia have more convenient access to SRHS (including legal and safe abortions) compared to other countries in Latin America, the rates of STIs, clandestine abortions and pregnancy remain high (Profamilia 2019).

#### Adolescents' Sexual and Reproductive Health in Colombia

To explore the ethical subject around adolescents' autonomy to access health services, this doctoral research project used the case of SRHS, for various reasons. First, as already mentioned above, adolescents' sexual and reproductive health problems constitute a serious global and public health concern. For example, pregnancy and childbirth complications are the leading cause of death worldwide for older adolescent girls (Dillon & Cherry 2014; Chandra-Mouli et al. 2014; UNICEF 2012), and this could be greatly reduced if adolescent girls had easier access to SRHS. Second, the topic of adolescents' sexuality is a controversial and taboo subject in many countries, especially when linked to the question of adolescents' autonomy, and this for the adolescents themselves, their parents, and healthcare providers. The sensitivity of SRHS is particularly noticeable when compared with access to other types of health services (e.g., ophthalmology, physiotherapy, rheumatology), where the involvement of parents does not appear to be as sensitive for adolescents or their parents.

Although substantial progress has been made in research on adolescent health, more work and targeted studies are needed with adolescents in their diverse socio-political and cultural contexts (Nature 2018). About 90% of the research conducted on adolescents is performed in high-income countries (HIC), yet 90% of adolescents worldwide live in low- and middle-income countries (LMIC) (Blum & Boyden, 2018; Vandermorris & Zulfiqar, 2017). From a justice perspective, it is critical to conduct research with adolescents in LMIC as they are entitled to be heard on topics that concern them. Just as importantly, their preferences and experiences might be very different from those of adolescents in HIC; we should not expect that the views and experiences of adolescents from HIC represent or speak for those of adolescents living in LMIC.

The present research took place in the middle-income country of Colombia, a unique context in which to explore the question of adolescents' autonomy to access SRHS. For one, Colombia does not have specific parental consent laws for adolescents to access some SRHS. This means that a 13-year-old may ask for contraceptives in a clinic without requiring her parents' consent. This context is radically different from other Latin American countries with strict parental consent laws. Nonetheless, there are some exceptions, such as that one needs to be at least 18 years old to get sterilized in Colombia. Also, despite this more liberal setting, Colombian adolescents do not use SRHS as needed, as observable, for example, with high rates of pregnancies (Pinzón-Rondón et al. 2018) and STIs (Villegas-Castaño et al. 2016) amongst the adolescent population.

Second, Colombia has a distinctive cultural context concerning sexual and reproductive rights compared to other Latin American countries, by being more liberal in their policies. For example, abortion and same-sex marriage are legal. But just as importantly, the Colombian government has invested in significant initiatives to promote adolescents' sexual and reproductive health and has a more sex-positive approach to adolescents' sexuality. According to the Colombian Health Ministry (2021), "it is time that adolescents and young people experience their rights from a positive perspective: the right to enjoy sexuality and self-determine their reproduction" (author translation). However, while some Colombian government initiatives have sex-positive perspectives, it is important to note that this outlook is not shared amongst the entirety of the Colombian population, as observed with some conservative religious groups fighting against LGBT+ rights (Corrales & Sagarzazu 2019). Further, while it could be assumed that Colombian adolescents would be more prevalent in their use of SRHS given that parental consent is not required – it is not the case. For example, the proportion of pregnancies amongst adolescents aged 15-19 years old in Colombia increased from 13% in 1990 to 20.5% in 2005 (Profamilia 2011) and then slightly lowered to 17.4% in 2015 (Murad-Rivera et al. 2018), which is still relatively high and suggests that adolescent girls are not accessing SRHS as needed.

Stressing the importance of developing adolescent-friendly clinics related to SRHS (Huaynoca et al. 2015), in 1965 the non-for-profit organization Profamilia was inaugurated and now provides

accessible SRHS for the Colombian population, including its adolescent population (e.g., family planning, counselling, contraceptives, HIV and STI testing). Profamilia is a network of over thirty clinics across the country and has mobile clinics in rural areas; they helped with recruitment for part of this doctoral research. As already mentioned, the research took place in the Colombian departments of Antioquia and Valle del Cauca, their largest cities being Medellin and Cali (with populations of over 2 million each). As explained during a meeting at Profamilia's head office in Bogotá, most of their research on adolescents is conducted in the country's capital, hence the value of performing this doctoral research in different regions of the country that have different local realities from those of the country's capital.

Sexual and reproductive health services are locally understood and referred to as "family planning" (planificación familiar) in Colombia, and the question of family planning has a particular history. In the 1960s, there were concerns from scientific experts across the globe about the perceived threat of rapid population growth. The notion of family planning (i.e., access to contraceptives) was seen as a solution to the "crisis." In 1966, Colombia's president implemented the first family planning policy and in 1969, "Colombia became the first country in South America to incorporate a population policy of lowering fertility into its national development plan" (Sánchez 2019: 59-60), which included the development of Profamilia and its mission to provide accessible family planning services to the Colombian population. However, there were strong critiques of this initiative, included from the Catholic Church. Nonetheless, access to family planning (contraceptives) in Colombia was made possible because it was marketed as a means of preventing abortions – i.e., the belief that if women have easier access to contraceptives there will be less abortions (Sánchez 2019). Nevertheless, despite the fact that contraceptives have been widely available across Colombia since the 1970s, Human Rights Watch estimated in 2015 that around 450,000 illegal abortions take place each year in the country (Parkins Daniels 2015), which signals a low use of SRHS despite their availability.

Concerning the question of youth access to SRHS, Colombia is one of the few countries in Latin America to adopt Youth Friendly Health Services (*Servicios de Salud Amigable para Adolescentes* 

y Jóvenes) and frames the issue of adolescents' sexual health as a national public health concern and priority (Huaynoca et al. 2015; Moreno-López & Púa-Mora 2012). In 2003, Colombia adopted the National Sexual and Reproductive Health Policy (Bosmans et al. 2012), which recognizes sexual and reproductive health as a human right (Ministerio de la Protección Social 2003); "Colombia has made great advancements in its legislation regarding rights to adolescents, including sexual and reproductive rights; the general intention of public policies is to empower adolescents and improve their sexual and reproductive health" (Alzate 2014: 253). Regarding respect of adolescents' autonomy, the Colombia Constitutional Court (Corte Constitucional, Sentencia T-477 de 1995) stated that "Children are nobody's property: neither are they the property of their parents, nor are they the property of society. Their life and their freedom are of their exclusive autonomy. From the moment a person is born, they are free, and the physical impossibility of exercising their free will does not sacrifice this freedom" (author translation). The judiciary has thus articulated a more liberal approach to the question of youth autonomy compared to, for example, the conservative social movement across Latin America called Con mis hijos no te metas ("Don't mess with my kids") (Meneses 2019). This Christian-based social movement notably advocates that parents should have wide ranging authority over their children (including adolescents), e.g., the right to refuse that children be taught "gender ideologies" in school.

Given this cultural context, the question of Colombian adolescents' autonomy to access SRHS appears to be a complex topic that warrants examination from a bioethics perspective, that is, by investigating what "fostering" adolescents' autonomy to access SRHS might mean in Colombia and examining the interrelated ethical issues.

# **Chapter 2: Theoretical Framework**

This chapter briefly presents the two main theoretical frameworks – *subjectivity* and *reproductive justice* – that will be used to examine the question of adolescents' autonomy to access SRHS, complemented by interrelated theoretical influences (e.g., intersectionality). The theoretical approach of subjectivity helps frame the conceptualization of the object of study for this research: the adolescent. In parallel, the reproductive justice framework helps situate the ethical approach to investigate the question of access to SRHS given that this topic is central to the reproductive justice movement. The reproductive justice movement is also mainly concerned with the ability of marginalized groups to make choices in healthcare from a justice perspective and has strong influences from feminism, as developed below. Adolescents constitute a marginalized population, notably, because adolescents tend to be economically dependent upon their parents and they may be less aware of their rights than adults. Hence, it is pertinent to adopt this theoretical approach to explore how adolescence is articulated in the reproductive justice movement, given that there are many barriers for this vulnerable group to access SRHS.

## Subjectivity

Since adolescent health constitutes a new topic in global health — and medicine in general (Katzman et al. 2008) — a relevant theoretical perspective to study this topic is the subjectivity approach used by the French philosopher Michel Foucault. Epistemologically speaking, Foucault's goal was to critically examine the development of knowledge that placed subjects at the centre of discourse (Chambon 1999: 52; Foucault 1976) and to "pay attention to the history of the different modes by which human beings are transformed into subjects" (Foucault 1982: 777). As shown in Chapter 1, there is ambiguity in defining adolescence, and there are tensions between scientific disciplines and socio-cultural beliefs to define who is an adolescent or an adult. Consequently, a Foucauldian approach to subjectivity is pertinent for this research as it helps us pay attention to the different influences, such as scientific disciplines, that seek to define the "adolescent subject," and subsequently this subject's relation to autonomy (e.g., determining who requires parental consent, and on the basis of which ethical arguments).

A subjectivity approach also helps on paying attention to the socio-historical context and the ways that subjects were perceived differently over time. For example, the historian Jeffrey Moran (2000: 1) explains how in the nineteenth century, in the United States, adolescents were considered "inferior adults" as opposed to a separate social group in itself, as currently used by the UN and WHO in advocating for the recognition of adolescents as their own unique category in global health and international development. Moran (2000: 15) adds that one of the main elements that helped push the construction of the adolescent subject in the United States was the wider access to public schools for the majority of adolescents, which led to marking a greater social separation between young people and adults. As such, rather than the frequently adopted psychological perspective to study adolescents' autonomy (e.g., normative developmental approach), the present research uses an alternative approach to examine the adolescent subject's autonomy, by paying attention to the socio-cultural context that influences the construction of adolescence.

With the "adolescent subject" as a new population category in global health, it is pertinent to approach adolescents as a novel medical subject and explore the relationship to the concept of autonomy in connection to accessing SRHS. Given that there is no consensus in the scientific literature (including in bioethics) regarding when a person starts to become an adult and should have the ability to make autonomous choices, a subjectivity approach allows for an examination of the different influences that construct the autonomous subject (or the subject that is deemed to lack autonomy). This theoretical approach is particularly pertinent for investigating young people and their autonomy since it does not take for granted that a 20-year-old (considered an adult by popular standards) might be as different as a 17-year-old adolescent with regard to sexual and reproductive health needs. The classic theoretical approach in psychology to study adolescents and their autonomy usually seeks to determine norms for adolescent age groups, e.g., normative development throughout adolescence stages. In parallel, a subjectivity approach does not take norms for granted but instead attempts to understand the various mechanisms and forces that construct the adolescent subject and their autonomy. In terms of ethics, a subjectivity approach to study adolescence allows for greater flexibility to explore the ethical

debates around adolescents' autonomy in healthcare by questioning and challenging the foundations of ethical norms. For example, reflecting on why a 14-year-old girl should be required to obtain her parents' consent when she wants to use contraceptives for the same reasons as an adult woman.

#### Reproductive Justice Framework and the Influences of Feminist Bioethics

The reproductive justice movement emerged in the 1990s, developed by women of colour in the United States, in response to popular debates about reproductive issues (Ross & Solinger 2017). Historically, feminist analysis structured ethical debates about reproduction around questions about the liberty to make choices (e.g., the "pro-choice" movement). However, a weakness with such an approach to reproductive ethics is that it fails to consider the broader context in which a person may actually have to make a choice (agency). No matter how legally possible it is to use the method of contraception one wants, if those methods are too costly then not all women will have the autonomy (agency) to choose (and access) the method of contraception they want to use. Faced with this issue, the reproductive justice movement advocates for developing policies that would enable greater equitable access to SRHS — and, more broadly, creating enabling environments to choose to have children, such as affordable childcare — in order for people to make genuine and free decisions regarding their reproductive and sexual autonomy (e.g., to decide if and when to have children, and having access to the healthcare resources to have children).

One of the great theoretical strengths of the reproductive justice movement, especially for bioethics, is that it analyzes the larger social context and seeks to understand how social structures (e.g., policies) directly influence the choices that people can actually make related to their sexual and reproductive health. Hence, the reproductive justice movement moves beyond the world of legal or conceptual debates about autonomy, and into broader spheres that contextualize autonomy, in practice, such as education, public health, politics, and economics. In its more macro-level analysis, the reproductive justice movement looks at the causes of people's

current sexual and reproductive health conditions and seeks to understand how this influences the possibility of making a *genuine* choice to want or be able to have children.

It is also important to note that a reproductive justice approach treats people with dignity and as warranting help, compared to a neoliberal approach to health that often expects people to take care of their health by themselves, without the help of social assistance (Gurr 2018). For example, a reproductive justice approach would argue that the sexual and reproductive health problems experienced by adolescents (e.g., high STI rates) are due to structural issues (e.g., policies preventing the promotion of comprehensive sex education) and not because of the adolescents themselves, such as conservative critiques arguing that adolescent girls are irresponsible individuals in terms of their sexuality (MacLeod 2014).

When exploring the question of reproductive justice, it is critical to discuss feminism and its relation to bioethics. One of central contributions of feminism to bioethics is to stress the problematic power imbalances in medical practice (Lindemann Nelson 2000: 493). For example, in the 1970s, the emergence of the feminist health movement sought to critique the control of health professionals over patients – i.e., medical paternalism (Epstein 1996: 9-10) – which was also a topic being developed in bioethics. Feminist bioethics highlighted how healthcare practice affects women differently than men, such as the fact that women's perspectives were (and are still) ignored by health professionals (Scully 2021). Another popular critique from feminist bioethics is the underrepresentation of women in clinical trials (Baylis, Downie & Sherwin 1999). A clear parallel can be made with the almost systematic exclusion of adolescents in research because of their age (Noel et al. 2021) and the censoring of adolescents' voices in healthcare decisions when there are strict policies in place, such as parental consent requirements to access SRHS.

## Intersectionality

Combining a subjectivity approach with reproductive justice is pertinent for examining the question of adolescents and their autonomy, particularly when employing an intersectionality

approach drawn from feminist philosophy. Kimberly Crenshaw (1995) popularised the concept of intersectionality as a means to pay attention to the different elements that socially construct an individual (e.g., gender, ethnicity, socio-economic status, disability); the aim is to understand how the intersection of these identities affect the life of people, whether in terms of privileges or discrimination (Brah & Phoenix 2004; Takeshita 2012: 8). Intersectionality is attentive in its analysis to structures of privilege and oppression (e.g., institutionalized racism, sexism) and how these directly affect people's everyday lives, such as the ability to make sexual and reproductive health choices.

Applying intersectionality to adolescents is essential since it is not only starting at adulthood that people experience oppression or benefit from certain privileges. For example, figures of authority (e.g., police) tend to be harsher towards youth of colour compared to white youth when dealing with the same crime (Cano 2010; Correll et al. 2007; Fitzgerald & Carrington 2011; Stewart et al. 2009). The same phenomenon applies in the clinic: health professionals tend to ignore or delegitimize the pain of Black people compared to white people (Hoffman et al. 2016; Trawalter, Hoffman & Waytz 2012), and be more attentive to the health complaints of men than of women (Samulowitz et al. 2018). Adopting an intersectionality approach for the present doctoral research is useful as it enables an exploration of how different systems of privilege or oppression can influence Colombian adolescents' access to SRHS. For example, in the Latin American context, and especially in Colombia, there are strong and dominant gendered ideologies, commonly known as *machismo* and *marianismo*, and these are intimately tied to questions of sexuality.

Machismo and marianismo are gendered social ideals to which men and women should aspire to in terms of identity and behaviour (Englander, Yáñez & Barney 2012). Machismo can be described as the performance of masculinity. It is often defined as synonyms of courage, stoicism, and virility. However, machismo is foremost based in misogyny and violence towards women (Gutmann 1996, 1999; Vigoya et al. 2003). In parallel, marianismo is rooted in classic Catholic representations of Mary and calls for women to be married mothers, passive and altruistic (Stevens & Pescatello 1973). In comparison to the marianismo ideal, there exist stigmatising

social representations of the "bad women" who do not aspire to be married and become a mother. As these social identities or ideals directly concern Colombian adolescents' autonomy and their access to SRHS, it is critical to pay attention to how these identities and their relations to privilege and oppression can influence adolescents' ability to make choices regarding sexual and reproductive health. And in terms of justice, it is important to explore how to create enabling environments so that all adolescents may equally have their autonomy fostered to access SRHS.

# **Chapter 3: Methodology**

The current research project used an empirical bioethics approach (Kon 2009) to explore the ethical questions pertaining to adolescents' autonomy to access SRHS. A mixed methods approach was employed to attain the research objectives of understanding Colombian adolescents' experiences and preferences. A quantitative survey was used to support a cross-sectional analysis, and semi-structured interviews were employed to provide a rich qualitative description. The purpose of using mixed methods was to balance out the limitations of each method and help strengthen the data analysis (Migiro & Magangi 2011). For this study, a convergent design was used with both methodological approaches occurring simultaneously (Guetterman et al. 2015) over six months, between August 2019 and February 2020.

This chapter first presents the participants' profiles, then summarises the qualitative and quantitative parts of the study. A description of the recruitment approach and data analysis for both parts are presented, followed by a discussion of the research ethics issues raised by this study. Then, the demographic profile of the participants is presented. To avoid repetitiveness with the manuscripts, the presentation of the methodology in this section is kept general as it will be explained in greater details in subsequent chapters.

## **Participants**

The participants invited for this research (for the surveys and interviews) were 10-24 years old. As previously mentioned, this age gap corresponds to the new definition of adolescence used in global health research and policy (Sawyer et al. 2018). The purpose of this larger age range was to enable the exploration of the differences and similarities between older and younger adolescents. For example, it was pertinent to observe if younger adolescents shared the same opinions as older adolescents. There were no specific exclusion criteria for the participants; the goal was to have diverse participants with different demographic profiles (e.g., from various socio-economic backgrounds).

Initially, when developing the research project, Venezuelan adolescents were included, because in recent years there has been an important (informal) migration of Venezuelans into Colombia due to Venezuela's severe economic and political crisis (Fernández-Nino & Bojorquez-Chapela 2018; Rodríguez-Morales et al. 2019). Most Venezuelans in Colombia are in highly precarious and vulnerable positions, notably due to their limited resources – e.g., lack of access to employment, formal education, and health services. Hence, it was important to include Venezuelan adolescents in the research to hear their opinions and experiences related to their autonomy to access SRHS (or lack thereof). However, no Venezuelan adolescent participated in the interviews (participants were asked to define their nationality at the beginning of the interviews). As expressed anecdotally by some Profamilia employees engaging in community work with vulnerable populations (e.g., Venezuelans living in the streets and *comunas*), Venezuelan adolescents did not want to participate out of fear that they might face repercussions from authorities for having entered the country informally.

#### **Qualitative Part: Semi-Structured Interviews**

Semi-structured interviews were a useful methodological approach to explore the opinions and experiences of participants as it relates to their autonomy and access to SRHS. The strength of open-ended questions allows participants to go into greater detail on the topic, and so permits the researcher to understand more thoroughly the experiences of participants (Savoie-Zajc 2009). Initially, the targeted minimum sample size was twenty participants, and the cut-off point was sixty; the aim was to have sufficient variability between participants to explore adolescents' distinct opinions, realities, and experiences (e.g., older vs. younger adolescents).

In line with the research objective, the goal was to have at least two main categories of participants – some who had previously accessed SRHS and some who had not – so as to compare factors that helped adolescents' autonomy to access SRHS, and factors that might have prevented other adolescents accessing SRHS. The format of the semi-structured interviews included open-ended questions which gave an opportunity for the participants to develop their opinions, while also describing past experiences (see the Interview guide in Appendix 4). The

descriptions of events by the participants regarding their autonomy to access SRHS proved to be very important for the research as it led to a much better understanding of the lived realities of Colombian adolescents. But just as importantly, the methodological approach of semi-structured interviews allowed observation and comparison of participants' diverse experiences.

Different approaches were used to recruit participants. One of the most effective was through the help of Profamilia: clinics in Cali, Medellin, and Palmira advertised posters, and health professionals who saw adolescent patients shared information about the research project. Another helpful approach was through social events involving Profamilia employees outside the clinics, at community events (e.g., educative initiatives) where young people were present (not as patients). The employees would present the research project while the researcher was there, and the employees would invite young people to approach the researcher or take an information sheet about the research project.

Another highly effective recruitment strategy was through snowball sampling, where participants and other young people would share information about the research with their friends and peers. Also, a nurse presented the research project in a high school in Santa Fe de Antioquia, which helped recruit participants from a rural area. As such, there was a variety of participants: some who had previously accessed SRHS (e.g., with Profamilia or other clinics) and some who had never used SRHS. It was left to the discretion of participants to choose where they wanted to do the interview (e.g., private room in a clinic, library, parc bench). Prior to starting the interviews, participants were asked to read the consent form and answer some demographic questions, such as their age and with whom they lived. The interviews were conducted in Spanish, and audio-recorded.

#### **Data Analysis**

The first step consisted of transcribing all the interviews in Spanish. The transcripts were read at least twice to get a general sense of the content. The main approach to analyzing the data was through thematic analysis (Clarke et al. 2015). For example, depending on the primary topic of

the manuscript (e.g., article where the data is presented), the main interview questions were categorized, and the respective responses were pasted under, while adding participants' demographic characteristics. Through this approach, it was possible to observe themes and tendencies or differences between participants' responses on specific topics.

#### **Quantitative Part: Cross-Sectional Survey**

A cross-sectional survey was used to understand how adolescents accessed SRHS, along with their preferences of access (see Appendix 3 for survey questions). The surveys were made available to adolescent patients in the Profamilia clinics in Medellin and Cali. Both clinics have "Youth Centres" dedicated to young people (e.g., psychologists specialized in young people), which help invite adolescents to use their services. Initially, *all* adolescent patients aged 10-24 years old that presented themselves at a Profamilia clinic in Cali and Medellin were supposed to be invited to answer the survey. The receptionists were to give an information sheet describing the research project so that the adolescent could make an informed decision as to whether or not they wanted to answer the survey.

In terms of representation bias, by inviting all eligible participants, this sampling approach was more rigorous as all patients had an equal chance of being invited to answer the survey. However, after the start of the study, the receptionists expressed that it was too challenging to invite all eligible adolescents to participate in the survey because of periods of higher patient volume. As such, the approach was changed to convenience sampling. The receptionists would thus invite participants when they deemed appropriate. For every invitation, the receptionist made a mark on a calendar, which allowed the calculation of participation rates at the end of the week.

#### **Data Analysis**

The purpose of the survey was to enable a cross-sectional analysis. The main variables of study were categorical: gender and age groups. As such, the goal was to observe if there were statistical relationships between the demographic groups. Since the variables of study were categorical, chi-scare test of independence were used to analyse the relationships between variables.

Because of lower participation rate for the "10–12 years old" category, this was merged with the "13–15 years old" category for some of the data analysis. To analyze the homogeneity between groups, z-tests (two-tailed) were performed for proportions. Statistical significance was evaluated as p < 0.05 for all tests. Percentages were rounded to the nearest tenth, including confidence intervals. The Université de Montréal's *Service de consultation statistique* helped validate some of the statistical tests. The statistics were analysed with the software SPSS.

#### **Research Ethics**

Research involving minors invariably raises important ethical issues. For this research, parental consent was not asked nor obtained. It was judged that parental consent requirements could be a barrier for participant involvement in the research. Also, for the survey or interview recruitment in the clinic, it would be difficult to ask for a parental consent if the adolescent came alone to the clinic. The decision to not require parental consent was supported by Guideline 17 (Research Involving Children and Adolescents) of the International Ethical Guidelines for Biomedical Research Involving Human Subjects (Council for International Organizations of Medical Sciences 2017). This guideline argues that it is ethically acceptable not to ask for parental consent when the research involves low risk and when parental consent could be a barrier for adolescents to participate in important research. As explained to the research participants (in the consent form for the interview and the information sheet for the survey), once the overall research project is completed, the results will be translated into an accessible language and will be made available in Profamilia's youth centres.

The research project was first evaluated and approved by the *Comité en éthique de la recherche en santé de l'Université de Montréal* (CÉRES), Project number: CERSES-19-049-P. The research ethics committee of Profamilia, which included a lawyer, also evaluated and accepted the research project.

## **Participant Profiles**

#### **Qualitative Part**

A total of 45 participants agreed to a semi-structured interview. Prior to recording the interviews, participants were asked basic demographic questions (e.g., age, if they were enrolled in school), and they were invited to define their gender. There was an almost equal representation between male and female participants, and one participant identified as non-binary. The age range for participants was between 14-23 years old, with close to a quarter of being 19 years old. Most participants were from the *estratos* two and three, which reflects a similar *estrato* representation of the country. *Estratos* are socio-economic classes assigned by the Colombian government based upon where one lives: *estrato* one represents the lowest *estrato*, whereas *estrato* six is the highest. There was a more or less equal representation of participants between the two Colombian departments.

**Table 4. Demographic Characteristics of Participants for Qualitative Part** 

Number of Participants	45			
Gender				
Male	21 (46.7%)			
Female	23 (51.1%)			
Non-Binary	1 (2.2%)			
Age				
14	1 (2.2%)			
15	4 (8.9%)			
16	5 (11.1%)			
17	2 (4.4%)			
18	3 (6.7%)			
19	11 (24.4%)			
20	2 (4.4%)			
21	10 (22.2%)			
22	5 (11.1%)			
23	2 (4.4%)			
Estrato				
1	3 (6.7%)			
2	12 (26.7%)			
3	25 (55.6%)			
4	4 (8.9%)			
5	0 (0.0%)			
6	0 (0.0%)			
Unknown	1 (2.2%)			

Residence of Participant				
Medellin, Antioquia	9 (20.0%)			
Rionegro, Antioquia	6 (13.3%)			
Santa Fe de Antioquia, Antioquia	5 (11.1%)			
Cali, Valle del Cauca	2 (4.4%)			
Palmira, Valle del Cauca	23 (51.1%)			

#### **Quantitative Part**

A total of 1,272 adolescents were invited to participate of whom 911 answered the survey (initial participation rate of 71.6%). From those who answered the survey, 99 were excluded because they did not answer enough questions for data analysis (e.g., left blank the demographic section). Hence, 812 surveys were used for data analysis (63.8% participation rate).

There was a lower participation rate for participants under 13 years old. More than half (57.7%) of participants were between 16-21 years old. Close to three quarters of participants were from Medellin, and the remainder were from Cali. More than a 90% of participants were female, which represents the general distribution of sex differences for patients using the services at Profamilia, across Colombia. More than half of participants were concentrated in the lower three *estratos*. A tenth of participants were internally displaced people, which is reflective of the country's situation as having one of the world's highest rates of internally displaced people because of violence (Reyes et al. 2019). More than half of participants (58.0%) were single and close to three quarters (30.9%) reported being in a serious relationship. The majority of participants were Colombian (92.9%) and a minority reported being Venezuelan (1.7%), while the rest did not answer the question of their nationality.

**Table 5. Demographic Characteristics of Participants for Quantitative Part** 

City	Medellin	Cali	TOTAL			
Participants, n (%)	593	219	812			
Age, n (%)						
10-12	8 (1.3)	0 (0.0)	8 (1.0)			
13-15	115 (19.4)	22 (10.0)	<b>137</b> (16.9)			
16-18	172 (29.0)	72 (32.9)	<b>244</b> (30.0)			
19-21	155 (26.1)	70 (32.0)	<b>225</b> (27.7)			
22-24	118 (19.9)	49 (22.4)	<b>167</b> (20.6)			
Missing	25 (4.2)	6 (2.7)	<b>31</b> (3.8)			
Sex, n (%)						
Male	54 (9.1)	10 (4.6)	<b>64</b> (7.9)			
Female	533 (89.9)	209 (95.4)	<b>742</b> (91.4)			
Missing	6 (1.0)	0 (0.0)	<b>6</b> (0.7)			
Estrato, n (%)						
1	111 (18.7)	55 (25.1)	<b>166</b> (20.4)			
2	236 (39.8)	47 (21.5)	<b>283</b> (34.9)			
3	178 (30.0)	71 (32.4)	<b>249</b> (30.7)			
4	24 (4.4)	16 (7.3)	<b>40</b> (4.9)			
5	7 (1.2)	11 (5.0)	18 (2.2)			
6	0 (0.0)	3 (1.4)	<b>3</b> (0.4)			
Missing/unknown	37 (6.2)	16 (7.3)	<b>53</b> (6.5)			
Displaced Person, n (%)						
Yes	75 (12.6)	8 (3.7)	<b>83</b> (10.2)			
No	466 (78.6)	193 (88.1)	<b>659</b> (81.2)			
Missing	52 (8.8)	18 (8.2)	<b>70</b> (8.6)			
Relationship Status, n (% Single	358 (60.4)	112 (51 6)	<b>471</b> (58.0)			
Serious relationship	168 (28.3)	113 (51.6) 83 (37.9)	<b>251</b> (30.9)			
Free union	21 (3.5)	10 (4.6)	<b>31</b> (3.8)			
Married	19 (3.2)	5 (2.3)	<b>24</b> (3.0)			
Missing	27 (4.6)	8 (3.7)	<b>35</b> (4.3)			
National Status, n (%)						
Colombian	555 (93.6)	199 (90.9)	<b>754</b> (92.9)			
Venezuelan	10 (1.7)	4 (1.8)	14 (1.7)			
Missing	34 (5.7)	16 (7.3)	<b>50</b> (6.2)			

### **PART 2: RESULTS**

The Results section is composed of three articles that correspond to the first two main objectives of the research: 1) define how Colombian adolescents understand the concept of autonomy and its relation to access to SRHS, and 2), describe the preferences of Colombian adolescents' as it concerns their access to SRHS. **Chapter 4** is a manuscript published in *Journal of Adolescent Research* in which are presented the qualitative data on Colombian adolescents' different understandings of the concept of autonomy and its articulation regarding to access to SRHS, using a reproductive justice framework to analyse the data. **Chapter 5** presents two articles. The first is an article published in the journal *Sexual and Reproductive Healthcare*, and presents quantitative data to paint a descriptive portrait on whether adolescent patients wanted to go accompanied or alone to Profamilia. The second article of the chapter, which is under review at the *Journal of Bioethical Inquiry*, uses a mixed-method approach to show how the classic understanding of autonomy in bioethics that frames the principle through independence does not adequately represent the preference of the study participants with respect to their access to SRHS.

# **Chapter 4: Colombian Adolescents' Understandings of Autonomy**

# Article I: Colombian Adolescents' Perceptions of Autonomy and Access to Sexual and Reproductive Health Care Services: An Ethical Analysis

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#### Abstract

There are conceptual and ethical challenges to defining adolescents' autonomy to access health care, and these can lead to health care norms and practices that could be maladjusted to the needs and preferences of adolescents. Particularly sensitive is access to sexual and reproductive health care services (SRHS). Yet, while there has been substantial conceptual work to conceptualize autonomy (e.g., as independence), there is a lack of empirical research that documents the perceptions of adolescents regarding on how they access or wish to access health care services. The main objectives of this research were to (a) understand how adolescents in Colombia interpret the concept of "autonomy," (b) describe how these adolescents articulate their autonomy (i.e., preferences) in accessing SRHS, and (c) analyze the ethical issues emerging from these data. Forty-five semi-structured interviews were conducted with participants aged 14 to 23 years old in the Departments of Antioquia and Valle del Cauca in Colombia. Our study showed that participants' understanding of autonomy was context-based and highly dependent on personal experiences, and these influenced their choice in how to access SRHS. Seen through the ethical lens of a reproductive justice framework, our results highlight the unequal opportunities for adolescents in terms of autonomy to access SRHS.

**Keywords:** adolescent, autonomy, bioethics, Colombia, sexual and reproductive health, reproductive justice

#### <u>Introduction</u>

One of the core ethical principles in contemporary bioethics, anchored in widely shared value systems and legal norms in North American and Western European liberal democracies, is respect for individual autonomy, whether in participation in research or access to health care

(Beauchamp & Childress 2001; O'Neill 2008). This entails recognizing individuals' right for self-determination and their ability to make choices for themselves, based on their view of what is in their best interest. The duty on the part of health professionals to adhere to this ethical principle is enshrined in contemporary codes of ethics, particularly in North America, and is part of an explicit rejection of strong medical paternalism. Contrary to competent adult patients, in the case of adolescents, respecting autonomy can become complex. One issue is how adolescents themselves understand the principle of autonomy and how it applies to them in their access to health care. Another is how parents or health care professionals determine when, how, and to what extent to respect an adolescent's choice regarding health care services, a topic that can be particularly challenging when the service relates to sexual and reproductive health (Bekaert & Southgate 2018).

Adolescence is a period of transition—physically, psychologically, and socially—between childhood and adulthood (O'Donohue et al. 2013; Sawyer et al. 2012). It is marked by the development of greater autonomy (e.g., as liberty, independence) and competencies (e.g., ability to rationally evaluate different choices). Adolescents are no longer children and in general have much greater capacity to make important decisions about their personal interests, but they are not yet adults. Furthermore, adolescence is a time when individuals begin exploring and engaging in "adult-like" behaviors such as sex. Yet, there are also no objective or universal biological markers to define exactly when a person is no longer an adolescent and becomes an adult capable of making independent decisions (Dahl et al. 2018; Ledford 2018). Nor are there specific biological markers to define the age at which an adolescent should have their autonomy respected in health care decisions (e.g., some jurisdictions have "mature minor" laws enabling 14- or 16-year-olds to make health care decisions without parental consent).

There are different overlapping definitions of autonomy that may create challenges to implementation, for example, autonomy as independence, as volition, as agency, as maturity, or as liberty (Soenens et al. 2017). Furthermore, determining the scope and limits of adolescent autonomy in health care is inherently a socio-legal and cultural issue, anchored in societal value

systems (Kagitçibasi 2017: 194); it can thus vary across regions, cultures, and type of health care service in question. This diversity in the characterization of adolescence was a factor in the introduction in global health policy of a new definition of adolescence. According to Sawyer et al. (2018), adolescence should be defined as being a stage of life between the ages of 10 and 24. One of the purposes for this extended age range is methodological, that is, it can allow for a more accurate description of how a person transitions from childhood to adolescence and from adolescence to adulthood, while also clarifying the similarities and differences between individuals within this age range. The latter points are especially relevant for studying the question of autonomy in adolescents with regard to health care in general, and sexual and reproductive health care services (SRHS) in particular.

The need to address barriers to adolescents' access to health care, some of which are related to their autonomy and competency, can be justified on public health grounds. Adolescents are one of the groups that least use health care services, despite having important health-related needs (Patton et al. 2018). This point has been highlighted as a serious problem to be tackled by the United Nations' Sustainable Development Goals and with the Global Strategy for Women's, Children's and Adolescent's Health (WHO 2015). Given the absence of consensus regarding how to determine the scope of adolescent autonomy to access health care services, as well as the lack of quantitative biological markers, clinicians and policy makers may lack the evidence needed to guide decision making regarding the provision of care to adolescents (e.g., with or without parental oversight).

Determining the scope of adolescent autonomy with regard to health care services requires the inclusion of adolescents' perspective. Designing public policies that ensure health care service delivery that best meets the actual needs of adolescents (and thus increases their uptake of these services) requires an understanding of how adolescents experience and understand autonomy and its connection to their access to health care services, such as those related to sexual and reproductive health.

The qualitative study presented in this article involved semi-structured interviews with 45 adolescents in five Colombian cities—Medellin, Rionegro, Santa Fe de Antioquia, Palmira, and Cali. The first objective was to describe how these adolescents understood the concept of autonomy, and their preferences and challenges in the context of accessing SRHS.<sup>1</sup> No specific definition of autonomy was used. As adolescence involves the development of different components of one's autonomy, participants were free to expand on the topic during the interview. Building on this information, the second objective was to analyze the ethical issues that emerged regarding adolescent autonomy to access SRHS, using the conceptual framework of reproductive justice. The goal was not to argue for specific positions with regard to adolescents' autonomy in accessing SRHS, nor to propose an age at which adolescents' autonomy should be fully respected in health care. Rather, this article aims to show—through a presentation of the descriptive data and an ethical analysis—the types of underlying ethical issues related to adolescent autonomy that arise in accessing SRHS in Colombia.

#### **Reproductive Justice Framework**

The reproductive justice movement – as developed by women of color in the United States in the 1990s – stresses the importance of creating contexts that are enabling and equitable for all, so that people can make genuine and free choices related to sexual and reproductive health (Luna & Luker 2013; Price 2010; Ross & Solinger 2017). For example, while contraceptives may be available, if they involve high fees, not all people will have the same opportunities to use them. People with limited economic resources (which oftentimes apply to adolescents as a group) will be restricted in their choice of contraceptives in comparison with people with greater economic resources. Hence, two core ethical principles of a reproductive justice framework are autonomy and justice. As the analysis of the study data below shows, not all participants had equal access to SRHS, raising issues of justice and equity.

<sup>&</sup>lt;sup>1</sup> In the context of this research, "access to sexual and reproductive health services" was an inclusive notion to represent all services related to sexual and reproductive health—for example, contraceptives, counseling, abortion, and HIV/STI testing.

#### **Research Context**

Around 90% of research done on adolescents is performed in high-income countries (HIC) even though 90% of adolescents worldwide live in low- and middle-income countries (LMIC) (Blum & Boyden 2018; Vandermorris & Zulfiqar 2017). It is thus pertinent to conduct research with adolescents in different socio-cultural contexts to understand the different lived realities and experiences of adolescents around the world, and specifically in LMIC, such as Colombia, a country that does not have specific parental consent laws regarding minors accessing SRHS. Colombia also has different governmental initiatives advocating for adolescent health, including sexual and reproductive health. For example, the Profamilia network of non-profit clinics is present throughout Colombia and provides specialized access to SRHS (e.g., abortion, contraceptives, vaccination) to the population, including for adolescents. (Profamilia was involved in this research and helped with some of the recruitment of participants.)

There are different reasons for choosing to focus on access to SRHS as opposed to other types of health care services (e.g., oncology). Sexual health and sexuality may be sensitive topics for discussion with parents, or even a taboo subject that is simply not discussed. Furthermore, research in various cultural contexts, such as the United States (Brittain et al. 2015), Ethiopia (Berhane et al. 2005), the United Kingdom (Burack 2000), or India (Sivagurunathan et al. 2015), has shown that adolescents prefer their parents not knowing they are accessing SRHS. Yet, some of the leading causes of deaths and disability for adolescents worldwide are related to sexual and reproductive health (e.g., childbirth, HIV; Patton et al. 2016). These issues underscore the need to explore adolescents' autonomy to make SRHS more accessible and youth friendly.

#### Method

#### **Data Collection and Analysis**

To better understand Colombian adolescents' perception of autonomy as it relates to accessing SRHS, a qualitative study was conducted in Colombia using semi-structured interviews during 2019 and 2020, allowing participants to share in detail their opinions and personal experiences

on the topics of autonomy and access to SRHS (Gaudet & Robert 2018). Collected data were analyzed by applying a reproductive justice framework.

The first author conducted the interviews. Before recording the interview, participants were asked demographic questions (e.g., age, gender, with whom they lived, highest level of education, whether they had an income). Participants could choose where to do the interview; the majority chose a private room in a clinic, library, or a public park. Interviews were conducted in Spanish, were audio-recorded and transcribed by the first author, then coded and analyzed manually on paper and with Microsoft Word. To protect participant confidentiality, participants were given a pseudonym. The interview excerpts presented in the current article were translated by the first author. All participants had the same interview guide that was composed of the same central themes presented as core questions (e.g., interpretation of the concept of "autonomy," barriers of access to SRHS, how the participants would want their autonomy fostered to access SRHS). However, each core question per theme had subcategories of questions depending on the participant's context. For example, a participant who had never accessed SRHS was not asked the same follow-up questions in comparison with a participant who had previously accessed SRHS. This latter participant would then be asked questions about experiences relating to their autonomy with the health care professional, whereas participants who had never accessed SRHS were asked how they would want to interact autonomously with a health care professional when they accessed SRHS. The interview guide was not piloted. The length of interviews was between 16 and 47 minutes. While the researcher would invite participants to develop their answers (e.g., asking whether they could "explain" or "elaborate" their answers), many participants kept their answers short and concise which led to some interviews ending more quickly than others. Many participants asked how long the interview would take, to which the researcher would respond that it was left to the discretion of participants, but that on average would last around 30 minutes. This clarification seemed to please participants more than the initial 60 minutes stated on the information and consent forms (it was initially believed that participants would talk much more during their interviews). On a methodological note, for future reference for conducting interviews with this population, aiming for shorter length of interviews could facilitate recruitment and encourage participation.

The coding of the interviews consisted of first regrouping participants' answers for the same interview question (e.g., How do you interpret the concept of "autonomy"?). Then, for each question, participants' answers were coded and regrouped based upon similarities of content. This approach allowed for the identification of some patterns and differences between participants' answers, while taking into consideration demographic factors (e.g., age, gender). When applying a reproductive justice framework to the analysis, it was possible to identify some of the ethical issues emerging from what participants shared during the interviews (e.g., whether there were unequal opportunities to access SRHS for adolescents based on autonomy).

Initially, when developing the research, the minimum recruitment sample size was 20. The goal was to have at least 10 participants who had never accessed SRHS and 10 participants who had previously accessed SRHS. The goal was to identify and analyze the differences between groups around the question of autonomy. The maximum recruitment sample size was 60, because the researchers wanted to have a diverse sample of participants. Recruitment stopped at 45 participants because the research project was coming to an end and the researchers had reached their objective of having a diverse sample of participants.

#### Recruitment

Participant recruitment took place at different locations and in various contexts over 6 months, from August 2019 to February 2020. The Profamilia network displayed recruitment posters in their clinics (e.g., waiting area) in the cities of Medellin, Palmira, and Cali, inviting participants to contact the researcher. Health professionals (e.g., youth psychologists, social workers) also shared information about the research project with their adolescent patients. When young people participated in activities with Profamilia (e.g., youth or activist groups) in and outside the clinics themselves, information about the research was shared with those present. One nurse also presented the research in a high school. This recruitment strategy was supplemented by snowball sampling, with participants sharing information about the research with their friends and peers. As such, there was a variety of participant profiles as some had never used SRHS for different reasons (e.g., prohibition from parent) and others had used SRHS from clinics besides

Profamilia (e.g., family doctor or other clinics). For this study, the only inclusion criteria were to be aged between 10 and 24 years old; adolescents from different backgrounds (e.g., gender, level of education) were invited to participate.

#### **Ethics**

The Science and Health Research Ethics Board of the University of Montreal approved the research, reference number: CERSES-19-049-P and the Profamilia Research Ethics Committee approved the study. Participants were asked to read and sign the consent form before participating in the interview. Participants were given a copy of the consent form and a list of resources to contact if they needed assistance (e.g., psychological support). Parental consent was not requested because it was deemed to be a potential barrier to participating in the research, notably because of its sensitive topic. The decision to not ask for parental consent was based on Guideline 17 (Research Involving Children and Adolescents) of the International Ethical Guidelines for Biomedical Research Involving Human Subjects (Council for International Organizations of Medical Sciences 2017), where it is argued that under certain conditions, it is possible to waive parental permission when it is not possible nor desirable and the research involves low risk for participants.

#### Results

#### **Participant Profiles**

A total of 45 participants were interviewed: 23 adolescent girls, 21 adolescent boys, and one gender non-binary adolescent. The age range was 14 to 23, with an average age of 19 and a standard deviation of 6.4. There were 20 participants from the Department of Antioquia: nine from Medellin (large urban region), six from Rionegro (small urban region), and five from Santa Fe de Antioquia (rural area). Twenty-five participants came from the Department of Valle del Cauca: two from Cali (large urban region) and 23 from Palmira (small urban region).

Colombia has six official socioeconomic classes (*estratos*) assigned to citizens based on their area of residency: 1 being the lowest, 6 the highest. Among the participants, three participants

belonged to *Estrato* 1, 12 to *Estrato* 2, 25 to *Estrato* 3, four to *Estrato* 4, and one participant did not know their *estrato*. This distribution of *estratos* among participants reflects the general distribution of *estratos* within Colombia, where the majority of the population belongs to the lowest three *estratos* and a minority belongs to the three upper *estratos*.

Three participants lived on their own, two with their romantic partner, 15 with both parents, and the remaining 25 participants had different living arrangements with various family members. For example, some lived with grandparents, aunts, or with a single parent. All participants 18 years or below were students enrolled at school at the time of the interview. For participants older than 18 years of age, all had completed the equivalent of a high school diploma; some were enrolled or had completed the equivalent of post-secondary education with a "technical diploma," whereas others were enrolled in or had completed university.

#### **Themes**

The following three sections are divided by the central questions that participants were asked during the interviews. Within each subsection, participants' answers (the names are pseudonyms) are categorized by similarities of responses, allowing differentiation of the emerging themes and patterns.

#### How Do You Understand the Concept of Autonomy?

One of the opening questions of the interview was how participants understand or interpret the concept of autonomy. Beginning with this question enabled the researcher to establish the groundwork or baseline of the participant's understanding of the concept, so that later on during the interview, he could make reference to the participant's definition when discussing other topics (e.g., their access to SRHS). As the following excerpts show, there were different understandings of the concept among the 45 participants.

The unfamiliar and the very informed. One of the most significant differences in participants' answers was that some were not familiar with the concept of autonomy.

Sofia (21-year-old, Estrato 3): Autonomy . . . Well . . . It's like . . . I dunno

Santiago (15-year-old, Estrato 3): I don't know that word.

Silvia (16-year-old, Estrato unknown): To be honest I don't understand the word autonomy.

Alberto (19-year-old, Estrato 1): I don't know what that word means.

By contrast, as the following interview excerpts demonstrate, others were very informed about the concept.

Juliana (20-year-old, Estrato 4): Autonomy, I interpret the word as deciding for your own body, without having anybody decide for you.

Carolina (21-year-old, Estrato 4): Well autonomy is the power to decide for one's self, based upon what one believes, from their own principles, the possibility to decide for yourself.

Manuel (20-year-old, Estrato 3): I would say that autonomy is the faculty to take things by your own account. The ability to decide on a personal basis for whatever and in whichever theme.

David (19-year-old, Estrato 3): Well, I interpret the word like knowing your rights and how to access them. It's like knowledge. Autonomy is the ability to access that. It is your own will.

"Autonomy as independence," "autonomy as choice," or as a mix of both. Among the participants who were familiar with the concept of autonomy, there were two common interpretations of the concept—autonomy as independence and autonomy as choice (liberty)—although for some, the definitions were a mix of both interpretations.

Francia (22-year-old, Estrato 3): The liberty to do the things that I want to do. That's how I interpret it (autonomy). It's like a synonym of liberty.

Diego (21-year-old, Estrato 3): Well, that you make the decisions yourself and that you go and find out without depending on anyone. "I want to go and find out," "I want to try this and that." You do that on your own.

Mateo (19-year-old, Estrato 3): The capacity for someone to develop, to take decisions.

Rafael (16-year-old, Estrato 4): It is the capacity for someone to do things by themselves. And when someone grows up, they are able to do more things alone without the help of anybody. That's how I would define autonomy.

Autonomy as a symbol of individuality, personality, and responsibility. A third common interpretation of autonomy was related to individuality, personality, and responsibility.

Sebastian (21-year-old, Estrato 3): The concept of autonomy, I think it means like, the determination, the value that someone attaches to themselves, to one's life. To respect yourself, to value yourself, to take care of yourself among other things.

Martin (21-year-old, Estrato 3): Autonomy . . . It could mean like the way you think, your own way. I would say that's what is autonomy, the authentic way each person is. It can be like your personality, your way of being, your way of thinking.

Paola (18-year-old, Estrato 3): Like, something that is your own. It is something that you do. It's kind of like "do-it-yourself," it's kind of like what you can do. To make your own decisions. To identify yourself.

Juan Martin (16-year-old, Estrato 3): Like it comes from yourself and having a very high autonomy and all that. It's like having a responsibility.

Hugo (16-year-old, Estrato 2): Autonomy is like the knowledge of yourself.

# <u>Do You Have Autonomy? When Did Your Autonomy Start? When Will You Have Complete</u> Autonomy?

After asking participants how they interpreted the concept of autonomy, they were invited to explain how the concept relates to them: whether they believe they have autonomy, and if so, since when. For those who were unfamiliar with the concept, some general definitions were shared by the interviewer (e.g., explaining that autonomy can be synonymous with independence in choosing which music to listen to). This explanation helped some to better understand the concept, whereas others remained uncertain. It became rapidly clear that some felt they had complete autonomy, whereas others felt they did not have complete autonomy for various reasons (e.g., economic dependence on parents). Some recalled a specific event that served as a trigger moment to define the start of their autonomy, while for others the development of autonomy was experienced as a gradual process.

Recognition of having autonomy. Most participants were able to recognize having at least some form or degree of autonomy. Nonetheless, while most could recognize having some autonomy, two female participants (16 and 19 years old) did not know whether they had autonomy or not. The following two excerpts highlight the contrast of experience between some participants.

# Silvia (16-year-old, Estrato unknown)

Interviewer: Are you someone that has autonomy?

Silvia: To be honest, I don't know, I don't know if I have autonomy.

# Martin (21-year-old, Estrato 3)

Interviewer: Would you say that you have autonomy at this moment?

Martin: Yes, thanks to God. My autonomy is very much rooted, and I can do and express

what I feel.

Interviewer: Can you give me some examples?

Martin: Let's say that in this moment I can, for example, go out and dress myself how I want in my own way [. . .] So yes, I am an autonomous person in my way of being, to speak, to think, to act.

Complete versus incomplete autonomy. For most participants, autonomy was perceived as a gradual process. Some felt they had reached complete autonomy, whereas others experienced partial autonomy.

# Elena (22-year-old, Estrato 2)

Interviewer: Do you feel like a person that has autonomy?

Elena: Not completely because I am not that independent, and I don't have my own resources to do the things how I want it, how I would want it. But in the choices and the things I can choose, yes I am autonomous.

Interviewer: Can you give me some examples in which you have autonomy?

Elena: Like . . . Like to take care of my own health, the way that I want to see myself in the decisions that I take. That if someone asks me something I can answer by my own will.

### Hugo (16-year-old, Estrato 2)

Interviewer: Would you say that you have autonomy?

Hugo: Yes, more or less. I take care of myself.

Interviewer: Can you give me examples for which you do not have autonomy?

Hugo: I don't know, maybe for the fact that I still live with my parents and I can't go out whenever I want.

### Jaime (22-year-old, Estrato 3)

Interviewer: Now you are 22 years old, would you say you have complete autonomy?

Jaime: Complete autonomy, no.

Interviewer: What are you missing to have complete autonomy?

Jaime: Become independent from the house.

Interviewer: That's the only thing? Jaime: Yes, that's what I'm lacking.

### Juliana (20-year-old, Estrato 4)

Interviewer: Would you consider yourself an autonomous person?

Juliana: I consider myself an autonomous person in many ways, but I also depend on others for other things. And I think that when you depend on others you lose a bit of autonomy.

Interviewer: Can you give me examples in what you have autonomy or not?

Juliana: I have not reached financial autonomy, because I am still dependent on my parents. I decide for me, for my own body, I can decide what I want to do and do not want to do, for things that go against my principles and for things that go with my principles. I do not act in a way that others ask me to do things, but I do it out of my own will, thoughts, and principles.

Trigger event: personal or general. For many participants, their sense of autonomy started after a very specific event, such as a personal experience or a general marker (e.g., a birthday), as opposed to being understood as a gradual process.

# Rosa (19-year-old, Estrato 3)

Interviewer: When would say you started to have more autonomy?

Rosa: More than anything else, I would say when my dad died. My mom had to start working a lot. I was 12 years old, so I had to start looking into what was good, what was bad, if I would do it, if I would not do it. So since that age I've been taking care of myself.

### Andres (23-year-old, Estrato 3)

Andres: My transition of boy to adolescent was around 14–15 years old, that's how I felt it (having autonomy).

Interviewer: Why is that?

Andres: Because that's when I had my first sexual contact with a woman. That's the moment that I felt it (autonomy). I felt that I stopped being a boy, because everything that I imagined actually happened and that's how I felt that change (of having autonomy).

# Elena (22-year-old, Estrato 2)

Interviewer: When did you start to have autonomy?

Elena: I think since I was an adolescent, since I was 15 years old.

Interviewer: And why at 15?

Elena: It is like at 15 people think they are already big. At 15 you're already starting to be

a grown up.

Interviewer: So at 15 years old you are an adult?

Elena: No but like you start feeling like you're already getting closer to being an adult. Obviously, you can't start doing all the things that an adult would do, but you start wanting to do them.

Interviewer: For you, it is at 15 years old you felt you started to feel more as an adult? Elena: Well, not to feel it. But that's when I started to think of things, like wanting to do things like an older person. Like wanting to travel, to discover new things, to start living by myself. Things like that, like to go out without asking for permission or not saying at what time I'll be back home.

### Jaime (22-year-old, Estrato 3)

Interviewer: When did your autonomy start?

Jaime: There was one event, or well, there were events that brought me to have an autonomy very early on. Since I was 12 years old, more or less.

Interviewer: And what happened at 12 years old?

Jaime: The separation of my parents. I went to live with my dad. My mom left to live by herself. To be honest, I was even younger, I was 11 years old. So that's when that my autonomy started because my dad was traveling a lot, so I was left alone at home with my little brother who's younger by 3 years. Look, how can I explain it to you...

Interviewer: To me it sounds like you had to take care of a house and a kid.

Jaime: Yes! Exactly! I had to take care of everything when my dad wasn't there. So that's why I've had a lot of autonomy since I was 11–12 years old.

Autonomy as a process. In comparison with participants who interpreted autonomy as starting after a specific event, others believed autonomy to be a developmental process.

# Paola (18-year-old, Estrato 3)

Interviewer: Would you say that you have autonomy?

Paola: Yes

Interviewer: And when did this autonomy start?

Paola: Well I would say that my autonomy was developed through a process. For example, in my childhood, my parents would say "do you want this or that? what is it that you would like? what do you want to study? what would you like to do as a career? what are your dreams?" So since then I started to develop autonomy as a process for the rest of my life.

### Sebastian (21-year-old, Estrato 3)

Sebastian: This autonomy of mine started when I started to learn from my own mistakes, so I started to educate myself and to listen to others. To learn from people who have good results in life and from there I was able to start to meet that autonomy in my life. Interviewer: And when did this start? When you were an adolescent?

Sebastian: Yes, I was an adolescent. I was around 18 years old. I was in high school and I was a very capricious young person, with my parents and in school. That's because I was not around good friendships and so on. So I think that my autonomy started in school, when I started to realize that I had to worry about myself, to take care of my things, to take care of myself, to love myself. So it's from there that this change all started, all this developmental process to reach my complete autonomy.

Unequal understanding of the concept of autonomy and its application. Autonomy is a core principle in Western bioethics. Health care professionals must respect patient autonomy, and this is especially relevant in the case of sexual and reproductive health. From the participants' answers, we see apparent differences in their understanding of autonomy. Some adolescents

were very knowledgeable and capable of linking the concept to themselves (e.g., recognizing that they have some form of autonomy and its limits), whereas others were unfamiliar with the concept. The distribution of those who were unfamiliar with the concept was more or less equal between genders, ages, and *estratos*. Some younger adolescents were more familiar with the concept than their older peers, even some who were considered by definition to be adults (i.e., 18 years old or older) and as such are fully autonomous from a legal perspective. Participants who were more knowledgeable tended to be older and had attended university (likely a representation bias because most participants older than 18 had been enrolled in university).

Lack of knowledge regarding the notion of autonomy, and how it applies to oneself, represents an ethical challenge from a reproductive justice perspective because it can limit or impede the exercise of autonomous decision making regarding sexual and reproductive health. Moreover, adolescents cannot hold health care professionals accountable for their responsibility to respect patient autonomy if they do not know or understand what autonomy is. This relates to a possible power imbalance whereby professionals know they must respect patient autonomy, yet the patient does not have the same knowledge. On the flip side, if professionals have a specific understanding of the principle of autonomy that does not resonate or apply to the adolescent patient's own understanding and experience, this can potentially lead to suboptimal care (e.g., involving miscommunication).

Finally, equity concerns arise when some adolescents are more knowledgeable than others about the foundation and significance of the principle of autonomy as it applies to SRHS. When some are in a more privileged position than their peers and are capable of advocating for their rights and interests compared with others (who are unfamiliar with the concept of autonomy and with their rights), a discrepancy is created in access to care. From a reproductive justice framework, these unequitable opportunities constitute challenges and call for initiatives to address this inequity, particularly as it relates to access to SRHS as will be shown in the following section.

# How Do You Want Your Autonomy to Be Respected to Access SRHS?

Participants were invited to share their opinions and personal experiences regarding their autonomy and ability to access SRHS. For example, participants were asked whether they preferred going to a health clinic by themselves or whether they wanted the assistance of someone (e.g., parent, friend) in deciding about a contraceptive option.

Knowledge of sexual and reproductive health. One must first have some knowledge of sexual and reproductive health in order to access SRHS when needed, for example, one needs to know that contraceptives exist and how they work before seeking to access them. Prior to starting the interview, each participant was asked whether they had received sex education in school. Nineteen of the 45 participants (42%) said they had received sex education in school while 13 (29%) had not; the remaining 13 participants (29%) explained that they had received "more or less" or "very bad" sex education. As the following excerpt from Manuel illustrates, some adolescents start from a more privileged position in comparison with participants who had never received sex education, whether from school or parents.

### Manuel (20-year-old, Estrato 3)

Manuel: When I was younger, when I was 12 years old, my mom hired a psychologist so she could talk to me about those themes (sexual and reproductive health). I don't know if it was specifically to talk about those themes, but the psychologist talked to me about those themes. She explained how reproductive organs work. She explained how to make a child, she explained how to use a condom, contraceptive methods, about sexually transmitted infections. So yes, my mom paid this for me.

Interviewer: And did you like that your mom did that?

Manuel: Yes, totally, absolutely. Because we can say that here, in Colombia, at 12 years old you don't know anything about that. Absolutely nothing. You only know that you have a penis and that's it. So yes, I find it cool.

Knowledge on how to access SRHS. The following interview excerpts show that many participants wished they had received education not only about sexual and reproductive health but also regarding how to access SRHS (e.g., information about whether an adolescent is allowed to access SRHS without their parents and how to do so).

### Alvaro (17-year-old, Estrato 2)

Interviewer: So for you it is important that we teach you about your rights (to access SRHS)?

Alvaro: Yes sir, to help me do things responsibly.

Interviewer: Did they teach you about your rights in the sexual education you received in

school?

Alvaro: Well, they said "you have rights" and that's it. They taught me other things, but they never explained our rights nor how to care for our rights (on how to access SRHS).

Interviewer: You would have liked for this be part of your sexual education?

Alvaro: Yes sir, I would have appreciated that.

# Juliana (20-year-old, Estrato 4)

Interviewer: You didn't know about Profamilia? (in relation to a 15-yearold friend asking the participant at 15 years old for help to get an abortion<sup>2</sup>)

Juliana: I didn't know Profamilia. Exactly for this lack of information. I only knew the "Pharmacy<sup>3</sup> Bad Death" (*la farmacia mala muerte*). So I brought her there and it was very traumatizing for her because it wasn't a legal way, the pharmacy was underground.

Interviewer: It was done through pills?

Juliana: Yes, it was through pills. But she was in her third month, so it was something very horrible for her. And if we would have had better information, we wouldn't have done it like that. She wanted to get an abortion, but her mom was super Catholic, so we were not able to ask for help. The baby was already quite big, my friend went to the bathroom and it came out in parts. It was super traumatizing. I was with her the whole time. We had to go to the hospital because the baby was coming out in parts [. . .] We had to go sell a gold ring in a shop to pay for the pills. We lived in a precarious neighborhood, we didn't have information, and abortion in this neighborhood is seen like sinful. So it was super difficult. I say that if we would have had more information, we wouldn't have made this huge mistake by going to an underground pharmacy.

Assistance to access SRHS. While some participants were unfamiliar with some aspects of how to access SRHS (e.g., their rights), others had the help of a parent to access SRHS.

Juan Martin (16-year-old, Estrato 3)

Interviewer: Have you ever used sexual and reproductive health services?

Juan Martin: Yes

Interviewer: At what age was your first time?

Juan Martin: Since I was 12 years old.

Interviewer: And where was it?

Juan Martin: At Profamilia. They gave me condoms and they also gave condoms to my

dad and he gave them to me.

Interviewer: So the first time was at 12 years old?

<sup>&</sup>lt;sup>2</sup> Abortion is legal in Colombia (ruling C-355 of 2006) and it would have been possible for the adolescent to get a free abortion at Profamilia, without parental consent.

<sup>&</sup>lt;sup>3</sup> The participant used the expression "pharmacy"; however, it was a clandestine location (i.e., not a genuine pharmacy nor clinic).

Juan Martin: Yes. It is my dad that went there because in my school they did not give out

condoms. So Profamilia gave them to my dad and after he gave them to me.

Interviewer: Is it you who asked for them or your dad gave them to you?

Juan Martin: I asked my dad for the condoms.

### Miguel (22-year-old, Estrato 3)

Interviewer: At what age was that (first time to access SRHS)? Miguel: I was 20 years old Interviewer: Did you go alone?

Miguel: I went alone, but it was my mom who scheduled the appointment.

Interviewer: It was your mom who scheduled the appointment?

Miguel: Yes, it was my mom who wanted me to go. It was her who asked for the appointment with *joven sano* (health program for youth focusing on sexual and reproductive health, for example, HIV testing).

Interviewer: What is your opinion that your mother took this decision for you?

Miguel: Let's see . . . I should have scheduled the appointment once I had started my sexual life, but there hadn't passed that much time either since I had started it. However, I think it's important that parents be interested in the sexual health of their kids, or whichever theme. If the son doesn't schedule the appointment, the parents should do it. For me it seems important.

# Francia (22-year-old, Estrato 3)

Interviewer: At what age was the first time (using SRHS)?

Francia: It is my mom who got me started by buying me injections for family planning at 15 years old. When she asked if I had a boyfriend, it had already been a year and a half I was with him, so I replied that I did have a boyfriend and I had already been intimate with him.

Interviewer: She asked you that?

Francia: Yes. It was quite uncomfortable, but she asked me. She did it by phone. She called

me and asked me, so I told her.

Interviewer: And why was it not in person?

Francia: I don't know. Like I was telling you before, maybe it's because of the lack of education on the topic. For example, my mom told me that she didn't have this conversation when she was pregnant at 19 years old. So she is with this fear, this fear that the same thing that happened to her, will happen to me. So she asked me, I told her "yes," and she said "alright, we'll start (family) planning with the injections" and she didn't let me choose anything. Everyone has different ways to do (family) planning and in my case it wasn't like that, "you're going to start with this and that's it."

Interviewer: So it is her who chose for you?

Francia: Exactly. And I asked her why this way and she replied that one of her friends uses injections. So I started to use them every month at the EPS (subsidized health promoting entities in Colombia).

Interviewer: And when you would go to the EPS, would you go by yourself or with your mom?

Francia: By myself.

As the previous example illustrates, some adolescents had their parents make decisions for them regarding access to SRHS, limiting or supplanting the adolescent's autonomous decision making. Some appreciated the involvement of parents, whereas others, such as Francia, disliked this involvement by a parent. Other participants wanted a stronger implication on the part of their parents (mothers in this case), but it was impossible for them to have such assistance for different reasons (e.g., contextual, personal beliefs).

# Isabella (14-year-old, Estrato 2)

Interviewer: Do you have any barriers to access sexual and reproductive health services?

Isabella: Yes, my mom. My mom doesn't let me.

Interviewer: And why won't she let you?

Isabella: She says I am not at an age to plan (planificar).

Interviewer: And you don't want to go to the clinic anyways?

Isabella: No. No I didn't do it because I want to respect her point of view. I want to respect

the opinion of my mom.

Interviewer: You would like for her to go with you to the clinic? Isabella: Yes, I would much

prefer that.

### Mariana (19-year-old, Estrato 1)

Interviewer: Did you go by yourself (the first time to use SRHS at 19 years old)?

Mariana: Yes Interviewer: Did you want to go by yourself?

Mariana: Well, I wanted to go accompanied, but my mom told me "no."

Interviewer: Why?

Mariana: She said that I had to go by myself because I am at a new stage in life.

Interviewer: But you wanted your mom to go with you? Mariana: Yes, so that she could be part of the whole process.

# Elena (22-years-old, Estrato 2)

Interviewer: At what age was the first time (to access SRHS)?

Elena: At 18.

Interviewer: Did you go by yourself or with your parents?

Elena: I went alone. Interviewer: Was it important for you to go alone?

Elena: No. The truth is I was in Argentina, I wasn't here. Interviewer: Your parents weren't

in Argentina with you?

Elena: No.

Interviewer: But if you would have had the possibility, you would have preferred to go

with your parents?

Elena: Yes, I would have liked to go with my mom.

While some participants wanted a parent present when accessing SRHS, others like Ariel and Bianca did not want to be accompanied by a parent.

# Ariel (21-year-old, Estrato 3)

Ariel: Yes, I went by myself (to get contraceptive pills at 15 years old).

Interviewer: Was this important for you to go by yourself?

Ariel: Yes, I wanted to go by myself. I decided to go by myself because I didn't know how my dad was gonna take it, because if you are doing family planning it is obvious that you are sexually active and that can generate conflict with parents. I didn't want to worry them either. I had easy access to the contraceptive, so I went by myself.[...]

Interviewer: And after, when you had that bad reaction to the contraceptive pills, did you also go alone to see the gynecologist?

Ariel: No. For that I had to go with the wife of my dad. She accompanied me in the process. Interviewer: But you wanted to go alone?

Ariel: Yes. Actually, there was something that I didn't like. They did a transvaginal echography and she was present for that procedure and that was very uncomfortable, and I did not like it. Beyond a question of being young or an adult, it is my sexuality. Interviewer: How old were you?

Ariel: 15 years old. I wasn't a child, but it is my sexuality, my privacy, and I should have been able to decide if I want to be accompanied or not.

# Bianca (22-year-old, Estrato 2)

Interviewer: The first time you went, did you go alone or accompanied (at 19 years old)?

Bianca: Alone

Interviewer: Was that important for you to go alone?

Bianca: I wanted to go alone because it was a decision in relation to my sexual life, so something very private with my health.

Unequal opportunities to exercise autonomy. From the participants' interviews, their understanding and recognition of autonomy are highly contextual and depend on personal experiences. This means that they have unequal opportunities, particularly regarding access to SRHS. For example, 16-year-old Rafael's father had died, and his mother was obliged to work long hours, sometimes 6 to 7 days a week. Similarly, when Jaime was a young adolescent, he was alone at home for long periods without a parent present. In such situations, it would clearly be very challenging for an adolescent such as Rafael or Jaime to have a parent accompany them to a clinic for SRHS. Another example is that of 12-year-old Juan Martin, whose father got him condoms at Profamilia when he asked for assistance, while 14-year-old Isabella wanted her mother's help to access contraceptives but did not have the same possibility because her mother refused for her daughter to be sexually active.

Participants shared these and other examples of unequal opportunities associated with their personal preferences regarding how to access SRHS. Some wanted the assistance of a parent but could not have it, others had such assistance available should they wish, while others explicitly stated wanting to access SRHS alone, but not always being able to do so. From a reproductive justice framework, this reality represents two serious ethical challenges:

- 1. Adolescents have unequal opportunities to access SRHS based on various contextual factors (e.g., unavailable parent to accompany them to the clinic).
- 2. Adolescents do not have their personal preferences equally respected in terms of autonomy in their access of SRHS.

While some participants described themselves as more autonomous than others, many still wanted or appreciated the assistance of a parent to access SRHS (e.g., scheduling the appointment for them or accompanying them to the clinic). Other participants described themselves as having less autonomy but would have preferred to access SRHS independently. Thus, participants' responses showed that their perception of whether or not they have complete (or almost complete) autonomy does not correlate with their wish to access SRHS independently (i.e., without a parent).

Adolescents may see themselves as very autonomous, but still want to be accompanied by or have the assistance of a parent to access SRHS. This observation challenges some of the common critiques in bioethics of third-party involvement in medical decision making that have sought to limit medical or parental paternalism to protect individual autonomy and freedom. Nonetheless, for the adolescent participants in our study, the majority (although not all) saw the involvement of their parents in access to SRHS as welcomed or even desired. This finding is different from the experiences identified in similar research conducted on the topic in other cultural contexts, such as in North America, where adolescents generally did not want their parents' involvement and saw this as a constraint on their autonomy to access to SRHS (Lehrer et al. 2007).

# Ethical Analysis Based on a Reproductive Justice Framework: The Need to Foster Adolescents' Autonomy to Access SRHS

Respect for autonomy means allowing adolescents to make choices based on their needs and preferences. Respect for justice means they should have equitable opportunities to access SRHS and have their preferences respected. How can we address the ethical challenges related to adolescents' unequal opportunities to autonomously access SRHS? In 2017, the WHO introduced the *Global Accelerated Action for the Health of Adolescents* (AA-HA!). The objective of AA-HA! is to develop initiatives to ameliorate the health of adolescents. Within AA-HA!, the WHO suggests "fostering the autonomy" of adolescents to empower them to access health services to protect them from potential harm. However, the AA-HA! lacks in-depth ethical justifications for why and how the autonomy of adolescents should be fostered. The present study shows the ethical pertinence of fostering autonomy to access health services, to help promote equity by ensuring adolescents have equal opportunities to access SRHS regardless of their unique life circumstances.

From the stories participants shared, it is evident that they did not have the same opportunities to access SRHS based on their own preferences. Some were taught how to access SRHS or even appreciated having their parents schedule appointments for them, which supported their autonomy. Others had limited autonomy because they had no knowledge about how to access SRHS or because parents made decisions for them without taking into consideration their own wishes.

One possible way of fostering adolescents' autonomy to access SRHS in their community would be through educational initiatives, notably within a sex education curriculum. Historically, sex education for adolescents has focused on prevention (e.g., prevention of sexually transmitted infections [STIs] like HIV, and pregnancy with condoms). However, there has not been the same effort to discuss and provide knowledge to adolescents regarding the principle of autonomy and decision making in health care (which should go beyond sexual and reproductive health) or explaining how to access SRHS if needed. For example, explain how to navigate one's local health

care system and teach adolescents about their rights and limitations to access SRHS, such as clarifying whether or not parental consent is required. Since during adolescence one starts to develop more independence and maturity, it is crucial that adolescents be provided with the knowledge on how to access health services and how to exercise their rights in medical contexts (e.g., the right to ask questions of health care professional, the right of confidentiality). As the ethical principle of autonomy constitutes a core principle in health care, a person should not have to wait to reach adulthood to be taught the value and application of autonomy in health care.

A concrete example of a previous intervention that demonstrated the pertinence of engaging in initiatives to foster adolescents' autonomy to access SRHS is Meuwissen et al.'s (2006) quasi-experimental intervention study in Nicaragua. Adolescent girls from disadvantaged contexts in Managua were given vouchers to access SRHS. The vouchers "could be used for 1 consultation and 1 follow-up visit for counseling, family planning, pregnancy testing, antenatal care, STI treatment, or a combination of these services" (Meuwissen et al. 2006: 56.e2). Compared with participants who did not receive vouchers, those with vouchers had significantly higher access to SRHS, which led them to increased use of contraceptives. Such an intervention highlights how providing tools to foster adolescents' autonomy to access SRHS can have very beneficial results. Taking Meuwissen et al.'s intervention into consideration for the present study, it is thus fair to suggest that by educating adolescents about their rights and autonomy to access SRHS, this would likely lead to increased access to SRHS, because when needed these adolescents would possess the required knowledge to exercise their autonomy.

Another challenge emerging from the data is related to the role of parents. If an adolescent wishes to be accompanied to a clinic by their parents, but the parents are unavailable or do not wish to assist in accessing SRHS, another ethical issue arises, namely, parents' rights and obligations in the context of their child's sexual and reproductive health. This would require further research, particularly with parents themselves (e.g., exploring their understanding of their adolescents' autonomy to access SRHS). Some parents may prohibit their adolescent from accessing SRHS, for example, because of cultural or religious beliefs, whereas others may

accompany their adolescents to clinics. This discordance between the experiences recounted by our participants highlights other important and complex ethical challenges raised by adolescents' access to SRHS. It points to the need for further research on the topic, especially because the reproductive justice framework is not obviously equipped to address this ethical question.

To highlight the complexity surrounding these questions, we may use the previous examples of Isabella (14 years old) and Juan Martin (12 years old). Isabella's mother did not want her to use contraceptives, because she believed her daughter was too young, whereas Juan Martin was given condoms by his father when asked for them at an even younger age. It is possible to observe some clear differences between the two young adolescents' access to contraceptives. Both participants display a form of autonomy in wanting to use contraceptives, yet the parents' reactions are quite different, which in turn influences their access to SRHS. This research did not interview the parents of adolescents to understand their perceptions of their adolescents' autonomy to access SRHS. Notwithstanding, cultural understandings of gender arguably shape approaches toward the question of adolescents' autonomy to access SRHS. Throughout Latin America, robust gendered roles and ideologies are present, which are commonly known as marianismo (Englander et al. 2012; Stevens & Pescatello 1973) and machismo (Gutmann et al. 2002). Marianismo pushes for women to be virgins, passive with men, and to become wives and mothers, whereas machismo pushes men to be assertive and sexually adventurous with women. If such gendered ideologies are transposed to adolescents, this can perhaps explain why Juan Martin's father got him condoms at 12, but Isabella's mother refuses for her 14-year-old to get access to contraceptives. If adolescents have unequal access to SRHS based upon a gendered ideology held by their parents, the situation makes it profoundly unjust from a reproductive justice perspective. It further points to the need to engage in initiatives with parents to help address the issue, perhaps through educative interventions with the parents of adolescents, although more research is needed on the topic.

# **Limitations**

It is important to take into consideration the limitations of this study. One critical limitation is the sample's representation bias. There are many significant socio-demographic differences across Colombia, some of which are particularly important to consider regarding adolescents' extreme vulnerability due to poverty and violence (Higgs 2020). Colombia has one of the world's highest rates of internally displaced people—approximately a tenth of the Colombian population has been displaced because of internal conflict (Reyes et al. 2019). Arguably, Colombian adolescents' autonomy to access SRHS varies between those living in precarious contexts with limited resources and more prevalent paramilitary presence, and those in stable contexts with more resources. There are adolescents in much more privileged situations, such as those from the upper estratos, who might have very different experiences; however, no adolescents from the Estratos 5 and 6 participated in an interview for this research. As such, this study's conclusions cannot be generalized for the whole Colombian population due to the limited sample size and the locations of data collection—For example, the Pacific coast and the Caribbean coast have different cultural contexts than the capital Bogota or the Amazonian region. Future research on the topic should look into exploring the question with different socio-demographic groups of adolescents and also compare with similar studies in other Latin American countries.

Another source of potential bias is single interviewer and data coding; a double coding approach could have helped improve reliability. Such factors should be taken into consideration for future research.

### Conclusion

Global health literature has shown that adolescents insufficiently use health care services despite having important health-related needs that can and should be addressed (Mazur et al. 2018; Patton et al. 2016). There are many reasons for this phenomenon, some of which are connected to adolescents' autonomy to access health care services, such as parental consent laws, economic barriers, and lack of knowledge on how to use health care services. As the findings of our study show, Colombian adolescents have diverse experiences and understandings regarding autonomy

when it comes to accessing SRHS. From a reproductive justice framework, unequal opportunities to access SRHS represent a serious ethical challenge.

To address this challenge, we argue in favor of fostering adolescents' autonomy to access health care services, for example, through educational initiatives. As shown by other studies, education is one of the greatest determinants of adolescent health (Viner et al. 2017). UNESCO's (2018) International technical guidance on sexuality education underscores the importance for comprehensive sex education for adolescents to be based on a human rights approach and to develop life skills needed to support healthy choices. As our findings and those of other studies show, it is essential to engage in initiatives with adolescents to promote their knowledge around the concept of autonomy and how to access SRHS, namely, in the name of equity for adolescents.

Furthermore, on a policy level, recognition of and respect for autonomy should be anchored in a more nuanced understanding of adolescents' preferences, which can legitimately involve (a) accessing SRHS by themselves, that is, autonomy as independence (a model often advocated in North America and Europe) or (b) being accompanied by a parent (or another person) in accessing SRHS. The present study did not interview parents of adolescents. However, the answers of participants underscored that parents seem to play a crucial role around the question of adolescents' autonomy to access SRHS. Future studies should investigate how to mobilize or engage with the parents of adolescents to help foster the autonomy of adolescents to access SRHS. One possibility might be through comprehensive sex education for parents of adolescents.

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# **Chapter 5: Colombian Adolescents' Preferences to Access SRHS**

Article II: Colombian adolescents' preferences for independently accessing sexual and reproductive health services: A cross-sectional and bioethics analysis

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### Abstract

**Objective:** Our study sought to (1) describe the practices and preferences of Colombian adolescents in accessing sexual and reproductive health services: accompanied versus alone; (2) compare actual practices with stated preferences; and (3) determine age and gender differences regarding the practice and these stated preferences.

**Methods:** 812 participants aged 11–24 years old answered a survey in two Profamilia clinics in the cities of Medellin and Cali in Colombia. A cross-sectional analysis was performed to compare participants' answers based on the variables of gender and age.

**Results:** A quarter of participants visited the clinic alone (25.4%). Females were more likely to go alone in comparison to males (26.3% vs 14.1%; p = 0.031), and older participants went alone more often than younger participants (p < 0.001). Most participants – 72.7% (95 %CI: 69.3–75.9) – expressed a preference in being accompanied to the clinic, and more than 90% had their preferences met. The preferences of older participants were, however, less likely to be met than those of younger participants (p < 0.001), notably, because they predominantly wanted to be accompanied.

**Conclusion:** Contemporary public health and bioethics literature advocates in favor of developing health services that better meet the preferences of adolescents. The present research highlights an apparent blind spot related to the role that others (e.g., parents, friends, partners) can or should play in accompanying adolescent patients when they access sexual and reproductive health services. Respecting adolescents' preferences, and hence their autonomy, is not simply a

matter of ensuring freedom from constraints (e.g., their right and ability to go alone). Rather, it should also consider the liberty to choose whether to be accompanied when accessing SHRS and by whom.

**Keywords:** Access; Adolescents; Autonomy; Colombia; Sexual health; Reproductive health

# **Background**

One of the leading global health challenges emerging from the literature on adolescent health is the recognition that adolescents have many unmet healthcare needs and demonstrate low use of healthcare services, particularly in the context of sexual and reproductive health (Mazur et al. 2018; Nature 2018; Patton et al. 2016). Reasons include adolescents' inexperience and lack of knowledge regarding how to access healthcare services in their communities (Patton et al. 2012), conflicting schedules with school, lack of economic resources to pay for health services, and issues of confidentiality when consulting healthcare providers without parental consent (Mazur et al. 2018; Santhya & Jejeebhoy 2015). Adolescents' autonomy is at the core of these challenges.

There are numerous different ways of defining and understanding the concept of autonomy, as evident in the philosophical, social sciences, legal, and biomedical literature (Soenens et al. 2017). In the context of this study, "autonomy" was framed – as commonly done in contemporary bioethics and health law - as "independence" and as having one's preferences regarding healthcare decisions met (Beauchamp & Childress 2012). Adolescents' autonomy to access healthcare services is ethically complex, because their capacity to make healthcare decisions evolves over time, and with it, the degree of liberty they have to make such decisions. Hence, tensions can arise between adolescents, their families (or legal guardians), and health professionals. Such tensions are particularly evident regarding sexual and reproductive health, a sensitive context that can be a source of discomfort for many parents. What are and what should be parents' roles regarding adolescents' accessing SRHS? What are the limits of parental authority? Should parental consent be required for adolescents to access contraception, for example? And if so, until what age?

These ethical issues have been the subject of significant conceptual analysis and reflection in the academic literature (Brierley & Larcher 2016; Garanito & Zaher-Rutherford 2019; Olszewski & Goldkind 2018). What is arguably lacking is empirical data on how adolescents themselves conceptualize their autonomy, and how they view and experience these ethical tensions. Specifically, how do adolescents wish to access a clinic specialized in SRHS (e.g., alone or accompanied)? Providing an opportunity for adolescents to voice their opinions on access to SRHS can enable the development of healthcare policies and practices that would better reflect adolescents' preferences. Furthermore, such empirical data can ensure the effective operationalization of the ethical principles of beneficence and justice, that are essential to the deployment of adequately adapted and equitable healthcare policies (Schröder-Bäck et al. 2014). Our study sought to contribute to the development of such empirical data by providing a description of how a group of adolescents accessed a clinic specialized in SRHS in Colombia, and what their preferences were regarding being accompanied.

There are several reasons for conducting our research in Colombia. First, there are no specific laws or policies regarding parental consent for adolescents to access some SRHS. This means that a 13-year-old girl in Colombia can, without parental consent, access contraceptives or have an abortion – which would be impossible in most neighboring Latin American countries. Colombia is thus a particularly interesting context in which to explore adolescents' autonomy and preferences regarding being accompanied – or not – when they access SRHS, since they may legally exercise greater autonomy than their peers in other countries. It is essential to highlight that while adolescents in Colombia can technically access some SRHS without parental consent, most adolescents are not aware of this. Furthermore, most research on adolescents is performed in high-income countries (HIC) – that have very different social, cultural, economic, and political contexts in comparison with low and middle-income countries (LMIC). This is even though 90% of adolescents worldwide live in LMIC, like Colombia (Blum & Boyden 2018; Vandermorris & Bhutta 2017). As such, policy recommendations for equitable and appropriate access to SRHS that are based on empirical studies of adolescents in HIC do not fully describe the realities of adolescents in LMIC.

# **Objectives**

This study's objectives are to (1) provide a description of how a sample of Colombian adolescents aged 11 to 24 accessed a clinic specialized in SRHS: accompanied vs. alone; (2) compare actual practices with stated preferences; and (3) determine differences by age and gender in the practice and stated preferences for being accompanied or going alone when accessing SRHS.

# **Hypotheses**

Previous research on the topic has shown that confidentiality plays a crucial role in accessing healthcare services for adolescents, especially as it relates to sexual and reproductive health (Berhane & Berhane 2005; Brittain et al. 2015; Burack 2000). Research shows that adolescents tend not to want their parents to know that they wish to use SRHS. Hence, the central hypothesis for our study was that most participants would want to access the SRHS clinic by themselves, rather than be accompanied. The second hypothesis was that younger adolescents would be more likely to access the clinic accompanied than older adolescents, based on view that autonomy as independence increases with age. The third hypothesis was that older adolescents (e.g., 18 and older) would be more likely to have their preferences to access SRHS realized than younger adolescents since, as adults, they can exercise greater independence and agency in health-related decisions.

# Methods

### Study setting and design

A cross-sectional study design was used to identify and analyze the differences and similarities of answers between participants based on demographics (e.g., age groups and gender). Participants were asked a series of questions, in Spanish, to build a descriptive portrait of how they accessed the clinic. For example, they were asked what the main reason was for being at the clinic that day (e.g., vaccination, contraceptives, counselling, abortion), if they came alone or were accompanied (and by whom), and if they wanted to be alone or accompanied.

Data collection took place between August 2019 and February 2020 in two Profamilia clinics in two Colombian cities, Medellin and Cali, both have populations of approximately 2.2 million habitants. Profamilia is a network of non-profit clinics specialized in providing accessible SRHS in Colombia (e.g., HIV/STI testing, abortions, contraceptives, vasectomies), including specialized services for young people (e.g., counseling). Adolescent patients who presented at the clinic were asked to fill out a survey while waiting for their appointment. The survey had questions on demographics and the topic of access to SRHS.

# Sampling and recruitment

The primary inclusion criteria was adolescents aged between 10 and 24 who presented themselves at the two Profamilia clinics. The choice of this age range was based on the new more expansive definition of adolescence in use in global health research (Sawyer et al. 2018). Adolescence is viewed as an important and lengthy transition period between childhood and adulthood, in which autonomy as independence is developed. Using this broader age range in our study would also allow for a better understanding of the similarities and differences between different age groups (e.g., younger vs. older adolescents).

Initially, the study's plan was for the receptionists at the two participating clinics to offer every patient aged between 10 and 24 an opportunity to answer independently the survey while they were in the waiting area. This sampling approach would have reduced representation biases since all eligible participants would have been invited to answer the survey. However, soon after the start of the study, the receptionists explained that some periods had higher volumes of patients, making it too challenging to invite all adolescent patients to answer the survey. The recruitment approach was thus modified to convenience sampling; the receptionists would invite participants to answer the survey when deemed appropriate (e.g., less busy periods). While less empirically rigorous due to potential sampling bias (i.e., the invitation to participate was dependent on the receptionist's availability), this was somewhat mitigated by receptionists being asked to track, on a calendar, the number of individuals invited to answer the survey, i.e., they would make a mark on the corresponding calendar day for every invitation. At the end of the week, it was then

possible to calculate the level of participation from the answered surveys in relation to the number of invitations.

Testing for HIV and other sexually transmitted infections (STI) is an essential service provided by SRHS clinics. However, at Profamilia, this service involves patients filling out substantial paperwork and receiving counseling from a nurse (e.g., teaching about safe sex practices). Staff and the research team were concerned that participation in the study might be too time-consuming and overwhelm already anxious adolescent patients, so participants at Profamilia for HIV/STI testing were not invited to answer the survey.

### Data analysis

Some of the data presented in the tables is descriptive (e.g., percentages) and is meant to provide an overview of participant characteristics and their access to the clinic. For the purpose of this article, only the first table presents the data divided by cities. For the subsequent data analysis, the data from the two cities were merged. A sampling approach analysis was used despite the convenience sample. Statistical significance was evaluated as p < 0.05 for all tests. Percentages were rounded to the nearest tenth, including confidence intervals. Since the variables were categorical, chi-square tests of independence were performed to analyze the relationship between variables (e.g., gender).

To analyze the homogeneity between groups, z-tests (two-tailed) were performed for proportions. These statistical tests allowed identification of associations between groups and a better understanding of similarities and differences between groups on the question of autonomy to access SHRS. The main independent variables were gender and age. As noted in the Results, because of lower participation rate for the "10–12 years old" category, this was merged with the "13–15 years old" category for some of the data analysis.

For participants who were accompanied to the clinic, they were asked who accompanied them. Participants could answer that they were accompanied by more than one person (e.g., mother

and sister), which led to recoding data for analysis (i.e., was entered as one entry). For participants who were accompanied by more than one person, this data was recoded in relation to parental status (i.e., "mother"), meaning that if a participant was accompanied by a parent and another person (e.g., aunt, partner, friend), the data was counted under the respective parent as one entry. If the participant was accompanied by a friend and their partner, the data was counted once under the partner. If accompanied by a family member and a friend or partner, the data was counted once under the respective family member. The only category for data analysis that included two people of accompaniment was for participants accompanied by both parents, which was counted as one entry.

The categories of preference for accompaniment were recoded as follows: the data of the categories "went alone and wanted to be alone," "went accompanied and wanted to be accompanied," and "does not matter" were merged to give the category of having one's preference met, i.e., "satisfied." The categories "went alone and wanted to be accompanied" and "went accompanied and wanted to be alone" were merged under the category "unsatisfied."

### Research ethics

Adolescents who expressed an interest in participating in the study were given an information sheet by the receptionists to read in order to make an informed decision about whether or not they wanted to participate. The information sheet clearly explained the purpose of the study, that all the answers would be anonymous, that the choice to participate, or not, would in no way affect the quality of care they would receive at Profamilia, and that participation was entirely voluntary. Participants were free to keep that information sheet if they wanted, which also contained contact information to reach out to if they had questions or concerns. Once they consented, participants received the anonymous survey to complete confidentially and independently in the waiting room; when completed, they were asked to fold it and put in a locked box in the waiting area, to which only the researcher had access. This approach enabled the protection of participant anonymity, both with regards to the clinic staff and the researcher.

Parental consent was not required nor requested for adolescents to participate in the survey. For one, it would have been challenging for adolescent patients who came alone to the clinic to ask for parental consent. More importantly, however, asking for parental consent was deemed a potential barrier to participation. The decision to not ask for parental consent was based on Guideline 17 (Research Involving Children and Adolescents) of the International Ethical Guidelines for Biomedical Research Involving Human Subjects (Council for International Organizations of Medical Sciences 2017), where is it argued that under certain conditions, it is possible to waive parental permission when it is not possible or desirable, and the research involves low risk for participants.

The University of Montreal's Ethics Committee in Health and Science first evaluated and accepted the research, reference number: CERSES-19-049-P. Subsequently, the Research Ethics Committee of Profamilia (which included a lawyer) evaluated and approved the research.

# **Results**

### Characteristics of study participants

A total of 1,272 adolescents were invited to participate, of whom 911 answered the survey (initial participation rate of 71.6%). From those who answered the survey, 99 were excluded because they did not answer enough questions for data analysis (e.g., left blank the demographic section). Hence, 812 surveys were used for data analysis (63.8% participation rate).

**Table 6** summarizes the participants' demographics by city: 73.0% of participants were from Medellin and 27.0% from Cali. Most respondents were female (91.4%); participants were able to answer "trans" or write their own gender if they wished, but none chose those options. Participants ranged in age from 11 to 24, although they were concentrated between 16 and 21 (57.8%). One out of ten participants were internally displaced people (10.2%), which is reflective of the country's situation as having one of the world's highest rate of internally displaced people because of violence (Reyes & Fattori 2019). The representation of *estratos* (i.e., socio-economic classes assign to citizens based on area residency, such as neighborhood) amongst participants

is similar to that of the country, where the majority of the population are in the lowest three *estratos*, and the remaining minority in the upper three *estratos* (1 = lowest; 6 = highest). More than half were single (58.0%), whereas almost one third were in a serious relationship (30.9%). A minority of participants reported being Venezuelan migrants (1.7%) and the remaining participants who answered the question on nationality were Colombian (92.7%).

**Table 6. Baseline data for participants** 

City	Medellin	Cali	TOTAL						
Participants, n	593	219	812						
Age, n (%)									
10-12	8 (1.3)	0 (0.0)	8 (1.0)						
13-15	115 (19.4)	22 (10.0)	<b>137</b> (16.9)						
16-18	172 (29.0)	72 (32.9)	<b>244</b> (30.0)						
19-21	155 (26.1)	70 (32.0)	<b>225</b> (27.7)						
22-24	118 (19.9)	49 (22.4)	<b>167</b> (20.6)						
Missing	25 (4.2)	6 (2.7)	<b>31</b> (3.8)						
Gender, <i>n</i> (%)									
Male	54 (9.1)	10 (4.6)	<b>64</b> (7.9)						
Female	533 (89.9)	209 (95.4)	<b>742</b> (91.4)						
Missing	6 (1.0)	0 (0.0)	<b>6</b> (0.7)						
Estrato, n (%)									
1	111 (18.7)	55 (25.1)	<b>166</b> (20.4)						
2	236 (39.8)	47 (21.5)	<b>283</b> (34.9)						
3	178 (30.0)	71 (32.4)	<b>249</b> (30.7)						
4	24 (4.4)	16 (7.3)	<b>40</b> (4.9)						
5	7 (1.2)	11 (5.0)	18 (2.2)						
6	0 (0.0)	3 (1.4)	<b>3</b> (0.4)						
Missing/unknown	37 (6.2)	16 (7.3)	<b>53</b> (6.5)						
Displaced Person, n (%)									
Yes	75 (12.6)	8 (3.7)	<b>83</b> (10.2)						
No	466 (78.6)	193 (88.1)	<b>659</b> (81.2)						
Missing	52 (8.8)	18 (8.2)	<b>70</b> (8.6)						
Relationship Status, n (%)									
Single	358 (60.4)	113 (51.6)	<b>471</b> (58.0)						
Serious relationship	168 (28.3)	83 (37.9)	<b>251</b> (30.9)						
Free union	21 (3.5)	10 (4.6)	<b>31</b> (3.8)						
Married	19 (3.2)	5 (2.3)	<b>24</b> (3.0)						
Missing	27 (4.6)	8 (3.7)	<b>35</b> (4.3)						
National Status, n (%)									

Colombian	555 (93.6)	199 (90.9)	<b>754</b> (92.9)
Venezuelan	10 (1.7)	4 (1.8)	<b>14</b> (1.7)
Missing	34 (5.7)	16 (7.3)	<b>50</b> (6.2)

The main reason for participants being at Profamilia was to access contraceptives (73.8%), followed by wanting to access information related to sexual and reproductive health (6.6%) and sterilization (6.5%). It is important to note that sterilization in Colombia is only available for individuals 18 years or older. Participants were also asked if they were at Profamilia for other services. Close to three-quarters of the participants were not looking for other services (72.0%), whereas the two main other reasons for being at Profamilia were to receive counseling (e.g., from a youth psychologist) (14.5%) and access information related to sexual and reproductive health (12.2%).

# **Accessing Profamilia**

Participants were invited to tell how they came to Profamilia on the day they completed the survey: alone or accompanied. A quarter responded that they came alone (25.4%), and the others were accompanied (74.6%). **Table 7** presents the participants' answers – by gender and age group – on whether they came alone to the clinic (excluding participants who did not answer the demographic questions). Female adolescents were more likely than their male counterparts to go alone to the clinic (26.3% vs. 14.1%). Nonetheless, for both genders, participants predominantly went to the clinic accompanied. As for age groups, an older participant was statistically much more likely to go to the clinic alone in comparison to a younger participant, which aligns with our hypothesis that younger adolescents would tend to go to the clinic accompanied, in comparison to older adolescents. However, for all age groups, more than half of the participants were accompanied.

Table 7. Did participant come alone to clinic (by gender and age)?

GENDER	<b>Total</b> n	Came Alone	<i>p</i> value
		n <b>(%)</b>	
Male	64	9 (14.1)	0.031
Female	742	195 <b>(26.3)</b>	
Total	806	204 <b>(25.3)</b>	
	<b>I</b> .		

AGE GROUPS	Total	Came	p value*				
	n	Alone					
		n <b>(%)</b>					
10-12	8	0 (0.0)	< 0.001				
13-15	137	6 <b>(4.4)</b>					
16-18	244	45 <b>(18.4)</b>					
19-21	224	80 <b>(35.7)</b>					
22-24	167	70 <b>(41.9)</b>					
Total	780	201 <b>(25.8)</b>					
GENDER BY	Total	Came	<i>p</i> value				
AGE GROUP	n	Alone					
		n <b>(%)</b>					
Younger Male	20	2 ( <b>10.0)</b>	Between Males: 0.543				
(10-18 years old)			Between Females: < 0.001				
Older Male	38	6 <b>(15.8)</b>	Between Younger Age: 0.671				
(19-24 years old)			Between Older Age: 0.003				
Younger Female	368	49 <b>(13.3)</b>					
(10-18 years old)							
Older Female	354	144 <b>(40.7)</b>					
(19-24 years old)							
Total	780	201 <b>(25.7)</b>					

<sup>\*</sup> The categories "10–12" and "13–15" years old were merged together.

To control representation bias, data were regrouped by gender and age group: "younger" (10–18 years old) and "older" (19–24 years old). There was no statically significant relation, for male participants (younger and older), in terms of accompaniment to the clinic (10.0% vs 15.8%), whereas for female participants, there was a statistically significant association, with older participants much more likely to go alone to the clinic in comparison to younger participants (13.3% vs. 40.7%). Amongst younger participants, there were no statistically significant difference between males and females, but there was a statistically significant difference between older participants, whereby older females were more likely to go alone to the clinic in comparison to older males. The present data thus suggest that participants who went alone tended to be older and female.

**Table 8** presents the categories of people who accompanied participants to the clinic. Under those categories, the most prevalent person to accompany a participant was their mother, which was the case for more than one-third of participants who went to the clinic accompanied (38.3%; 95% CI: 34.5–42.4) – excluding the category of those who came with both parents. By contrast,

only 4.3% (95% CI: 2.8–6.2) were accompanied by their father (and not their mother), and only 0.8% (95% CI: 0.3–1.9) of participants came with both parents. The proportion of participants accompanied by a family member (including mother-in-law and sister-in-law), as opposed to a non-family member, was more than half: 374/605 = 61.8% (95% CI: 57.9-65.7). The present data suggest that family members play an important role in accompanying Colombian adolescent participants when accessing SRHS.

Table 8. Who accompanied the participant to the clinic (by gender and age)?

PERSON WHO		GENDER		AGE					TOTAL	
ACCOMPANIED	Female	Male	Missing	10-12	13-15	16-18	19-21	22-24	Missing	
	n (%)	n (%)	n	n (%)	n (%)	n (%)	n (%)	n (%)	n	n (%)
Both parents	5 ( <b>0.9</b> )	0 (0.0)	0	1 (12.5)	1 (0.7)	2 (1.0)	1 (0.7)	0 (0.0)	0	5 <b>(0.8</b> )
Mother	220 ( <b>40.2</b> )	11 (20.0)	1	4 (50.0)	90 ( <b>68.7</b> )	79 ( <b>39.7</b> )	27 ( <b>18.8</b> )	21 ( <b>21.6</b> )	11	232 ( <b>38.4</b> )
Father	24 (4.4)	2 (3.6)	0	2 ( <b>25.0</b> )	6 ( <b>4.6</b> )	10 ( <b>5.0</b> )	4 (2.8)	3 <b>(3.1</b> )	1	26 ( <b>4.3</b> )
Friend	96 ( <b>17.6</b> )	8 (14.5)	0	0 (0.0)	6 ( <b>4.6</b> )	30 ( <b>15.1</b> )	37 ( <b>25.7</b> )	27 ( <b>27.8</b> )	4	104 ( <b>17.2</b> )
Partner	85 ( <b>15.5</b> )	29 ( <b>52.7</b> )	2	0 (0.0)	3 ( <b>2.3</b> )	32 ( <b>16.1</b> )	46 ( <b>31.9</b> )	29 ( <b>29.9</b> )	6	116 ( <b>19.2</b> )
Cousin (female)	21 (3.8)	0 (0.0)	0	0 (0.0)	1 (0.7)	9 <b>(4.5</b> )	6 <b>(4.2</b> )	5 <b>(5.2</b> )	0	21 ( <b>3.5</b> )
Aunt	15 ( <b>2.7</b> )	2 (3.6)	0	0 (0.0)	7 (5.3)	7 (3.5)	2 (1.4)	0 (0.0)	1	17 ( <b>2.8</b> )
Uncle	2 (0.4)	0 (0.0)	0	0 (0.0)	0 (0.0)	2 (1.0)	0 (0.0)	0 (0.0)	0	2 (0.3)
Sister	36 ( <b>6.6</b> )	1 (1.8)	0	0 (0.0)	9 ( <b>6.9</b> )	7 (3.5)	13 ( <b>9.0</b> )	7 ( <b>7.2</b> )	1	37 ( <b>6.1</b> )
Sister-in-law	6 (1.1)	0 (0.0)	0	0 (0.0)	1 (0.7)	2 (1.0)	1 (0.7)	2 ( <b>2.1)</b>	0	6 ( <b>1.0</b> )
Mother-in-law	6 (1.1)	0 (0.0)	0	0 (0.0)	0 (0.0)	4 (2.0)	1 (0.7)	0 (0.0)	1	6 ( <b>1.0</b> )
Grandmother	22 ( <b>4.0</b> )	0 (0.0)	0	1 (12.5)	3 ( <b>2.3</b> )	13 ( <b>6.5</b> )	3 (2.1)	1 (1.0)	1	22 ( <b>3.6</b> )
Other <sup>1</sup> /Missing	9 (1.6)	2 (3.6)	0	0 (0.0)	4 (3.1)	2 (1.0)	3 ( <b>2.1</b> )	2 ( <b>2.1</b> )	0	11 ( <b>1.8</b> )
TOTAL	547	55	3	8	131	199	144	97	26	605

<sup>1.</sup> E.g., maid, neighbor, social worker.

Family members who accompanied participants were more often female (e.g., mother, aunt, sister) in comparison to male (e.g., father, uncle). The proportion of participants who came accompanied by at least one female family member (excluding those who came with both parents) was 340/368 = 92.4% (95% CI: 89.2-94.9), whereas the proportion of participants who came accompanied by at least one male family member (excluding those who came with both parents) was 28/368 = 7.6% (95% CI: 5.1-10.8). The statistical difference between those proportions (p < 0.001) shows that participants who were accompanied by a family member, were statistically much more likely to be accompanied by a female than a male.

The relation between participants' gender and the gender of the family member that accompanied them (excluding those who were accompanied by both parents) was not significant

(p = 0.45). Similarly, the relationship between age groups and the gender of the family member that accompanied the participant (excluding those who were accompanied by both parents) was not significant (p = 0.89). Hence, there was no statistically significant association between participants' gender or age, and the gender of the family member who accompanied them.

The data from Table 8 hint that there are important gendered dimensions to the question of accompaniment to a SRHS clinic. Over 90% of participants who were accompanied by a family member were accompanied by a female family member; and female participants were more likely to come with their mother (40.2%) as opposed to their male peers (20.0%). In parallel, 52.7% of males who came were accompanied by their partner (as opposed to 15.5% for females). It is important to note that the gender of the partner was not asked. Further, younger participants were more likely to be accompanied by their mother, whereas older participants were more likely to be accompanied by their partners.

# Preferences of participants

With this description of how the participants accessed two clinics specialized in SRHS, it is essential to also explore what were their preferences regarding their access to the clinic. **Table 9** presents the distribution of participants' preference of accompaniment and how they came to the clinic according to gender and age group. Most participants (60.1% under the gender category) were accompanied and wanted to be accompanied, and approximately one fifth of the participants did not mind whether they came alone or accompanied (20.4% under the gender category). By contrast, only 11.1% of participants (under the gender category) went alone to the clinic and wanted to be alone, with only 2.2% (under the gender category) who were accompanied but wanted to be alone. The present data challenge our hypothesis that most participants would want to go to the clinic alone – in reality, only a minority of participants wanted to go alone.

Table 9. Preference of accompaniment to access clinic in relations to gender and age

Preference of	GENDER					AGE							
Accompaniment to Access	Female	Male	p value <sup>1</sup>	TOTAL		10-12	13-15	16-18	19-21	22-24	p value <sup>2,3</sup>	TOTAL	
Clinic	n (%)	n (%)		n (%)		n (%)	n (%)	n (%)	n (%)	n (%)		n (%)	
	[95%CI]	[95%CI]		[95%CI]		[95%CI]	[95%CI]	[95%CI]	[95%CI]	[95%CI]		[95%CI]	
Went alone and wanted to	83 ( <b>11.2)</b>	6 ( <b>9.4</b> )	0.660	89 (11.1)		0 (0.0)	5 ( <b>3.7</b> )	15 ( <b>6.2</b> )	38 ( <b>16.9</b> )	31 ( <b>18.6</b> )	< 0.001	89 (11.4)	
be <b>alone</b>	[9.1-13.7]	[3.5-19.3]		[9.0-13.5]			[1.2-8.4]	[3.5-10.0]	[12.2-22.4]	[13.0-25.3]		[9.3-13.9]	
Went accompanied and	455 ( <b>61.6</b> )	28 ( <b>43.8</b> )	0.005	483 ( <b>60.2</b> )		8 (100)	112 (83.0)	164 ( <b>67.5</b> )	113 <b>(50.2</b> )	68 ( <b>40.7</b> )	< 0.001	465 ( <b>59.8</b> )	
wanted to be accompanied	[58.0-65.1]	[31.4-56.7]		[56.7-63.6]		[67.6-100]	[75.5-88.9]	[61.2-73.3]	[43.5-56.9]	[33.2-48.6]		[56.2-63.2]	
Does not matter	136 ( <b>18.4</b> )	28 ( <b>43.8</b> )	< 0.001	164 ( <b>20.4</b> )		0 (0.0)	16 ( <b>11.9</b> )	48 ( <b>19.8</b> )	48 ( <b>21.3</b> )	46 ( <b>27.5</b> )	0.005	158 ( <b>20.3</b> )	
	[15.7-21.4]	[31.4-56.7]		[17.7-23.4]			[6.9-18.5]	[14.9-25.3]	[16.2-27.3]	[20.9-35.0]		[17.5-23.3]	
Went alone and wanted to	49 ( <b>6.6</b> )	0 (0.0)	N/A	49 <b>(6.1</b> )		0 (0.0)	1 (0.7)	10 (4.1)	22 ( <b>9.8</b> )	17 (10.2)	< 0.001	50 ( <b>6.4</b> )	
be <b>accompanied</b>	[5.0-8.7]			[4.6-8.0]			[0.0-4.1]	[2.0-7.4]	[6.2-14.4]	[6.0-15.8]		[4.8-8.4]	
Went accompanied and	16 ( <b>2.2</b> )	2 (3.1)	0.643	18 (2.2)		0 (0.0)	1 (0.7)	6 ( <b>2.5</b> )	4 (1.8)	5 ( <b>3.0</b> )	0.507	16 ( <b>2.1</b> )	
wanted to be alone	[1.2-3.5]	[0.4-10.8]		[1.3-3.5]			[0.0-4.1]	[0.9-5.3]	[0.5-4.5]	[1.0-6.9]		[1.2-3.2]	
TOTAL	739	64		803		8	135	243	225	167		778	
Preference met ("satisfied")	674 ( <b>91.2</b> )	62 ( <b>96.9</b> )	0.114	736 ( <b>91.7</b> )		141 ( <b>98.6</b> )		227 ( <b>93.4</b> )	199 (88.4)	145 (86.8)	<0.001	712 ( <b>91.5</b> )	
	[88.9-93.2]	[89.2-99.6]		[89.5-93.5]		[95.0	-99.8]	[89.5-96.2]	[83.5-92.3]	[80.7-91.6]		[89.3-93.4]	

- 1. z-test for two-tailed hypothesis.
- 2. The data "10-12 years old" and "13-15 years old" were merged together.
- 3. Chi square test of independence.

Less than a tenth of participants did not have their preference met by either having to go alone to the clinic but wanting to be accompanied, or having been accompanied to the clinic but wanting to go alone. The relation between gender and the realization of preferences was not significant (p = 0.114), so it does not appear that one gender was more likely than the other to have their preferences met. For the variable of gender, the only two statistically significant results were for the categories "went accompanied and wanted to be accompanied" and "does not matter." Thus, a female participant was more likely than her male counterpart to be accompanied and wanting to be accompanied (61.6% vs. 43.8%); and male participants were more likely to not mind whether they were accompanied or come alone to the clinic (43.8% vs. 18.4%).

The relation between age group and met preference was significant (p < 0.001). Younger participants were statistically more likely than their older peers to have their preferences met. From the table it is possible to observe a decreasing tendency of being "satisfied" as one gets older (86.8% for the eldest group vs. 98.6% for the youngest). However, it is important to note that the proportions are relatively high – over 85% for each category – meaning that the vast majority of participants for each age group had their preferences met. In terms of tendency, there is a clear decreasing tendency as participants get older to respond, "went accompanied and wanted to be accompanied." For the categories "went alone and wanted to be alone" and "does not matter," there is an evident increasing tendency as participants get older. Overall, based on

data from the gender variable, the majority of participants wanted to be accompanied: 532/732 = 72.7% (95 %CI: 69.3–75.9).

The biggest discrepancy occurred among participants aged 19–24, where a tenth went alone but wanted to be accompanied, as opposed to their younger peers (<1%). The present data challenge our hypothesis that older participants, who can exercise greater agency and independence as legal adults, would be more likely to have their preferences met than younger participants. This tendency appears to be explained by the fact that most participants wanted to be accompanied.

# **Discussion**

The purpose of this cross-sectional study was to describe the preferences of adolescents to access SRHS and identify whether there are significant differences between groups of adolescents in terms of autonomy (i.e., preference being met) to access a clinic specialized in SRHS in Colombia. A quarter of the participants went alone to the clinic: more females than males went alone, and older participants were more likely to go alone than younger participants. Those who came accompanied were predominantly accompanied by a family member who tended to be female (the most prevalent answer being the mother). Hence, the research data suggest there are important gendered influences on the question of Colombian adolescents' access to SRHS.

Our initial hypothesis proved to be wrong. Based on previous research on the topic (Berhane & Berhane 2005; Brittain et al. 2015; Burack 2000), we assumed most adolescents would want to access the clinic alone, as opposed to being accompanied. Our survey data show the contrary, i.e., that the vast majority of participants (approximately two-thirds) wanted to be accompanied and around one-fifth did not have a preference regarding whether they went to the clinic alone or were accompanied. These findings challenge the common assumption that parental presence may impeded the autonomy of adolescents in relation to healthcare access. Generally speaking, in Western bioethics, the principle of autonomy is often framed in highly individualistic terms (Mackenzie & Stoliar 2000; Walter & Ross 2014). The conclusion is often that patients, and in this case, adolescents accessing SRHS, will likely be constrained by parents and health professionals,

e.g., because parents can be uncomfortable in relation to adolescent sexuality. It follows then that to ensure ethical access to SRHS, adolescents should be able and empowered to access health services alone, so they can exercise autonomous choice.

However, the findings of our survey show that an important number of participants in the Colombian context did not want to go to the clinic alone, but rather wanted to be accompanied. This data can help reframe how both healthcare professionals and policy makers think about service provision that best meet the wishes of Colombian adolescent patients in relations to SRHS. In a patient-centered view, healthcare professionals have a deontological duty to respect patient autonomy (e.g., preferences for type of care and how it is provided) and work for the patient's best interests, as defined by the patient (Beauchamp & Childress 2012; Pellegrino & Thomasma 1988). Similarly, policy makers are encouraged to develop health policies that promote patient autonomy, e.g., by creating situations in which patients can authentically articulate their choices for service provision (Moulton & King 2010).

In North America, these values have often been articulated through the protection of patient confidentiality and right to choose, even when this means, in the context of adolescents and access to SRHS, excluding parents from decision making in some situations (e.g., choosing a contraceptive option). In our study sample, the majority of participants wanted to be accompanied. This does not mean that adolescent participants in Colombia were less autonomous than their peers in North America, nor that the notion of autonomy is misapplied. What this difference clarifies is the importance of genuine and free choice to be accompanied or not when accessing SRHS. Thus, respect for autonomy does not only mean allowing adolescents to go alone, but rather involves providing diverse types of support, such as having the possibility of choosing to have a trusted person present (e.g., parent, family member, friend), with whom to share the burden of decision making. Future research on this topic should explore the question of why adolescents might prefer to be accompanied, in order to understand the factors behind this phenomenon.

Regarding the question of adolescents' preferences, our other main hypothesis also proved to be inaccurate. Interestingly, the preference of older adolescents was met less than their younger peers. It is commonly believed that with age, one gains greater independence and agency, which would suggest allowing one to actualize more easily one's preference in healthcare. However, most participants wanted to be accompanied. Around 10% of older adolescents (19–24 years old), who are by law defined as adults, went alone but wanted to be accompanied. The survey did not ask questions that would allow to explain this tendency. This calls for further research to better understand this trend. Nonetheless, the answers of older adolescents challenge the idea that being older translates to having one's preferences met more than when one is younger.

The data in our study also raise other ethical questions, notably for those being asked to accompany adolescents in accessing SRHS. For example, what are the ethical implications of a situation in which an adolescent wants to be accompanied by another person (e.g., by their mother) but that individual does not want to accompany the adolescent or is uncomfortable with discussing SRHS? This could be a source of tension or conflict between the adolescent and the person accompanying them, or refusing to accompany them, as well as the healthcare professional (e.g., duty to the patient vs. respect for the family member). The study did not explore these aspects, which would be important to develop further, e.g., through qualitative research, in order to articulate more clearly the potential challenges, as well as strategies to ensure effective and ethical access to SRHS. Common bioethical frameworks focus on the patients themselves and the deontological duties that health professional have towards patients. However, the roles of an accompanying person (e.g., parent, friend, partner) constitute a blind spot that raises different sets of ethical questions in need of investigation.

# **Limits**

One of the limits of the study was its convenience sampling approach, that introduces the possibility of representation biases, since not all potential participants had an equal chance of being invited to participate by the receptionists. A 63.8% participation rate can also hint towards representation bias, since those not willing to participate did not have their answers counted and

may differ from those more eager to participate. Further, the survey was presented to adolescents who were at Profamilia, while adolescents who do not go to Profamilia may have different opinions on the topic. For example, Profamilia is popularly known as a clinic specialized in SRHS, whereas adolescents may have different type of preferences (and experiences) for accessing SRHS in a family medicine setting.

While participants were asked if they wanted to be accompanied, those who did were not asked by whom they wished to be accompanied (e.g., mother, friend, partner). Perhaps participants who were accompanied would have wanted to be accompanied by a different person. Furthermore, there might be differences in preferences by types of services. For example, an adolescent may want to be alone for one type of service (e.g., abortion) but may want to be accompanied for another service (e.g., contraceptives). Future research on the topic should take those elements into consideration.

There are other essential factors that can influence adolescents' autonomy to access SRHS, such as having knowledge on how to access health services, the opening hours of the clinic, living close enough to a clinic, having health insurance or the financial means to pay for health services, etc. It is also important to recognize that Colombian adolescents have different living situations and relationships with their family (e.g., parents) (Brisson et al. 2021). Some adolescents might not have one or both parents actively present in their lives or might be living with extended relatives (e.g., grandmother, aunt). Such diverse realities can greatly influence adolescents' experience of accompaniment by family members to access SRHS.

#### Conclusion

This study presented a quantitative description of how a sample of Colombian adolescents accessed and wished to access two clinics specialized in SRHS in two large Colombian cities. Most participants were accompanied and wanted to be accompanied to access SRHS. A much smaller proportion of participants than originally anticipated did not have their preferences met (<10%), and contrary to the initial hypothesis, older adolescents had their preference for access less met

than their younger peers – the reason being that some older adolescents wanted to be accompanied but went alone to the clinic.

Previous research on the theme in other cultural contexts has shown that adolescents tend to want to access SRHS alone. However, the findings of this research show that most participants wanted to be accompanied when accessing SRHS. The fact that a significant number of Colombian adolescent participants wish to be accompanied to access SRHS raises important ethical insights regarding the respect of their autonomy that are in need of further investigation. Notably, it would be highly relevant to explore the ethical tensions raised by situations in which adolescents want to access SRHS accompanied, but the person they want to be accompanied by does not want to accompany them.

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# Article III: A Mixed-Methods Study Exploring Colombian Adolescents' Access to Sexual and Reproductive Health Services: The Need for a Relational Autonomy Approach

Brisson, Julien; Ravitsky, Vardit; Williams-Jones, Bryn. (Under Review). *Journal of Bioethical Inquiry*.

#### Abstract

This study's objective was to understand Colombian adolescents' experiences and preferences regarding access to sexual and reproductive health services (SRHS), either alone or accompanied. A mixed-method approach was used, involving a survey of 812 participants aged 11-24 years old and 45 semi-structured interviews with participants aged 14-23. Previous research shows that adolescents prefer privacy when accessing SRHS and often do not want their parents involved. Such findings align with the longstanding tendency to frame the ethical principle of autonomy as based on independence in decision making. However, the present study shows that such a conceptualization and application of autonomy does not adequately explain Colombian adolescent participants' preferences regarding access to SRHS. Participants shared a variety of preferences to access SRHS, with the majority of participants attaching great importance to having their parents involved, to varying degrees. What emerges is a more complex and nonhomogenous conceptualization of autonomy that is not inherently grounded in independence from parental involvement in access to care. We thus argue that when developing policies involving adolescents, policymakers and health professionals should adopt a nuanced "relational autonomy" approach to better respect the myriad of preferences that Colombian (and other) adolescents may have regarding their access to SRHS.

Keywords: adolescent; autonomy; bioethics; Colombia; reproductive health; sexual health

# <u>Introduction</u>

In 2017, the World Health Organization (WHO) introduced the *Global Accelerated Action for the Health of Adolescents* (AA-HA!) (WHO 2017), which stressed that, as a group, adolescents have been neglected in global health research and the delivery of adapted health services. Addressing adolescents' health-related needs has been recognized as urgent and a part of the United Nations

(UN) Sustainable Developmental Goals for 2030 (Every Women Every Child 2015; UN 2015). Many of the health problems encountered by adolescents are due to their low use of health services (Patton et al. 2012; Patton et al. 2015), many of which are related to adolescent's autonomy (e.g., parental consent laws, lack of knowledge on navigating local health system). To address this issue, AA-HA! suggests "fostering the autonomy" of adolescents to empower better access to health services (WHO 2017). While a laudable affirmation, there are still serious challenges in understanding what are (or should be) the bases for adolescent autonomy in healthcare, and how this autonomy might be fostered (Brisson et al. 2021). The study presented in this article sought to shed light on these questions and explore some of the interrelated ethical questions by using the case of access to sexual and reproductive health services (SRHS) for Colombian adolescents.

One of the main reasons for choosing Colombia is that there is no official minimum legal age for an adolescent to access some SRHS without their parents, i.e., a 13-year-old can be prescribed contraceptives without requiring parental consent. As such, in principle, Colombian adolescents can have their autonomy respected in healthcare decision-making (with some exceptions),<sup>4</sup> which makes it very different from neighbouring countries with strict parental consent laws. From a methodological perspective, the Colombian context makes it particularly relevant to explore adolescents' autonomy to access healthcare services since, technically, they may choose to access SRHS alone or to be accompanied. However, it is important to note that Colombian adolescents are not necessarily aware of their rights and so may instead believe that they must have parental consent to access SRHS.

The topic of sexual and reproductive health can be a highly taboo and sensitive subject for adolescents, especially in comparison to other types of health services (e.g., ophthalmology, physiotherapy, odontology). Previous research in different cultural contexts has shown that very often, adolescents do not want their parents (or others) knowing that they wish to access SRHS,

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<sup>&</sup>lt;sup>4</sup> For example, one needs to be at least 18 years old to be sterilized in Colombia. Nonetheless, an adolescent younger than 18 years old would be allowed to consult a doctor to obtain information about sterilization procedures without legal obligations for the doctor to inform the adolescent's parents or legal guardians.

suggesting that adolescents want their autonomy respected through the protection of their independence and patient privacy and confidentiality (Fuentes et al. 2018; Garside et al. 2002; Reddy et al. 2002). Thus, it is appropriate to use the case of SRHS<sup>5</sup> to explore the question of adolescents' autonomy to access health services since adolescents may express wanting to make autonomous decisions related to their health but be unable to do so for various reasons (e.g., parental prohibition to use contraceptives).

The ethical principle of autonomy plays a central role in contemporary bioethics thinking – e.g., the ethical imperative to respect patients' healthcare decisions (Beauchamp and Childress 2012) - and has been widely operationalized, particularly in North America and Europe, in health professional training and professional codes of ethics, as well as being enshrined in law. Yet, while laws and professional guidelines have clearly circumscribed how and why autonomy should be respected for adults – and under what circumstances this autonomy might be justifiably limited - the same cannot be said for adolescents. There are no biological or objective markers to define at what age a person becomes autonomous to make health related decisions (Dahl et al. 2018) or when as a patient they should have their autonomy respected. If the common age threshold of majority, i.e., 18 years, is used without nuance to define adulthood and determine when a person can autonomously decide to access SRHS, critical injustices may result; adolescents are entitled to be heard on topics that directly concern them, including regarding their sexuality (Mabaso et al. 2016). This view is notably reflected in the concept of "progressive autonomy," (Turner and Varas Braun 2021; Espinoza 2017), and articulated in the United Nations' Convention on the Rights of the Child, which argues that adolescents are entitled to be heard and express their views even if they are not yet adults (UN 2011).

The concept of autonomy can represent different notions – e.g., agency, liberty, independence, maturity (Soenens et al. 2017). For this study, the concept was understood as involving both independence (i.e., going to a clinic alone) and respect for choice (i.e., from the classical framing of the ethical principle in contemporary bioethics). The period of adolescence is a stage where

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<sup>&</sup>lt;sup>5</sup> For this research, "sexual and reproductive health services" was an inclusive concept representing all related services (e.g., contraceptives, vasectomy, abortion, HIV/STI testing).

one starts to develop autonomy at different levels, which was also considered in the study design and data analysis. As shown in the Results section and explored in the Discussion, it is important to pay attention to these different components of autonomy, which interconnect and overlap, especially as they relate to access to SRHS.

The first part of this paper presents quantitative data and describes how a sample of adolescent patients in Colombia wished to access services at Profamilia, a clinic specialized in SRHS. Then, the qualitative data are presented to share adolescents' opinions and experiences related to their autonomy to access SRHS. Finally, the paper discusses the ethical questions emerging from the data related to AA-HA!'s call to foster adolescents' autonomy to access health services. Our main argument is that instead of mobilizing an individualist "asocial" view of autonomy as equivalent to "freedom from parental intervention," health professionals and policy makers in Colombia (and possibly other contexts) would benefit from using a "relational autonomy" approach that sees individuals (i.e., adolescents) as rooted within social networks (e.g., family, friends), as this better conceptualizes the different ways that Colombian adolescents (and others) may wish to access SRHS. For example, a relational autonomy approach would recognize the importance that an adolescent might attribute to having their mother accompany them to a clinic in order to choose a contraceptive option, while another adolescent might instead appreciate the support of their friend. In both instances, the adolescents desire the involvement of others in actualizing their autonomy to access SRHS – they do not wish for complete independence throughout the whole process.

## **Objectives**

The first objective for this study was to develop a descriptive portrait of adolescents' preferences regarding accompaniment to consultations with health professionals regarding their sexual and reproductive health, e.g., alone or accompanied by a parent (or friend). The second objective was to observe if there were differences between how adolescents wanted to access the clinic itself (either alone or accompanied) and when consulting a health professional (either alone or accompanied). The third objective was to understand the reasons for adolescents' preferences as it touched upon their autonomy to access SRHS. Those objectives reflect an essential approach

in empirical bioethics to first have a descriptive portrait of patients' preferences and experiences before addressing the ethical issues at hand (Kon 2009). Finally, the last objective was to analyze the emerging ethical questions in relation to the WHO's call to foster adolescents' autonomy to access health services.

## Methods

A mixed-method approach was used to achieve the research objectives. The first part consisted of a survey with Colombian adolescents, with a view to generating a descriptive portrait through a cross-sectional analysis of how adolescents wanted to access a clinic specialized in SRHS. The second part involved semi-structured interviews with adolescents (not necessarily the same participants from the survey) to better understand their preferences regarding how they wished to access SRHS (e.g., participants were invited to explain why they would want to go alone to a clinic or to be accompanied). For this study, a convergent design was used with both methodological approaches occurring simultaneously (Guetterman et al. 2015) over a period of six months between August 2019 and February 2020.

## **Participants**

In global health research, a new definition of adolescence has been proposed that includes individuals aged 10 to 24 years old (Sawyer et al. 2018). Extending the definition of adolescence beyond 18 years has important methodological and policy implications because it allows for a more accurate and nuanced understanding of the transition from childhood to adolescence and then from adolescence to adulthood. As already mentioned, there are no biological or objective markers to define when one ceases to be an adolescent and begins to be an adult (Dahl et al. 2018). Often, it is social factors or cultural events (e.g., rituals) that define the start of adulthood (Worthman and Trang 2018). As such, the only inclusion criteria for participating in this study – for both the survey and interviews – were to be between 10 and 24 years old. Participants from different demographic backgrounds were invited to participate in order to have a diverse sample. The research took place in Colombia's departments of Antioquia and Valle del Cauca.

# Cross-Sectional Study (survey)

For the cross-sectional analysis, a survey was used with adolescents who presented themselves at a Profamilia clinic in the large Colombian cities of Medellin and Cali. Profamilia is a network of non-profit clinics across Colombia that provide SRHS, including youth-friendly services. Adolescents who presented themselves at Profamilia clinics were invited to independently answer a survey on the topic of their autonomy to access SRHS while they were in the waiting area. The use of a cross-sectional study allowed for an analysis of statistical trends while paying attention to potential differences in demographic groups. Such a methodological approach is particularly relevant for studying the question of adolescents' autonomy as it allows for the observation of differences and similarities between younger and older participants.

The initial plan was for the receptionists at the clinics to offer the survey to every patient aged 10 to 24. However, shortly after the start of the study, the receptionists expressed that it was too challenging to invite every patient in that age group due to periods of higher patient volume. The sampling approach was changed to convenience sampling: receptionists would invite patients to answer the survey when deemed appropriate. It is important to acknowledge that this sampling approach increases the risk of representation bias. Nonetheless, for every invitation to participate in the study, receptionists would mark a calendar which allowed us to calculate the participation rate.

Participants who expressed an interest in answering the survey were first given an information sheet detailing the study, to make an informed decision prior to choosing whether to answer the survey. The information sheet explained in accessible language the purpose of the study, that the answers would be anonymous and that the choice to participate would not influence the quality-of-care they would receive at the clinic. When the participants were done answering the survey

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<sup>&</sup>lt;sup>6</sup> At the request of the Profamilia staff, patients who were at the clinic for STI/HIV testing were not invited to answer the survey. At Profamilia, young people receiving tests for STI/HIV need to fill out paperwork and receive counselling from a nurse on safe sex practices, which can be time consuming for the patient. To not overwhelm patients seeking such testing, they were not invited to participate in the survey.

independently, they were asked to put it in a locked box in the waiting area for which only the researcher had the key.

For the analysis presented in this paper, the two independent variables of study were gender and age, and the main variables of study were related to categorical preferences. Since the study variables were categorical, z-tests and chi-square tests of independence were used to analyze the associations between variables and participants' answers. The goal was to observe if there were significant similarities or differences between demographic groups, e.g., to see if younger and older adolescents both equally preferred to consult a healthcare professional alone. Statistical significance was evaluated as p < 0.05, and percentages were rounded to the nearest tenth (including confidence intervals). The variable "age" was grouped in blocks of three years: 10-12, 13-15, 16-18, 19-21, 22-24. Because of lower participation rates for the group 10-12 years old, the data for the categories "10-12" and "13-15" were merged for the statistical analyses but are presented separately in the tables. The survey was not pretested.

#### **Interviews**

The use of semi-structured interviews enabled adolescent participants to express their opinions and share their experiences and preferences related to their autonomy to access SRHS, data that helps provide context and meaning to data generated in the cross-sectional study. Before starting the interviews, participants were asked to read an information sheet and then sign a consent form, and they were afterward asked demographic questions (e.g., how they identified their gender, level of formal education). The individual interviews, which were conducted by the first author, were audio recorded, and then transcribed and translated from Spanish to English. The interview questions were not pretested.

Profamilia clinics advertised the research in their waiting area, and health professionals who saw adolescent patients (e.g., youth psychologists, social workers) shared information about the study with their patients. Further, a nurse presented the study in a high school. The most

effective recruitment approach was through snowball sampling, where participants shared information about the study with their friends and peers, who then contacted the researcher.

The semi-structured interviews had core questions that were asked to all participants (e.g., the first time you accessed SRHS, did you go alone or accompanied, and did you want to be alone or accompanied?). For data analysis, the participants' answers were regrouped by core questions and then categorized by similarities (Paillé and Mucchielli 2008). This approach enabled the identification of trends and differences (e.g., various steps involved) regarding adolescents' understanding of and preferences for access to SRHS (Imbert 2010). It enables analysis of the pertinence of AA-HA!'s concept of "fostering adolescents' autonomy", e.g., determining how the concept could be implemented in light of the participants' answers. Subsequently, a mapping was done of the different processes and experiences of participants to access SRHS. Through this categorisation and mapping of answers, it was then possible to compare the qualitative interview data with the cross-sectional survey data to see if there were similarities, for example, related to trends of answers in connection to gender and age groups.

#### **Research Ethics**

The University of Montreal's Research Ethics Committee in Science and Health first evaluated and accepted the research project. The Profamilia Research Ethics Committee, which included a lawyer, then evaluated and approved the research. For both the survey and the interviews, parental consent was not asked. This decision was supported by the *International Ethical Guidelines for Biomedical Research Involving Human Subjects* which argues that under certain conditions, it is acceptable to waive parental consent when the research involves low risks for adolescent participants and when parental consent might prevent young people from participating due to the research topic (Council for International Organizations of Medical Sciences 2017). It was explained to the participants that a summary of the findings of the research would be made available at Profamilia clinics, in their youth sections.

# **Results**

The first part of the results section presents the quantitative data of the cross-sectional study to generate a descriptive portrait of participants' answers, and to identify emerging tendencies (e.g., more prevalent answers within certain demographic groups). The presentation of the interview excerpts then follows to provide further meaning and explanations to the statistical data.

#### **Cross-Sectional Results**

**Table 10** presents the characteristics of the participants who answered the survey. Of the 1,272 adolescents who were invited to participate in the survey, 911 agreed to participate. However, 99 were excluded because they did not answer enough questions for data analysis (e.g., unanswered demographic section). As such, a final sample of 812 completed surveys were used for data analysis, i.e., a 63.8% participation rate.

The study allowed for participants aged 10 and older to answer the survey; however, the youngest participants were 11 years old. The majority of participants were female (91.4%), which reflects the general trend of patients who visit Profamilia clinics across Colombia. Participants were given the opportunity to answer as being trans or to write down their own gender, but none of those answers were chosen. The distribution of participants' *estratos* (socio-economic classes assigned based upon area of residency – e.g., neighborhood – with 1 being the lowest and 6 the highest) reflects the country's *estratos* distribution: the majority of participants were concentrated in the lower three *estratos*.

Table 10. Characteristics of participants for the surveys

Number of participants	812			
Age, n				
10-12	8 (1.0%)			
13-15	137 (16.9%)			
16-18	244 (30.0%)			
19-21	225 (27.7%)			

167 (20.6%)							
31 (3.8%)							
Gender, n							
64 (7.9%)							
742 (91.4%)							
6 (0.7%)							
166 (20.4%)							
283 (34.9%)							
249 (30.7%)							
40 (4.9%)							
18 (2.2%)							
3 (0.4%)							
53 (6.5%)							
National Status, n							
<b>754</b> (92.9%)							
<b>14</b> (1.7%)							
<b>50</b> (6.2%)							

**Table 11** presents participants' preferences, by gender and age, on whether they preferred to be alone or accompanied to a consultation with a health professional regarding their sexual and reproductive health. Approximately half of participants wished to be alone when consulting a health professional regarding SRHS, a result similar for males and females. For age groups, it is possible to observe a statistically significant difference: as participants get older, they are more likely to want to be alone when consulting a health professional.

The second most frequent answer was wanting to have one's mother present when consulting a health professional, which was the case for approximately one-fifth of the participants. However, there was a statistically significant difference between genders, with women being more likely to want to consult with their mother in comparison to men (21.0% vs. 6.3%). As for age groups, there was a statistically significant difference for younger participants, who were more likely to want to consult with their mother in comparison to their older peers. In parallel, only 1.0% (under the gender category) of participants expressed wanting to be accompanied by their fathers. This data suggests that there might be an important gendered dimension to the question of Colombian adolescents' autonomy to access SHRS, which calls for further research on the

question. For example, it would be pertinent to evaluate how mothers could be engaged in public health initiatives (e.g., educative measures), as our data suggests that an important number of participants appreciate the involvement of their mothers in accessing SRHS.

About one-fifth of participants answered that they did not mind if they were alone or accompanied to consult a health professional regarding SRHS. Yet, when dividing the answer by gender, there was a statistically significant difference for a quarter of men (26.6%), but only around a tenth of women (10.9%). As for age, there was a statistically significant increasing tendency within participant age groups in not minding if they are alone or accompanied to consult a health professional. The same phenomenon was observed for the "partner category." More men than women preferred to be accompanied by their partner (17.2% vs. 8.9%). This phenomenon was also seen as participants got older, with a statistically significant increasing tendency to be accompanied by a partner.

Table 11. Preference of accompaniment to consult a health professional regarding sexual and reproductive health (by gender and age)

		GEND	GENDER			AGE					
	Man	Woman	p value*	TOTAL	10-12	13-15	16-18	19-21	22-24	p value <sup>1,2</sup>	TOTAL
PREFERENCE	n	n	'	n	n	n	n	n	n		n
	(%)	(%)		(%)	(%)	(%)	(%)	(%)	(%)		(%)
	[95%CI]	[95%CI]		[95%CI]	[95%CI]	[95%CI]	[95%CI]	[95%CI]	[95%CI]		[ 95%CI]
I prefer to be alone	30	369	0.645	399	1	56	115	126	94	0.004	392
	(46.9)	(49.9)		(49.6)	(12.5)	(40.9)	(47.3)	(56.0)	(56.3)		(50.3)
	[34.3-59.8]	[46.2-53.5]		[46.1-53.1]	[0.3-52.7]	[32.6-49.6]	[40.9-53.8]	[49.2-62.6]	[48.4-63.9]		[46.7-53.8]
I prefer to be with	4	155	0.005	159	6	55	61	21	10	< 0.001	153
my mother	(6.3)	(20.9)		(19.8)	(75.0)	(40.1)	(25.1)	(9.3)	(6.0)		(19.6)
	[1.7-15.2]	[18.1-24.1]		[17.1-22.7]	[34.9-96.8]	[31.9-48.9]	[19.8-31.0]	[5.9-13.9]	[2.9-10.7]		[16.9-22.6]
I prefer to be with	1	7	0.581	8	1	2	2	1	1	0.500	7
my father	(1.6)	(0.9)		(1.0)	(12.5)	(1.5)	(0.8)	(0.4)	(0.6)		(0.9)
	[0.0-8.4]	[0.4-1.9]		[0.4-2.0]	[0.3-52.7]	[0.2-5.2]	[0.1-2.9]	[0.0-2.5]	[0.0-3.3]		[0.4-1.8]
I prefer to be with	1	38	0.201	39	0	6	15	10	5	0.490	36
another family	(1.6)	(5.1)		(4.9)	(0.0)	(4.4)	(6.2)	(4.4)	(3.0)		(4.6)
member	[0.0-8.4]	[3.7-7.0]		[3.5-6.6]		[1.6-9.3]	[3.5-9.9]	[2.2-8.0]	[1.0-6.9]		[3.3-6.3]
I prefer to be with a	0	24	0.146	24	0	1	7	8	5	0.400	21
friend	(0.0)	(3.2)		(3.0)	(0.0)	(0.7)	(2.9)	(3.6)	(3.0)		(2.7)
		[2.1-4.8]		[1.9-4.4]		[0.0-4.0]	[1.2-5.8]	[1.5-6.9]	[1.0-6.9]		[1.7-4.1]
I prefer to be with	11	66	0.030	77	0	5	19	28	23	0.005	75
my partner	(17.2)	(8.9)		(9.6)	(0.0)	(3.7)	(7.8)	(12.4)	(13.8)		(9.6)
	[8.9-28.7]	[7.0-11.2]		[7.6-11.8]		[1.2-8.3]	[4.8-11.9]	[8.4-17.5]	[8.9-20.0)		[7.6-11.9]
Does not matter	17	81	<0.001	98	0	12	24	31	29	0.048	96
	(26.6)	(10.9)		(12.2)	(0.0)	(8.8)	(9.9)	(13.8)	(17.4)		(12.3)
	[16.3-39.1]	[8.8-13.4]		[10.0-14.7]		[4.6-14.8]	[6.4-14.3]	[9.6-19.0]	[11.9-24.0)		[10.1-14.8]
TOTAL	64	740		804	8	137	243	225	167		780

<sup>\*</sup>z-score (two-tailed)

<sup>1.</sup> The categories "10-12" and "13-15" were merged for analysis.

<sup>2.</sup> Chi-square test of independence

**Table 12** presents the preferences for how participants wanted to access Profamilia (alone or accompanied), and their preference for consulting a health professional (alone or accompanied), compared by gender and age. The purpose of this analysis was to see if there were any consistencies between preferences of accompaniment to access the clinic *and* consulting the healthcare professional.

As observable in the table, the most frequent answer was wanting to be accompanied to the clinic and also accompanied when seeing the health professional. This was the case for one-third of the participants. When dividing the answers by gender, there is a statistically significant difference between genders: women more than men wanted to be accompanied to the clinic and when seeing the health professional (34.8% vs. 15.6%). As for age groups for the same category, there was a statistically significant decreasing tendency with age for wanting to be accompanied to the clinic and when seeing the health professional. In parallel, the second most prevalent answer was wanting to be accompanied to the clinic but to be able to see the health professional alone. This was the case for more than a quarter of participants. When looking at the answer by gender and age, there were no statistically significant differences. In comparing the answers by gender for each category, the distribution for women is predominantly concentrated in four main answers, whereas for men, there is more variability. The latter phenomenon is observed for age groups: for younger participants, there is more limited diversity of prevalent answers, whereas for older participants, there is more variability amongst the distribution of preferences.

Table 12. Preferences related to accessing SRHS and consulting a health professional in relation to gender and age

PREFERENCES OF ACCESS AND	GENDER				AGE						
CONSULTATION	Man	Woman	p value*	TOTAL	10-12	13-15	16-18	19-21	22-24	p value <sup>1,2</sup>	TOTAL
	n	n		n	n	n	n	n	n		n
	(%)	(%)		(%)	(%)	(%)	(%)	(%)	(%)		(%)
	[95%CI]	[95%CI]		[95%CI]	[95%CI]	[95%CI]	[95%CI]	[95%CI]	[95%CI]		[95%CI]
Wanted to go alone to clinic and	7	81	0.992	88	0	5	16	36	30	< 0.001	87
wants to be <b>alone</b> with health	(10.9)	(10.9)		(11.0)	(0.0)	(3.7)	(6.6)	(16.0)	(18.0)		(11.2)
professional	[4.5-21.3]	[8.8-13.5]		[8.9-13.3]		[1.2-8.4]	[3.8-10.5]	[11.5-21.5)	[12.5-24.6]		[9.1-13.6]
Wanted to go alone to clinic and	1	9	0.781	10	0	1	3	2	3	0.800	9
wants to be accompanied with	(1.6)	(1.2)		(1.2)	(0.0)	(0.7)	(1.2)	(0.9)	(1.8)		(1.2)
health professional	[0.0-8.4]	[0.6-2.3]		[0.6-2.3]		[0.0-4.1]	[0.3-3.6]	[0.1-3.2]	[0.4-5.2]		[0.5-2.2]
Wanted to go alone to clinic and	0	3	0.612	3	0	0	0	1	2	0.223	3
does not matter if	(0.0)	(0.4)		(0.4)	(0.0)	(0.0)	(0.0)	(0.4)	(1.2)		(0.4)
alone/accompanied with		[0.1-1.2]		[0.1-1.1)				[0.0-2.5]	[0.2-4.3]		[0.1-1.1]
healthcare professional											
Wanted to go accompanied to	12	212	0.090	224	1	44	75	65	38	0.263	223
clinic and wants to be alone	(18.8)	(28.7)		(27.9)	(12.5)	(32.6)	(30.9)	(28.9)	(22.8)		(28.7)
with health professional	[10.1-30.5]	[25.5-32.1]		[24.8-31.2]	[0.3-52.7]	[24.8-41.2]	[25.1-37.1]	[23.1-35.3]	[16.6-29.9]		[25.5-32.0]
Wanted to go accompanied to	10	257	0.002	267	7	63	93	57	34	< 0.001	254
clinic and wants to be	(15.6)	(34.8)		(33.3)	(87.5)	(46.7)	(38.3)	(25.3)	(20.4)		(32.7)
accompanied with health professional	[7.8-26.9]	[31.4-38.4]		[30.0-36.7]	[47.4-99.7]	[38.0-55.4]	[32.1-44.7]	[19.8-31.5]	[14.5-27.3]		[29.4-36.1]
Wanted to go accompanied to	6	40	0.190	46	0	6	8	16	14	0.100	44
clinic and does not matter if	(9.4)	(5.4)		(5.7)	(0.0)	(4.4)	(3.3)	(7.1)	(8.4)	0.200	(5.7)
accompanied/alone with health	[3.5-19.3]	[3.9-7.3]		[4.2-7.6]	(/	[1.7-9.4]	[1.4-6.4]	[4.1-11.3]	[4.7-13.7]		[4.1-7.5]
professional								,			,
Does not matter to go	11	75	0.083	86	0	6	24	25	26	0.012	81
accompanied/alone to clinic and	(17.2)	(10.2)		(10.7)	(0.0)	(4.4)	(9.9)	(11.1)	(15.6)		(10.4)
wants to be alone with health	[8.9-28.7]	[8.1-12.6]		[8.7-13.1]		[1.7-9.4]	[6.4-14.3]	[7.3-16.0]	[10.4-22.0]		[8.4-12.8]
professional											
Does not matter to go	6	23	0.010	29	0	4	8	9	7	0.900	28
accompanied/alone to clinic and	(9.4)	(3.1)		(3.6)	(0.0)	(3.0)	(3.3)	(4.0)	(4.2)		(3.6)
wants to be accompanied with	[3.5-19.3]	[2.0-4.6]		[2.4-5.2]		[0.8-7.4]	[1.4-6.4]	[1.9-7.5]	[1.7-8.5]		[2.4-5.2]
health professional											
Does not matter to go	11	38	<.001	49	0	6	16	14	13	0.630	49
accompanied/alone to clinic and	(17.2)	(5.2)		(6.1)	(0.0)	(4.4)	(6.6)	(6.2)	(7.8)		(6.3)
does not matter to be	[8.9-28.7]	[3.7-7.0]		[4.6-8.0]		[1.7-9.4]	[3.8-10.5]	[3.4-10.2]	[4.2-12.9]		[4.7-8.2]
accompanied/alone with health											
professional											
TOTAL	64	738		802	8	135	243	225	167		778

<sup>\*</sup>z-score (two-tailed)

In looking at both Tables 11 and 12, we can observe a heterogeneity of participant preferences regarding how they wish to access SRHS and consult with healthcare professionals. Within demographic groups (gender, age), there is also a notable variety of preferences. As will be explored in the Discussion section, it is critical to recognize this multiplicity of preferences for adolescents as it relates to their autonomy to access SRHS and consult with health professionals; and just as importantly, the data highlights the pertinence of a "relational autonomy" approach instead of an individualistic perspective.

#### Interviews Results

Building on the descriptive portrait generated by the cross-sectional data, the data from the semistructured interviews can then help provide further meaning. It is important to note that the

<sup>1.</sup> The categories "10-12" and "13-15" were merged together.

<sup>2.</sup> Chi-square test of independence.

participants in the interviews did not necessarily have experiences specifically with Profamilia. Some had accessed SRHS<sup>7</sup> through other clinics or with their family doctor, while others had never used SRHS, for example, because their parents prohibited them from accessing such services. In this section, the demographic profiles of participants are first presented, followed by the steps involved in accessing SRHS, which help clarify the complexity of the question of adolescents' autonomy. This presentation is intended to demonstrate the variety of adolescent preferences and experiences, while also paying attention to the question of autonomy. The interview excerpts are all identified by pseudonyms.

**Table 13** presents the characteristics of the interview participants. Participants were free to define their own gender at the beginning of the interview. Of the 45 participants, 21 identified as male, 23 as female, and one as non-binary. The youngest participant was 14 and the eldest was 23 years old. The majority of participants were from *estratos* two and three. 44.4% came from the department of Antioquia: Medellin (large city), Rionegro (small city), and Santa Fe de Antioquia (rural area); and 55.5% from the department of Valle del Cauca: Cali (large city) and Palmira (small city). All participants were Colombian, although Venezuelan migrants were also invited to participate.

Table 13. Characteristics of participants for the interviews

Number of Participants	45
Gender	
Male	21 (46.7%)
Female	23 (51.1%)
Non-Binary	1 (2.2%)
Age	
14	1 (2.2%)
15	4 (8.9%)
16	5 (11.1%)
17	2 (4.4%)
18	3 (6.7%)
19	11 (24.4%)
20	2 (4.4%)

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<sup>&</sup>lt;sup>7</sup> It should be noted that the expression "sexual and reproductive health" was challenging to understand for an important number of participants. As shown in the interview excerpts, the expression "family planning" (*la planificación*) – which is popularly used in Colombia – was instead used during some of the interviews.

21	10 (22.2%)
22	5 (11.1%)
23	2 (4.4%)
Estrato	
1	3 (6.7%)
2	12 (26.7%)
3	25 (55.6%)
4	4 (8.9%)
5	0 (0.0%)
6	0 (0.0%)
Unknown	1 (2.2%)
Residence of Participant	
Medellin, Antioquia	9 (20.0%)
Rionegro, Antioquia	6 (13.3%)
Santa Fe de Antioquia, Antioquia	5 (11.1%)
Cali, Valle del Cauca	2 (4.4%)
Palmira, Valle del Cauca	23 (51.1%)
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#### The Initial Choice

Prior to accessing SRHS, a person must make the decision to use SRHS – for example, to want to start using contraceptives or to get an HIV test – and know how to access those services. Participants were thus invited to share how they came to make the choice to access SRHS. For an important number of participants, that initial decision came from themselves, by recognizing a need. In terms of autonomy, this phenomenon reflects a common practice where an adolescent starts to make health decisions by themself. However, for other participants, there were external influences, such as was the case for Natalia (21 years old):

- Natalia: I started family planning with the implant at 17 years old.
- Interviewer: And how did you end up choosing that option?
- N: It had been two months that I was seeing my boyfriend and my parents saw that I was spending a lot of time with him, so they sat down with me and told me I had to start family planning. They didn't ask details, but they asked me if I had started my sexual life and then told me that I had to start family planning. So, it was like a little push from them (...) Then I went to the *EPS* [subsidized health-promoting entities in Colombia], I asked for a consult to see which method was the best and that is how I started.
- I: Did you go alone?
- N: I went with my boyfriend.
- I: Did you want to go alone or accompanied?
- N: I wanted to go accompanied.
- I: Accompanied by whoever?

 N: No. I did not want to be accompanied by my mom or dad, I wanted to be with my boyfriend.

Within the classical bioethics framing of the principle of autonomy, it is usually interpreted as being problematic when others "push" individuals into making specific health-related decisions since this can represent a form of coercion, and thus not be a genuine or autonomous choice for the patient. Yet, when asked if she disliked this intervention by her parents in "pushing" her to start using contraceptives, Natalia expressed that she appreciated their gesture. In this case, Natalia's parents could be seen to having engaged in a form of "fostering autonomy" to access SRHS, which Natalia appreciated. But it is important to recognize that other participants expressed that they greatly disliked having their parents telling them what to do with regards to their sexual and reproductive health or that they simply did not talk about sex with their parents. As for Natalia's case, when it came to actually accessing a clinic, she clearly knew her preference and decided to go accompanied by her partner as opposed to going alone or with her parents.

#### The Actual Choice to Access SRHS

While an adolescent might want to access SRHS, this may not translate into knowing exactly how to do so (e.g., knowing which clinic to go to for HIV/STI testing, knowing if there are fees for the services) nor knowing which choice to make (e.g., which contraceptive option to use). As such, before accessing a clinic, an adolescent might seek guidance within their social network (e.g., friend, cousin, parent, teacher), which could embody another form of fostering the adolescent's autonomy by obtaining information from others. For example, as the following interview excerpt shows, the initial choice to start using contraceptives may come from the adolescent herself. However, the concrete decision of which contraceptive option to choose and the question of how to access SRHS can involve the assistance of another person, i.e., the adolescent's mother in the following excerpt:

## Paola (18 years old)

- Interviewer: Did you go alone or with your parents? (the first time to access SRHS at 17 years old)
- Paola: I went with my mom. My mom always accompanies me in everything! (laughs)
- I: So, it was important for you to go with your mom?

- P: Yes. Yes, it was important because I was confused, and she had my back. I want to make the right decisions in life, and I want to do the right things, so my mom has always been a person in who I could have trust in. So, I spoke with her and she said "ok, let's go check it out to see what we will do" and then she brought me to Profamilia.

  (...)
- I: And you did not mind that your mother was present in the room with the doctor?
- P: No (...) For example, she was asking, "And this will not cause harm? Will this cause her anemia?", because I've had bad symptoms before to medications, so my mom was asking a lot of questions (...)

It is worth noting that Paola wanted the assistance of her mother to help in choosing a contraceptive option. Yet, her mother did not necessarily have more knowledge than Paola to help her daughter make an informed decision on which contraceptive option to choose, as shown by the mother's questions to the doctor. Nonetheless, we can observe that Paola's mother engaged in a form of fostering the autonomy of her adolescent daughter's choice to use contraceptives by bringing her to Profamilia and asking pertinent questions to the healthcare professional.

# Accessing the Clinic

After deciding to use SRHS comes the issue of accessing these services, which can be done alone or accompanied. With the previous two examples, we can understand the participants' appreciation for some parental involvement. However, that was not the case for all participants. As the following participant illustrates, he explicitly did not want his mother to know that he planned to access SRHS, and instead would like the choice to have his friend accompany him to the clinic but then remain in the waiting room.

#### Diego (21 years old)

- Interview: Would you prefer to go alone or accompanied (to get HIV/STI testing)?
- Diego: Accompanied
- I: By whom?
- D: A friend.
- I: Why is that?
- D: It's because I would not be able to tell my mom. And with my friend, I have a lot of trust in him and I know that if I would need help, he would help me.
- I: And to see the health professional?
- D: Alone.

- I: Why not with the friend?
- D: It's because in case of something, the professional will help with that and then afterward, the friend will help emotionally.
- I: So, you would like your friend to wait for you in the waiting room?
- D: Yes.

Diego's case highlights the clear distinction there can exist in autonomous preferences regarding accessing the clinic and consulting a healthcare professional. This phenomenon was notably reflected in the cross-sectional data presented above, where participants had a variety of preferences. For those who wished to access the clinic accompanied but see the healthcare professional alone, one of the common explanations was the need for confidentiality, which echoes data on the topic from previous research (Fuentes et al. 2018). Nonetheless, other participants shared that they wanted the whole process to be confidential, which is why they did not want others to know they were using SRHS and so wanted to access the clinic alone.

# Consulting the Healthcare Professional

The previous examples underscore the importance that adolescents can attach to their preferences of being accompanied (or alone) to access SRHS. However, as was shown in the cross-sectional data section, some participants did not have a specific preference even with regards to consulting the healthcare professional. This was notably the case for Martin (21 years old):

- Interviewer: If you would have had the option, would have you preferred to be accompanied or you preferred to be alone? (to get STI/HIV testing)
- Martin: Normal. If there would have been a family member with me, I would have done it with a family member. It depends on the context. I was leaving work and saw the opportunity, so I took advantage of it. But I would have not had a problem that a family member comes with me or that I be alone. It is the same for me. Family is family.

This lack of a specific preference regarding how participants consulted a healthcare professional – either alone or accompanied – was a more prevalent answer for men in both the interviews and the survey (as shown in the previous section, 26.6% vs. 10.9%). This study did not investigate in-depth the influences for the gendered responses. The data suggests that the question of gender might influence the experience of autonomy for Colombian adolescents to access SRHS,

which points to the need for further research on this specific topic, e.g., to explore why adolescent boys may be more inclined towards independence to access SRHS in comparison to adolescent girls who tend more to prefer to be accompanied.

## Discussion

The data from this study can help contextualize and clarify AA-HA!'s concept of "fostering adolescents' autonomy" to access health services. The study invites reflection on what "fostering autonomy" might actually entail in practice and supports further reflection on the interrelated ethical issues. Here, we explore the pertinence of using a relational autonomy approach as it relates to Colombian adolescents' autonomy to access SRHS, and make suggestions for practical application by policymakers and healthcare professionals, that also consider the possible ethical challenges for adolescents (and the other stakeholders).

# The Pertinence of Relational Autonomy for Colombian Adolescents

As previously mentioned, respect for autonomy is a core principle in bioethics and enshrined in professional codes of ethics, guidelines, and the law. The origins of the concept's development are rooted within a specific Western tradition that might not always easily translate to other cultural contexts (Candib 2002; Dove et al. 2017; Frosch and Kaplan 1999; Ravez 2020). The autonomous subject (e.g., patient) is thus often framed as needing to make choices independently and without external influences – the subject needs to be self-reliant in order to protect their agency and autonomy (Gómez-Vírseda et al. 2019). From this framing is often derived a highly individualistic, ahistorical and asocial view of the patient (or research participant). In application, to show respect for individual human dignity means that health policy and the practice of health professionals should strive to promote patient-clinician relations and clinical practices that respect patient autonomy as independence (Ho 2008). Conversely, when external influences affect a patient's choices, e.g., when doctors or family members influence patients' decisions, these are understood as problematic or even unethical because they are disrespectful of the patient's right to self-governance. Thus, in contemporary bioethics there is strong advocacy for respect for autonomy, for example, through ensuring free and informed

consent for patients and research participants, with the goal of ensuring respect for one's personhood (Beauchamp and Childress 2012). In parallel, as previously mentioned, on the question of adolescents' access to SRHS, previous studies in different cultural contexts have shown that adolescents wish for their autonomy to be respected in terms of independence (Fuentes et al. 2018; Garside et al. 2002), such as by not requiring parental consent to access SRHS and protecting adolescents' confidentiality.

When applying such a conceptualization of autonomy to the data generated in our study, it is possible to observe some important disconnects. Note that we are not here challenging the importance of ethical principles at the heart of contemporary bioethics, e.g., that a patient's independence and personal choices should be respected. For example, if a woman wishes to use a contraceptive option, she should have her choice fully respected, without any restrictions. Rather, our intention is to point to the need to reframe the concept of autonomy – in both health policy and professional practice – to move it beyond a narrowly individualistic model so that it is pertinent for Colombian adolescents and the promotion of AA-HAI's notion of fostering autonomy. More concretely, we wish to challenge the notion that self-reliance and independence in healthcare should be an ethical ideal or be conceived as more important than a patient's desire to have the support of others in healthcare decisions (e.g., parents). Instead, we argue that a relational autonomy approach could better respect and foster Colombian adolescents' autonomy to access SRHS, and thus effectively articulate in practice the "fostering autonomy" advocated by AA-HAI.

Relational autonomy emerged from feminist philosophy (Heidenreich et al. 2018; Mackenzie & Stoljar 2000) in reaction to the aforementioned individualist and asocial conceptualizations of autonomy that focused on a patient's complete independence. Feminists sought to highlight how individuals (e.g., patients) are first and foremost social beings embedded within networks of relationships with others; as such, they are contextual beings and have important social identities that should not be ignored by healthcare professionals or policy makers (Ells et al. 2011; Gilabr & Miola 2015). Advocates of a relational autonomy view sought to challenge the notion that patient self-sufficiency should be understood as intrinsically better than interdependency, or that

relying on others for help was a sign of insufficient autonomy and thus a form of ethical failure of the patient-clinician relationship or of broader health policies.

If interdependence is viewed as appropriate, even beneficial, then relying on help from others is not an expression of weakness. Instead, such help — when it is freely chosen and accepted — is an authentic expression of autonomy; the patient recognizes their own limitations and needs, and thus freely, i.e., autonomously, solicits help from another person. This help-seeking is voluntary, chosen and an authentic act of agency — in so doing, their autonomy is not reduced. On the contrary, such a relational view might enhance autonomy because having the aid of others in decision making can support information acquisition and comprehension (i.e., the "informed" in informed consent) and give emotional strength to patients in the face of challenging decisions. Such support can thus enable a person to make more informed and voluntary decisions that they might find very difficult to make on their own, and supports the UN's notion of "progressive autonomy" for adolescents.

The findings from our study show that most participants placed significant importance on having others (especially parents) be involved, to varying degrees, in their autonomous access to SRHS. From an ethical perspective, it should not be interpreted as problematic or worse that an adolescent might appreciate the involvement of others in accessing SRHS, in comparison to an adolescent who might want to go through the whole process independently and without additional support. When engaging in initiatives to foster adolescents' autonomy to access health services, as advocated by AA-HA!, in the context of Colombia, this should not be done exclusively with the goal of achieving absolute independence. Rather, there needs to be recognition of the legitimacy of Colombian adolescents' wish to have others involved – with the nature and scope of this involvement determined by the adolescent – in supporting their autonomy to access SRHS.

# A Policy Suggestion

As highlighted by Gómez-Vírseda et al. (2021) relational autonomy is often theorized but there is a lack of literature on how to apply it in practice. Our research shows the pertinence of applying a relational autonomy approach when developing health initiatives and policies related to

Colombian adolescents' access to SRHS (and potentially other types of health services), which aligns with AA-HA!'s objective of fostering adolescents' autonomy.

Historically, when it comes to comprehensive sex education for adolescents, public health initiatives have tended to be very individualistic in their approach. For example, having teachers or nurses teach sex education directly to young people so that they can make their own individual, autonomous decisions. It is essential to provide the skills to adolescents on how to be self-reliant when making choices related to their sexual and reproductive health (e.g., teaching how to use condoms). However, there has not been the same effort invested in teaching adolescents how to access SRHS, for example, by teaching the steps involved in getting a prescription for contraceptives at a clinic (Guttmacher Institute 2015). Providing this information to adolescents – e.g., with tools that are adapted according to age, gender, education and are easily accessible – should be part of a comprehensive sex education curriculum in schools, that informs both individual action (e.g., how to use a condom) and the processes or contexts in which that action can be deployed (e.g., where, how and under what conditions they can obtain condoms or access SRHS).

Based on our research findings, which show that many Colombian adolescent participants place a high value on having others – including friends and parents – accompany them in their access to SRHS, it would be worth investing in initiatives that involve and empower parents to foster adolescents' autonomy. For example, this could be done through the development of public health campaigns encouraging parents to talk more openly with their adolescents and explain that they would be willing to accompany them to access SRHS, all the while respecting their adolescent's choice if they preferred to consult the healthcare professional alone once at the clinic. Instead of laying all the responsibility on adolescents themselves to independently navigate their access to SRHS (i.e., autonomy as self-reliance), providing skills to parents on how they can foster the autonomy of their adolescents could be a promising approach to explore, at least in the Colombian context.

There are certainly challenges to engaging in public health initiatives targeted at parents of adolescents. One is obviously the possibility of an underlining moralistic messaging in telling parents what they should do with their children. Also, if those public health recommendations do not align with the parents' values, this can raise another set of ethical issues that should be explored, notably, with parents themselves. There is additionally a potential ethical issue of equity since some adolescents may have healthier (e.g., more open, active listening, share decision-making) parent-child relationships than their peers, which could lead to some adolescents being more likely to have their preferences respected than their peers. For example, a parent can disapprove of their adolescent wanting to be sexually active and refuse to talk about the subject or assist them in accessing SRHS; whereas the parent of another adolescent may be more supportive and help schedule an appointment in a clinic to assist their adolescent in accessing the needed SRHS. Depending on the parent-child relationship, adolescents will not necessarily have equitable access to SRHS nor have their preferences met or respected.

# **Limits**

This study used the case of sexual and reproductive health services, which includes different types of services – there could potentially be important differences in answers and preferences between the types of health services, which were not explored in depth in this study. An adolescent might have one type of preference for a certain health service but a different preference for another. A further limitation of the study is that the quality of the parent-adolescent relationship was not investigated as it pertains to adolescent participants' preferences for access to SRHS; and the quality of this relationship could be an important influencing factor. For example, adolescents who can talk more openly with their parents about sexuality might be more prone to have their parents assist them to access SRHS, as opposed to parents who refuse to talk about sexuality with their adolescent. Future research should explore those differences with adolescents and their parents.

Another limitation is the representation of the sample, both for the surveys and interviews. For the survey, there is a representation bias due to its convenience sampling approach. Another limitation relates to participants who might not know how to answer the questions (e.g., survey). It is also important to note that the patients who presented themselves at Profamilia are most likely not representative of adolescents who do not go to Profamilia. On the question of access to SRHS, it is important to note that a multiplicity of factors can influence an adolescent's autonomy in accessing SRHS (e.g., the adolescent's agency, knowledge of available services, location, and hours of the clinic), but in the context of this study, those factors were not addressed. It would be pertinent, for example, to conduct research with Colombian adolescents who do not access SRHS in order to explore their opinions on the topic of autonomy as their experiences and preferences may be different from the adolescent participants in our study.

# Conclusion

The WHO's AA-HA! recommendations underscore the urgency of addressing issues related to adolescents' autonomy with the goal of implementing change to ameliorate the health of adolescents. The present study explored the question of Colombian adolescents' autonomy to access SRHS. Our findings revealed that adolescent participants expressed a multiplicity of preferences and experiences as these relate to their autonomy to access SRHS. The findings also showed that the common understanding of the ethical principle of respect for autonomy as articulated in contemporary bioethics and professional codes of ethics (i.e., individualistic and asocial), and as described in research with adolescents in different cultural contexts, does not resonate with most Colombian adolescent participants. For the vast majority of participants, an important component of their autonomy was closely related to the involvement of others (e.g., friends, family), to different degrees, in how they accessed SRHS. We therefore advocate in favour of adopting a relational autonomy approach to better support Colombian adolescents' autonomy and access to SRHS. The present findings are rooted within a specific cultural context and this conclusion might not be transferable to other cultural settings. Nonetheless, in many other cultural contexts, including in North America and Europe, a relational autonomy view could be pertinent as it explicitly highlights the reality of human interdependence, something that is particularly important when a young person is seeking healthcare services. Further empirical research with adolescents and their parents, and in different cultural contexts, could help enrich

reflections on how to operationalize relational autonomy approaches to respecting adolescents and fostering their autonomy in access to important healthcare services, such as SRHS.

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# **PART 3: RECOMMENDATIONS**

After the presentation of the preferences of participants regarding their access to SRHS, the next objective is to present ethically informed recommendations based on the research findings (**Table 14**). In the following chapters, one of the manuscripts provides recommendations based on empirical data collected in Colombia; the other manuscripts are of a conceptual nature, and thus, the recommendations are not exclusively relevant to the situation in Colombia, but are generalizable to other contexts seeking to promote ethical access by adolescents to SRHS.

## **Table 14. Synthesis of Recommendations**

**Recommendation 1:** Provide parents with comprehensive sex education so they may discuss the topic with their adolescents and assist them in making informed decisions regarding their SRHS (e.g., help them access SRHS).

**Recommendation 2:** Remove parental consent requirements for adolescents wishing to access SRHS independently.

**Recommendation 3:** Use ombudsperson offices as independent resources to defend the rights of adolescents in healthcare and help foster (i.e., assist) their autonomy to access the health services they need if parental consent requirements are a barrier.

**Recommendation 4**: Educate adolescents about the basis of consent and its application in sex. Teach adolescents comprehensive sex education, such as the risks involved with sex and how to address those risks (e.g., explain how contraceptives work and how to access them), in order for adolescents to be able to make informed decisions to consent to sex.

**Chapter 6** includes four articles. The first article, which is published in *Sexuality and Culture*, builds on the recurrent desire expressed study participants that their parents receive comprehensive sex education so that they could better discuss the subject with their adolescents and thus help them make informed decisions regarding their sexual and reproductive health (e.g., accompanying the adolescent to a clinic).

The second manuscript is a conceptual paper under review in the journal *Clinical Ethics*. The manuscript questions the pertinence of parental consent requirements for adolescents to access SRHS. Given that the issue of parental consent is central to the question of adolescents' autonomy to access health services, it was essential to address the subject in this thesis.

The third manuscript was published in *Éthique publique* for a special number on "accompanying autonomy today" (*accompagner l'autonomie aujourd'hui*). Drawing on my experience over the last three years working for an ombudsperson office for Quebec's Health Ministry, the article argues that ombudspersons — as independent offices within health systems — could be a promising mechanism to help foster the autonomy of adolescents to access health services, e.g., by promoting adolescents' rights in healthcare.

The fourth manuscript is under review in the journal *Sex Education*, and mobilizes the bioethics principle of respect for autonomy, operationalized through free and informed consent, to argue that for adolescents to be able to authentically consent to sexual relations, they need to have first been educated on the concept of consent and been informed on how to access SRHS, e.g., understand the risks involved with sex and how to address them.

Chapter 6: How to Foster Adolescents' Autonomy to Access SRHS

Article IV: Colombian Youth Express Interest in Receiving Sex Education from

their Parents

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<u>Abstract</u>

Despite having essential health needs regarding sexual and reproductive health services (SRHS),

young people (e.g., adolescents) in many countries show low use of such services. The World

Health Organization advocates fostering young people's autonomy to access health services to

address this global health problem. However, there are gaps in the literature to understand how

young people's autonomy can be fostered to access SRHS. In 2019-2020, we conducted semi-

structured interviews with 45 young people aged 14-23 years old in Colombia to explore how

they might wish to have their autonomy fostered in accessing SRHS. Research in different cultural

contexts has shown that young people generally do not wish to discuss sex with their parents. By

contrast, most of our participants expressed a strong wish for the ability to talk openly with their

parents about their sexual and reproductive health. One of the main complaints of these young

people was that their parents lacked the necessary knowledge to help them make informed

decisions related to their sexual and reproductive health (e.g., choosing a contraceptive option).

As a potential solution, participants were enthusiastic about initiatives that could provide parents

with comprehensive sex education to assist young people in making informed choices for their

sexual and reproductive health, including how to access SRHS.

**Keywords:** adolescent; autonomy; Colombia; parent; sex education; sexual health; reproductive

health; young people

Introduction

In 2015, the Global Strategy for Women's, Children's and Adolescents' Health (Every Woman

Every Child 2015) was introduced to help achieve part of the United Nation's (UN) Sustainable

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Development Goals related to health (UN 2015). The Global Strategy notably includes ensuring universal access to sexual and reproductive health services (SRHS), and was the first time that a global health initiative of this magnitude recognized adolescents as a distinct group — different from children and adults — with unique health needs and challenges that must be addressed. To help reach the goals of the Global Strategy related to adolescents (i.e., young people), in 2017 the World Health Organization (WHO) introduced the Global Accelerated Action for the Health of Adolescents: guidance to support country implementation (AA-HA!) (WHO 2017).

One of the leading global health challenges emerging from the literature on young people's health is that they have many unmet healthcare needs, such as those related to sexual and reproductive health (Mazur et al. 2018; Nature 2018; Patton et al. 2016). This situation results from many factors, including young people's inexperience and lack of knowledge about how to access and use healthcare services in their communities (Patton et al. 2012). As a solution, AA-HA! suggests fostering young people's autonomy to access health services, including SRHS, in specific cultural contexts. However, there are gaps in the literature regarding what fostering young people's autonomy to access SRHS would entail in different countries (Brisson et al. 2021b). Thus, raising important questions for researchers and policy makers: Should fostering autonomy be done through public health promotion campaigns targeted specifically to young people? Should it be part of sex education in schools? Do young people wish to have their autonomy fostered to access SRHS, and if so, how? The answers to these questions will most likely vary across countries and cultural communities.

From a justice perspective, and as advocated in AA-HA!, young people should be meaningfully involved in initiatives that directly affect them (Mabaso et al. 2016). Just as importantly, for group-specific health initiatives to be efficient and effective (i.e., pertinent and adapted to the needs of the group), and to maximize the chance of the intervention's success, members of the target group should be consulted (Israel et al. 2010; Kon 2009; Minkler et al. 2003). With these considerations in mind, our study consulted young Colombian people to ask whether they would

want their autonomy fostered to access SRHS (as suggested by the WHO), and if so, how they would want their autonomy fostered.

There were different reasons for choosing Colombia as the focus of our research. One important reason is that most research done with young people is conducted in high-income countries (HIC), yet most young people live in low and middle-income countries (LMIC), like Colombia (Blum & Boyden 2018; Vandermorris and Zulfiqar 2017). Given the evident cultural, socio-political, socio-economic differences between HIC and LMIC, including different healthcare delivery environments, one cannot expect research in the former to necessarily represent the reality of people in the latter.

Adolescence is socially and culturally defined, and cultural markers will often define an adolescent's entry into adulthood (Ledford 2018; Sawyer et al. 2018); simultaneously, there are no objective (e.g., biological) markers to define the end of adolescence and the start of adulthood (Bédin 2009; Sawyer & Patton 2018). In parallel, human sexuality is also culturally shaped (Parker 2009), which also influences questions of autonomy to access and use SRHS. Hence, it is crucial to conduct research with young people in different cultural contexts in order to understand their diverse experiences worldwide.

In terms of young people's autonomy to access SRHS, Colombia is unique since there are no laws preventing adolescents from accessing some health services without parental consent or accompaniment. For example, a 13-year-old girl in Colombia may independently access contraceptives or have an abortion in a clinic without parental involvement, although this may not be widely known by young people (Brack et al. 2017; Brisson et al. 2021a; Prada et al. 2011).

Furthermore, compared to neighboring countries, the Colombian government has taken a more sex-positive approach to young people's sexuality, notably by investing in initiatives to promote young people's sexual and reproductive health. According to the Colombian Health Ministry website (2021) "it is time that adolescents and young people experience their rights from a positive perspective: the right to enjoy sexuality and self-determine their reproduction" (first

author's translation). This view differs substantially from fear-based approaches to young people's sexuality that are still common in many other LMIC, including in Latin America (Schalet, 2004). However, while some governmental initiatives have sex-positive perspectives, this view is not necessarily shared by the majority of the Colombian population, and high-profile conservative religious groups still actively fighting against LGBT + rights (Corrales & Sagarzazu 2019), for example.

Previous research on the topic of young people's sexuality, in general, has shown that they tend not to want to discuss sex with their parents – particularly concerning their access to SRHS. This is the case in different countries, such as in the United States (Lehrer et al. 2007), Ethiopia (Muntean et al. 2015), South Africa (Vujovic et al. 2014), and the United Kingdom (Garside et al. 2002). Data show that confidentiality and privacy are central for young people regarding accessing SRHS; for example, young people generally do not want their parents to know that they want to use contraceptives or get tested for a sexually transmitted infection (STI) (Fuentes et al. 2018; Lawrence et al. 2011; Pampati et al. 2019). Hence, we initially assumed at the outset of our research that young Colombian people would want to have their autonomy fostered to access SRHS without parental involvement, but interestingly, this proved not to be the case, and for multiple reasons.

#### **Objectives**

The study's first objective was to learn *whether* young people would want to have their autonomy fostered to access SRHS. In the event that that some adolescent participants wished to have their autonomy fostered, the second objective was to understand *how* this should occur. The third objective was to understand why young people would want their autonomy fostered in a particular way and then explore how this could be implemented.

#### Methodology

#### Design

Between August 2019 and February 2020, the lead author conducted semi-structured audio-recorded interviews, in Spanish, with 45 young Colombian participants; the interviews were then transcribed and translated from Spanish to English. The methodological approach of semi-structured interviews enabled a detailed exploration, with participants, of their views on the topic (Adams 2015; Pope et al. 2002; Sankar & Jones 2007), specifically if and how they would want their autonomy fostered to access SRHS. Participants were also given the opportunity to share past experiences and to provide meaning to their answers (e.g., elements they might have enjoyed that fostered their autonomy to access SRHS).

Before the interviews, participants were asked demographic questions, such as how they identified their gender and whether they were currently enrolled in school. All participants were asked the same core questions from the interview guide, e.g., how they interpreted the WHO concept of "fostering autonomy" for adolescents to access SRHS. However, during the interviews, participants were asked different questions depending on their answers. For example, a participant who would never have accessed SRHS because their parents forbid them did not have the same followup questions as participants who shared having already accessed SHRS with a parent.

As mentioned above, previous data on the topic in different cultural contexts have shown that young people generally do not want to discuss sexual and reproductive health with their parents. Hence, in this research project, the guide for the interview questions were not initially developed with the view that participants would attribute an important role to parents regarding their autonomy to access SRHS. Originally, there were no specific questions about parents to be asked during the interviews (the interview guide was not pretested). However, the methodological approach incorporated flexibility in adjusting questions as needed (Galletta 2013). After the first five interviews, it became evident that participants wanted to talk about their parents' involvement in fostering autonomy. As such, a new section was added to the interview guide:

the remaining forty participants were asked if they would want their parents to receive sex education and were then invited to expand upon their answers, particularly as these related to the question of their autonomy.

## **Participants and Recruitment**

Participants were between the ages 14 and 23 years, consonant with our main inclusion criterion of participants to be aged between 10 and 24 years, corresponding to the new definition of adolescence increasingly used in global health research and policymaking (Sawyer et al. 2018), and which also corresponds to the WHO's definition of young people (WHO 2014). As previously mentioned, the period of adolescence and the transition into adulthood is culturally defined. As such, there is a critical methodological reason for extending the age range for studies with young people: it allows to understand the similarities and differences between younger and older adolescents and young adults.

The initial targeted minimum sample size was twenty participants, and the cut-off point was sixty participants, in order to maximise the diversity of young people's opinions, realities, and experiences (e.g., compare answers between older and younger participants). In line with the research objective, the recruitment goal was to have at least two main categories of participants – those who had and had not previously accessed SRHS – in order to hear young people's voices regarding their experiences with autonomous access to SRHS.

Interviews were conducted between August 2019 and February 2020 in the two Colombian departments, Antioquia and Valle del Cauca, in both rural and urban contexts. In Antioquia, participants were recruited in the cities of Medellin (large city), Rionegro (small city), and Santa Fe de Antioquia (rural area), while in Valle del Cauca participants were from Cali (large city) and Palmira (small city). It was left at the discretion of the participants to choose where they wished to do the interview, e.g., in private room in a clinic, at a library, on parc bench.

Different approaches were used to recruit participants. One approach was through the help of Profamilia, a network of non-profit health clinics across Colombia that offer accessible SRHS to the population and which is a strong advocate of sexual and reproductive health rights (e.g., trans rights, access to abortion, promotion of comprehensive sex education). Profamilia also offers services specialized for young people (e.g., youth psychologists, social workers) and frequently organizes events for young people, in and outside their clinics. Recruitment posters for the study were posted in two Profamilia clinics (Medellin and Cali), and health professionals who saw young patients shared information about the research project.

In addition, study information was shared at social events involving Profamilia employees outside the clinics in community events (e.g., educative initiatives with schools, community organizations and promotion events) where young people were present (not as patients). The employees would present the research project while the researcher (first author) was there (e.g., community centers), and the employees would invite young people to approach the researcher or take an information sheet about the research project. Snowball sampling was the most effective means of recruitment, with participants and other young people sharing information about the research with their friends and peers. Further, a nurse presented the research project to students in a high school (in Santa Fe de Antioquia). These various recruitment strategies ensured diversity in young people's experiences with access to SRHS (e.g., with Profamilia or other clinics) and some participants that had never used SRHS.

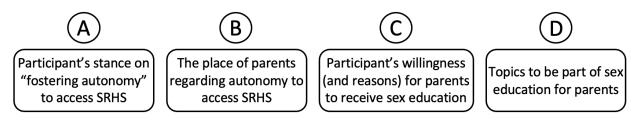
At the beginning of the study, some young people asked if they would have to talk about their sexual practices to participate in the interview and hinted that they would feel uncomfortable discussing this subject. The researcher clarified that no specific questions would be asked about the participants' sexual practices, and that the focus of the interview was on young people's autonomy and access to SRHS. From then on, this clarification was presented to all potential and actual participants, through the consent form and information sheet (which stated that participants did not have to answer any questions that made them uncomfortable, nor would

they be required to give any justification), and prior to each interview. These written and verbal confirmations appeared to help participants feel more at ease with participating in the interview.

## **Data Analysis**

The interviews were first transcribed in their original language (Spanish), and transcripts initially analyzed in Spanish to preserve the cultural meanings of participants' answers. Each transcript was read at least twice to generate a preliminary sense of the themes and participants' opinions. The first step of data analysis consisted of classification (Gaudet & Robert 2018). The core interview questions were separated into sections (e.g., "Would you want your parents to receive sex education?" "What kind of topics would you want to be part of the sex education for your parents?"). The interview excerpts answering the particular question were then documented under each section for thematic analysis (Braun and Clark 2006) (Fig. 1).

Figure 1. Core Interview Questions by Section



The interview excerpts were analyzed by highlighting and coding the similarities and differences of responses while simultaneously paying attention to participants' demographic characteristics (e.g., gender, age) (Maher et al. 2018). This coding approach allowed for the identification of specific trends and variations between answers and experiences based upon participants' various contexts (Coenen-Huther 2006).

The analysis of Part A involved getting a general sense of the participants' position regarding the WHO concept and call to "foster autonomy" for young people to access SRHS and to better understand the reasons behind the participant's stance (e.g., why the participant accepted or rejected the WHO initiative). For Part B, the goal was to analyze the place or role that participants

attributed to their parents on the question of supporting their autonomy to access SRHS (e.g., if the participant discussed the topic with their parents). Part C entailed documenting participants' willingness for their parents to receive comprehensive sex education, in order to then be able to understand the reasons behind participants' answers. Finally, Part D consisted of an analysis by themes (Paillé and Mucchielli 2012), i.e., the topics that participants would want to be part of their parents' sex education were classified into main categories.

After the mapping and analysis of the data, we conducted an ethical analysis as an analytic frame for a rich conception of autonomy and its application to the WHO notion of fostering young people's autonomy to access SRHS. The purpose was to identify the ethical questions arising from participants' answers and determine the potential implications for health policy, and then to develop possible practical recommendations.

#### **Ethical considerations**

The University of Montreal's Research Ethics Committee first evaluated and approved the research project (CERSES- 19-049-P), which was then evaluated and approved by the Profamilia's research ethics committee (which included a lawyer). Before participating in the interview, participants were asked to read an information sheet about the project and sign a consent form. Participants were provided all the necessary information to make an informed decision about whether they wished to participate in the interview. Participants were also given a list of free local resources in the event that they were in need of support following the interview (e.g., social workers). Pseudonyms were given to every participant to protect their anonymity.

Parental consent was not asked nor required (as approved by the research ethics committees), based on the grounds that asking for parental consent could be a potential barrier to free and informed participation in the study. The decision to not ask for parental consent was supported by national and international research ethics guidelines, including the International Ethical Guidelines for Biomedical Research Involving Human Subjects (Council for International Organizations of Medical Sciences 2017). Under certain conditions and with justification (and

approval by a research ethics committee), it is possible to waive parental consent for research with minors, notable when it is not possible or desirable, and the research involves low risk for participants.

#### Results

The first part of the results section presents the participant profiles and is followed by participants' responses regarding whether they wanted their autonomy fostered to access SRHS and the reasons supporting this view. Subsequently, participants' responses will be presented on why they would want comprehensive sex education to be provided to their parents to help foster autonomy to access SRHS. Finally, we present the topics that participants would like to be part of the sex education for their parents.

## **Participant Profiles**

A total of 45 young Colombian people were interviewed; before recording the interviews, participants were asked demographic questions (see **Table 15**). Five participants were recruited in a school through the help of a nurse, 29 participated via snowball sampling and participation at social events (e.g., presentation of the research in a community center), and the other 11 participants were recruited from visiting Profamilia clinics (e.g., poster). Participants were free to define their gender. There was a close equal representation of male and females, with one non-binary participant. The age distribution for participants was from 14 to 23 years old (the inclusion criteria was 10–24 years old), with 19 years old being the average. Participants were invited to share their estrato; Colombian socio-economic classes assigned by the government regarding one's area of residency. In Colombia, there are six officials estratos: 1 is the lowest and 6 the highest. Most of the Colombian population is in the lower three estratos, with a minority in the upper three estratos. More than three-quarters of participants were from the estratos two and three, and none from the upper two estratos (five and six).

**Table 15. Demographic Characteristics of Participants** 

Demographic characteristic	n (%)
Gender	
Man	21 (46 79/)
Woman	21 (46.7%)
	23 (51.1%)
Non-binary	1 (2.2%)
Age	
14	1 (2.2%)
15	4 (8.9%)
16	5 (11.1%)
17	2 (4.4%)
18	3 (6.7%)
19	11 (24.4%)
20	
21	2 (4.4%) 10 (22.2%)
22	5 (11.1%)
23	
23	2 (4.4%)
Estrato	
1	3 (6.7%)
2	12 (26.7%)
3	25 (55.6%)
4	4 (8.9%)
5	0 (0.0%)
6	0 (0.0%)
Unknown	1 (2.2%)
Chichewh	1 (2.270)
Residence of Participants	
Medellin, Antioquia	9 (20.0%)
Rionegro, Antioquia	6 (13.3%)
Santa Fe de Antioquia, Antioquia	5 (11.1%)
Cali, Valle del Cauca	2 (4.4%)
Palmira, Valle del Cauca	23 (51.1%)

## The Pertinence of Fostering Autonomy to Access SRHS

The study did not take for granted that participants would necessarily want their autonomy fostered to access SRHS; they might have rejected the AA-HA! initiative, for example, seeing it as paternalistic or believing that they already possessed the necessary knowledge and skills to exercise their autonomy to access SRHS. However, this was not the case. Participants were unanimous regarding the pertinence of initiatives to foster their autonomy to access SRHS. They understood the idea of "fostering autonomy" as an opportunity to gain more knowledge that could be useful for them, and many noted that they lacked some understandings of topics related to sexual and reproductive health. This perceived lack of knowledge around accessing SRHS was more pronounced for some participants than others (e.g., those that did not receive comprehensive sex education in school).

Participants were asked if they had received sex education in school. While many participants had received sex education in school (42%), the remaining participants (58%) stated either having received no sex education or had received "very bad" sex education. Some participants received abstinence-only education, which does not qualify as comprehensive sex education according to international guidelines, e.g., UNESCO's International technical guidance on sexuality education: an evidence- informed approach (2018). Regardless of whether participants had received sex education in school, there was an overwhelming perception that their sex education was lacking in many aspects, including teaching about how to access SRHS. The following interview excerpt exemplifies participants' experience with sex education in school:

## Andres (male, 23 years old)

- Interviewer: You told me earlier that you received sex education in school, would it have been something you would have liked to be part of your sex education? (teaching how to access SRHS)
- Andres: That is something I would have liked very much, that they amplify it a lot more. Because when I received sex education in school, the teachers presented it in a very silly way, like very childish. To teach properly in great depth to teach truthfully what needs to be taught it has to be realistic with a kid.
- I: Can you elaborate a bit more?
- A: Alright, look, let's say I am a 14-year-old kid... I'll tell you my own experience when I received sex education in school. I was sitting in the classroom and saw the teacher saying "these are the parts of the body, these are the genital parts, and the genital parts are the penis and testicles." So, it was super basic. You want them to teach you about real stuff. I was thinking like "what am I seeing here?" I saw this as unimportant material. I knew that in the future I would want to have sexual relations, so that material was not useful for me. So yeah, I had "sex education" but I never had a class that went in depth to explain what really happens between a man and a woman, never.
- I: So as a young person you wanted your sex education to go beyond the basic biology and talk about relationships?
- A: Exactly! All of it!
- I: What about teaching how to access sexual health services?
- A: Yes, I would have wanted that they give information on where I can go ask questions, where I can get condoms, and so on. So, it wasn't really sex education, it was super basic, it was biology stuff and that's it.

As evident from this interview excerpt, Andres recognized the shortcomings of the sex education he received in school and he could confirm the topics he would have liked to be discussed, such as how to access SRHS and where to obtain more information related to sexual and reproductive

health. Andres' opinion echoed most of the other participants' perceived gaps in their knowledge related to sexual and reproductive health, which led participants to endorse AA-HA!'s concept of developing ways to foster young people's autonomy to access health services, and SRHS in this case.

## The Place of Parents Regarding their Children's Autonomy to Access SRHS

The question of fostering autonomy to access SRHS was initially framed in the interviews in relation to sex education in school. However, many participants would bring the discussion back to their parents. As previously mentioned, and in keeping with previous research on the topic, the study was not originally conceived with the view that participants would attribute much importance to the role or place of their parents in supporting autonomy to access SRHS. Mariana was one of those first interviewed who led to the introduction of a new section in the interview guide about parents and their relation to the question of young people's autonomy:

#### Mariana (female, 19 years old)

- Interviewer: Do you think we should do the promotion of adolescents' autonomy in healthcare as part of sex education?
- Mariana: Yes, but I think it should be the responsibility of parents.
- I: More than sex education in school?
- M: Equally.
- I: And why with parents?
- M: Because young people should always talk first with their parents about sex.

Mariana explained during her interview that it was important for her to have her mother involved in helping her choose a contraception option, as opposed to making the decision by herself. As will be developed in the next sections, like many of the other participants, Mariana's mother did not have more knowledge than her daughter about contraceptives. Nonetheless, Mariana accorded great importance to her mother being involved in discussions around her contraceptive choice.

Analysis of the interviews found an almost unanimous belief among participants that their parents lacked general knowledge about sexual and reproductive health, which reflects

participants' own sense of missing sufficient or complete knowledge related to their sexual and reproductive health. Two main points emerged regarding the information that participants believed their parents were missing: 1) a lack of parental understanding of the reality of young people's experiences concerning sexual and reproductive health, and 2) a general lack of parental knowledge about accurate sexual and reproductive health information. The following interview excerpt helps highlight these two points:

## Sebastian (male, 21 years old)

- Interviewer: How do you think we could promote the autonomy of adolescents to access sexual and reproductive health services?
- S: In school and with parents.
- I: Both?
- S: Well, I think more with parents.
- I: Why is that?
- S: Who is gonna know you more than your own parents? With who are you gonna have more trust than in your parents? So, I think parents should be the first people we talk with when we start being sexually active.

(...)

- I: Do you think it would be a good idea to start giving sex education classes to the parents of adolescents?
- S: Yes. Yes, I think it would be good, as much for adolescents as for parents. Because like I was telling you, this is something we should start to implement in the 21<sup>st</sup> century. We already know or we should start to be aware that parents are from an older era and had completely different education. Maybe they've had sex education or maybe they didn't get any, but I think you're never too old to learn. Because as much for us young people as for parents, we can all learn something.

When asked why participants attributed such importance to discussions with their parents about sexual and reproductive health, a significant number were unable to give a concrete response. Nonetheless, for those who were able to develop an answer, the question of trust was a central element, notably as observed in the previous interview excerpt.

#### Discussing Sexual and Reproductive Health with Parents

The previous interview excerpts helped provide a foundation for grouping the opinions of participants on the topic. When analyzing the interviews more thoroughly, it is possible to recognize different experiences for participants in discussing sexual and reproductive health with

their parents. The following sections presents those different realities by types of experiences and participant preferences.

## Wanting to Talk but Being Unable To

Some participants expressed wanting to talk about sexual and reproductive health with their parents but being unable to, either because they did not feel comfortable initiating the conversation with their parents, or because parents refused to discuss the topic when it was brought up by the young person. This latter situation was the case for Isabella. During her interview, she explained that she had wanted to start using a birth control implant because she wanted to begin having sexual relations with her boyfriend:

#### Isabella (female, 14 years old)

- Interviewer: What would have you liked to be your mother's reaction? (when asked to start using contraceptives)
- Isabella: Well, from my mom, I was expecting this reaction because she's very closed-minded around the topic of sexuality. I always want to talk to her about the topic, but she always asks me to change the topic.

#### Wanting to Talk and Being Able to

While some parents, like Isabella's mother, avoided the topic, other participants explained that their parents were more engaged with or open to discussing sexual and reproductive health.

#### Sebastian (male, 21 years old)

- Interviewer: You're telling me you've spoken to your parents about your experiences?
- S: Yes. I've spoken to my parents about it. Now it is not a mystery. I'm gonna tell them that I'm gonna go out with a (girl) friend and it is not a mystery.
- I: At what age was the first time you had that talk?
- S: At like 16 or 17.
- I: And your parents were not uncomfortable that you wanted to talk to them about that topic?
- S: No. They've always supported me with this topic. When I would return from school and tell them I've had classes on sex education and learned how to use condoms and prevent diseases and all of that, I shared that with my parents, and they supported me. They said "learn and pay a lot of attention, it's going to be useful for you one day." The recommendations I've always received from my parents was "take care of yourself, take care of yourself, put the condom on."

#### *Not Wanting to Talk*

While many participants recounted the important place for them of discussions with their parents about sex, this was not the case for a minority of participants who expressly did not to want to discuss the subject with their parents.

#### Santiago (male, 15 years old)

- Interviewer: Other participants during their interviews said that they would like to be able to talk more about sex with their parents, it doesn't sound like that is your case.
- Santiago: No, not for me.
- I: Some participants expressed that they would like for their parents to receive sex education to afterward be able to talk more openly with their adolescents on the topic.
- S: No, no. That's not the case for me.
- I: You prefer receiving sex education on the Internet and in school?
- S: I say that maybe for some young people it could be the case for them, but it is not my case for me, I don't wanna talk about sex with my parents.

Young people have distinct preferences regarding discussing sex, as do parents (Blakey & Frankland 1996; Walker 2001). While some might enthusiastically welcome initiatives promoting comprehensive sex education for parents so that they may better discuss the topic with their children, this enthusiasm might not be collectively or universally shared, something that must then be taken into consideration for any health promotion or policy initiatives.

#### **Topics to Teach Parents**

As previously mentioned, most participants supported the idea of initiatives to provide comprehensive sex education to their parents. As follow-up questions, participants were asked what themes or topics they would want their parents to learn about as part of their sex education. Many participants were unable to identify specific topics, but the following sections are some of the main topics suggested by the participants who could answer the question.

## Gender Relations and Sexual Identities

A few women participants expressed that in Colombia, the question of sexual and reproductive health (locally referred to as "family planning") was framed as a responsibility of women. These participants critiqued this view, arguing that family planning should also be something involving men, and that men (e.g., their partners) should have better understandings of reproductive

health (e.g., understand how contraceptives work). In echo to this point, there was also criticism about an unequal gendered conception of young people's sexuality, e.g., some women participants stated that parents were more lenient towards men being more sexually active, whereas women did not experience the same permissive attitude. Participants felt that sex education for parents should involve discussions to challenge these problematic gendered representations.

#### Elena (female, 22 years old)

- Interviewer: You think there is a difference between men and women? (regarding perceptions about young people having sexual relations)
- E: Yes.
- I: Like?
- E: I say that men have a lot more liberty. And for women... For women, it's seen as bad according to some people.
- I: Do you believe that it is a problem?
- E: Yes, I believe it should be equal between both.
- I: Do you think this topic should be part of sex education for parents?
- E: Yes! Obviously! It would be a good thing to change that way of thinking.

In the same vein of wanting to challenge problematic gender ideologies amongst parents, some participants expressed wanting to challenge parents' homophobic beliefs through sex education. This was notably the case with Jaime (male, 22 years old):

- Interviewer: Are there specific themes that you would like them (psychologists teaching sex education) to be specialized in?
- J: More than anything else, sexual orientation. It is because there are many taboos in relations to that theme. And that taboo affects a lot the liberty of expression. And what I would like from those psychologists is to not only help young people but also their parents. It is because in a lot of homes there is a lot of homophobia. For example, if the son says to his dad that he is a homosexual, his dad is going to reject him.
- I: So, you would like for the psychologist to talk with the child and their parents together?
- J: No, better separated. First with the parents to educate them.

## **Healthy Relationships**

Most participants associated sex education with the classic biological approach of prevention, e.g., prevention of pregnancy and STIs. Participants were asked if they would appreciate sex education that went beyond questions of human biology and also explored other themes, like

how to have healthy relationships between partners (e.g., how to have good communication with a partner or recognize abusive relationship patterns like jealousy). Collectively – except for three men participants who did not see the pertinence – participants expressed a certain enthusiasm for the idea, particularly as it relates to discussing the topic with parents.

#### Francia (female, 22 years old)

- Interviewer: In previous studies, young people have criticized sex education focused too much on biology and they would have liked to talk about other themes like...
- F: Pleasure?
- I: Yes, also that, but on how to have healthy relationships. Is that something you would have liked to be part of sex education for yourself or your parents?
- F: Yes, obviously. When I was at a stage of falling in love, with my first boyfriend, it would have been something important, because, for example, with my first boyfriend, it was terrible, very bad. And I tell myself that if I would have had better support... For example, I'll give you a comparison between me and my best friend. Her parents were always super close with her, and my parents were very distant. So, I was telling myself that she has the foundations on what to do (in her relationships). I didn't have the foundations to know what to do.

## Options and Advice Regarding Accessing SRHS

While some participants could name with ease topics they would like to be part of the sex education provided to their parents, others had more difficulty. Nonetheless, by analyzing what they shared, we observed that participants wanted their parents to possess knowledge on the topic of sexual and reproductive health so that they can give advice and guide their children in making choices related to their sexual and reproductive health.

## Juan-Martin (male, 16 years old)

- Interviewer: Do you think it would be a good idea that we give sex education to the parents of young people?
- Juan-Martin: It would be cool because you would teach parents and after that the parents can teach to their kids so that they can learn from them.
- I: So, you would like that?
- JM: Yes.
- I: More with your dad or your mom?
- JM: Both. So that both my parents can give me good advice.

# <u>Comprehensive Knowledge of Sexual and Reproductive Health, and the Lived Experiences of Young People</u>

In connection to the previous point, it is important to note that for parents to be able give sound advice and help guide their children to make informed choices, they must possess factual knowledge related to sexual and reproductive health. Some participants felt that their parents had erroneous beliefs regarding some sexual and reproductive health information (e.g., incorrect notion that contraceptives are unsafe and make young people sterile). This misinformation translated into misunderstanding the reality and aspirations of young people as it relates to their sexual and reproductive health. Consequently, participants expressed wanting to challenge those misconceptions through sex education for their parents.

## Luz (female, 19 years old)

- Interviewer: So, you would like that we do that with your mom? (give her comprehensive sex education)
- Luz: Yeah, that would be cool.
- I: And what would you like that we teach her?
- L: I think more than anything else to make her understand that when someone wants to start family planning it is not because they want to sleep with everyone, it is a form of protection.
- I: So, beyond a question of pure "biology" as to how contraceptives work, to discuss about the life of young people?
- L: Yes, exactly.

#### Fostering Autonomy as a Form of Support

As it relates to the question of autonomy (i.e., the ability to make choices), participants made it clear that they wanted to make their own choices regarding their sexual and reproductive health – they wanted their autonomy respected. None of the participants suggested that they would want their parents (or anyone else) to make decisions for them. Yet, most participants gave importance to the role or place of their parents in supporting their autonomy regarding their sexual and reproductive health (e.g., helping to choose a contraceptive option). Why would young people want the involvement of someone else (e.g., a parent) if they ultimately wanted to make their own decisions about SRHS? And why would young people want their parents to receive comprehensive sex education to discuss the topic with them if they do not want their

parents telling them what to do regarding their sexual and reproductive health? The answer to these two related questions might be that young people want their parents to confirm and agree with the choices they want to make (e.g., to start using contraceptives or get an HIV test at a clinic). And they want to know that their parents have accurate knowledge of sexual and reproductive health, which would then validate the choices they make through their parents' confirmation and support. The following interview excerpt help clarify the value participants attributed to having their parents' support around their autonomy and sexual and reproductive health.

## Monica (female, 23 years old)

- Interviewer: What do you think of the idea that we provide sex education to the parents of young people?
- Monica: Yes, I would love that so much.
- I: Why is that?
- M: Like I was telling you, because oftentimes us young people want to make decisions that do not agree with them (parents). Obviously, we have to understand that they are the parents and they worry about you and they are responsible of their kids until a certain age. But there is so much stigma and myths and they reproduce it with you without knowing why. They never ask themselves "why am I thinking this way?" So, they simply tell you things like "no, a woman cannot be a single mother," like those types of things. They simply tell you things like that without actually knowing why they tell it to you. I say that those things are prejudices and that it is very important to eliminate them. It is a very difficult task, but I think that gradually it could happen. But yeah, it is very much needed.

This interpretation of the phenomenon is a hypothesis. Future research is needed to empirically examine whether young Colombian people want their parents to receive comprehensive sex education so that their parents will support and agree with the choices the young people want to make regarding their sexual and reproductive health.

## **Discussion**

In general, and in many countries, the traditional format for teaching sex education to young people has been through content in the school curriculum (Moran 2002; Pilcher 2004). Usually, sex education in schools does not involve parents but is done by employees – e.g., teachers, nurses, sexologists, psychologists, or nuns in some cases in Colombia (as was the situation for some of the participants). Many debates have taken place around sex education for young

people, one of the dominant being between "abstinence-only" with "comprehensive sex education" approaches (Beh 2006; Irvine 2002). Part of that debate is about determining the level of information about sex and sexuality to be shared with young people, ranging from none to sometimes erroneous information, or either complete, comprehensive, and scientifically based information (e.g., teaching young people their healthcare rights and how to access local SRHS).

Ethically speaking, one major point of tension is determining what is best for adolescents, considering that they are not yet adults but have emerging autonomy that evolves over several years. Often, arguments to limit adolescents' autonomy and grant parents a greater authority depend on views about when adolescents become "sufficiently" competent and autonomous to learn about and make informed decisions about their sexual and reproductive health.

Parental consent laws differ between countries, but in general have to do with circumstances where parents are allowed to decide whether they permit their adolescents to receive sex education in school or to access SRHS (e.g., STI testing). The ethical reasoning behind parental consent laws is that parents are, de facto, responsible for and often best able to determine what is in the best interests (e.g., health and well-being) of their adolescent children. Our findings can contribute to this debate by looking at the issue from a different angle. If one accepts as a starting point the WHO's AA-HA! initiative recommendations that adolescent autonomy can and should be fostered, including regarding SRHS access, then we should understand in a nuanced way the place given to parental responsibility and involvement in their adolescent's autonomy.

First, adolescents' autonomy is emergent, growing and changing over time (Boykin McElhaney & Allen 2012); second, adolescence is a concept that is socially and culturally constructed, and that is experienced differently depending on the adolescents and on their parents (Ledford 2018; Sawyer et al. 2018). Because adolescent autonomy is multifaceted and variable across cultures, countries, and socio-economic groups, fostering autonomy necessarily involves multiple stakeholders: not just adolescents, but also their parents, educators, and health professionals, amongst others.

Participants in our study felt that their parents lacked the necessary knowledge to help them foster their autonomy to make choices related to their sexual and reproductive health. While we did not investigate the level of knowledge parents had about sexual and reproductive health, it is very likely that participants had an accurate view of the situation. Despite these perceived shortcomings on the part of parents, most participants still wanted their parents involved (in different ways) in their sexual and reproductive health choices..

Furthermore, most of the participants trusted their parents regarding their sexual and reproductive health, regardless of whether parents had (or were perceived to have) accurate and in-depth knowledge on the topic. From a social policy perspective, this nuance is important and merits further research to explore the implications for related policies and initiatives (e.g., educative projects with parents) that could lead to beneficial effects for young people's health and well-being. In terms of fostering young people's autonomy, providing comprehensive sex education to parents would likely ameliorate respect for young people's choices and increase young people's use of SRHS, because both young people and their parents would be more knowledgeable on the topic and so be better equipped to make or support more informed decisions.

Previous studies have explored the topic of parents discussing sex education with their adolescents (Mullis et al. 2021; Walker 2001), for example, documenting the perspectives and attitudes of parents in Nigeria (Orji & Esimai 2003), Greece (Kakavoulis 2001), the UK (Walker 2004), Mexico (Atienzo et al. 2009), and Australia (Robinson et al. 2017). However, the focus of those studies was mainly on sex education with the objective of educating young people on sexual health from a classic perspective, such as preventing STIs (e.g., Ashcraft & Murray 2017; Shtarkshall et al. 2007; Walker 2001). Other studies have explored adolescents' general interest in discussing sex education with their parents – e.g., in Canada (Byers et al. 2003). Some studies have investigated the factors that can help parents discuss sex education with their adolescents, such as communication skills (Baldwin & Baranoski 1990; Jerman & Constantine 2010; Malacane

et al. 2016), and studies have explored gender differences in communication patterns between parents and their adolescents (Evans et al. 2020). In parallel to our research's findings that demonstrate that Colombian adolescent participants wanted to discuss sex with their parents, studies in different cultural contexts shows that adolescents can be unsure about wanting to talk about sex with their parents, notably, because of shyness and embarrassment (Diiorio et al. 2003). This is the case, for example, in Kenya (Crichton et al. 2012), Nambia (Nambambi & Mufune 2011), Scotland (Ogle et al. 2008), the US (Afifi et al. 2008), and Vietnam (Trinh et al. 2009). However, to our knowledge, studies have not yet explored extensively the question of choice and autonomy of young people to access SRHS, as in the present research. As previously mentioned, research in different cultural contexts has shown that adolescents prefer privacy and confidentiality when SRHS are concerned (e.g., Lehrer et al. 2007). It would be pertinent for research to explore the relationship between parents' discussions about sex education and adolescents' access to SRHS.

Our study demonstrates that one possible way to foster the autonomy of Colombian youth to access health services, and specifically SRHS, would be through providing comprehensive sex education to their parents. Comprehensive sex education to parents should thus be seen as a complementary measure to the sex education provided to young people in school. While not investigated in the context of this research, it may be the case that discussing the question of autonomy (i.e., making choices) and access to SRHS may be less suitable in a classroom context, in some countries or cultures, and so be more appropriately addressed through discussions between parents and their children.

#### Recommendations

The study findings enable us to propose two major recommendations.

## The need for further research on parental views of young people's autonomy

Research should be conducted with Colombian parents to determine whether 1) they would want to receive comprehensive sex education, and 2) they would want to talk about sexual and

reproductive health with their children. While Colombian youth might want to discuss sex with their parents, it is possible that their parents are either not interested or uncomfortable discussing this topic, and so might (or might not) prefer teachers, health professionals, or other educators to be responsible for providing sex education (or abstinence) to their children. Documenting parental views on the topic would allow for the development of initiatives that also take into consideration their preferences, and not only the perspectives of young people.

#### Empirically test the public health effects of comprehensive sex education

It would be pertinent to empirically test and validate the public health effects and efficacy of providing comprehensive sex education to parents of Colombian youth. Previous studies in the United States have shown that involving the family in young people's sex education can have positive results (Grossman et al. 2013; Grossman et al. 2014). One possible option would be to conduct a prospective cohort study. In one geographical region, comprehensive sex education could be provided to parents of adolescents (exposed group) and a neighboring region could be the control group where no sex education is provided to parents. Various outcomes could be measured longitudinally to explore whether providing comprehensive sex education to parents leads to positive health outcomes for young people, e.g., level of access to SRHS and use of contraceptives, adolescent pregnancy rates, and rates of HIV/STI testing.

#### Limitations

A non-negligible limit of our study is representation bias. The opinions and experiences of the participants might not reflect those of the other youth populations of Colombia (e.g., the Caribbean coast has a different cultural context than the departments of Antioquia and Valle del Cauca). Also, it is important to note that most participants were older, thus younger adolescents (e.g., under 14 years old) might have different views on the topic. While most participants expressed a certain enthusiasm regarding their parents receiving comprehensive sex education to enable better discussion of the topic, this attitude may not be shared amongst the rest of young people in Colombia.

Further, some participants were less at ease expressing themselves during the interviews. The researcher would use keywords to invite participants to develop their answers (e.g., "could you *expand* or *elaborate* this idea?") but some participants still kept their answers short. As a result, the researcher had to reformulate questions to be more direct. For example, if the participant did not know what topic could be part of sex education for their parents, the researcher would present suggestions; the participant could then confirm whether they agreed. In terms of data collection, this can engender a certain bias since the possible answer to the questions were first presented by the researcher as opposed to being generated by the participant.

Finally, another limitation is the potential of desirability bias: some participants might have responded to questions with what they believed to be a "good answer," or because they wanted to please the researcher, who is not Colombian. Conversely, the fact that the researcher was a foreigner might have helped participants feel more comfortable sharing their beliefs, since the researcher did not belong to the local community and thus could be seen as impartial.

## Conclusion

The main goal of this study was to explore issues raised by the fostering of Colombian youth's autonomy to access SRHS. Through the methodological approach of semi-structured interviews with young people, most participants expressed their wish for their autonomy to be fostered to access SRHS, including 1) the participation of their parents in decision making, and 2) the provision of comprehensive sex education to their parents to facilitate discussions. These findings contradict the initial assumption, based on the literature in different cultural contexts, that participants would not want their parents involved in fostering their autonomy to access SRHS.

There may be specific cultural reasons behind these findings related to young Colombian people (and their parents) that might not apply to other countries or cultural contexts (e.g., North America). Hence, it would be pertinent to do more in-depth research (e.g., interviews) with Colombian parents to further examine the issue. But it would also be pertinent to conduct similar research with young people (and their parents) in other cultural contexts, to see whether there

is a need for more nuance in understanding *why* and *how* young people may or may not want parental involvement or support in autonomous decision making related to accessing SRHS.

Adolescence is a culturally diverse concept, and adolescent autonomy evolves over time and varies between individuals. Our findings show that fostering adolescent autonomy should be seen as a multi-stakeholder project. With a view to supporting the practical and effective implementation of the WHO's AA-HA! initiatives to foster young people's autonomy in access to SRHS, we argue that critically important lessons can be learned when we listen to the voices of both young people and their parents and include them in evidence-based policy making.

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## Article V: Questioning the Pertinence of Parental Consent Requirements for Adolescents to Access Sexual and Reproductive Health Services

Brisson, Julien. (under review). Clinical Ethics

#### Abstract

This article challenges the pertinence of mandatory parental consent requirements for adolescents' access to sexual and reproductive health services (SRHS). The main argument is that in the specific context of SRHS (contraceptives, abortion, testing and treatment of sexually transmitted infections), adolescents' autonomy should be respected if they request to access those services independently – i.e. parental consent should not be mandatory. Three points are presented to support this argument: 1) There is a lack of objective evidence to determine when a person can start to have their full autonomy respected in healthcare and consent to health services while no longer requiring their parents to make healthcare decisions for them; 2) Empirical evidence is lacking that parental consent requirements actually protect adolescents' health and wellbeing when accessing SRHS (on the contrary, empirical data demonstrate that parental consent requirements can be a serious barrier for adolescents to access needed SRHS); and 3) Empirical evidence is also lacking that parents (simply as parents) are inherently in a better position (i.e. in possession of relevant competencies) than healthcare professionals or adolescents themselves to determine what is best for adolescents' sexual and reproductive health. The article calls for developing measures (e.g. training health professionals to be 'adolescent-competent') to ensure adolescents have the necessary resources (e.g. adequate knowledge) to make informed decisions when requesting to access SRHS independently.

**Keywords:** adolescent, autonomy, bioethics, consent, parental consent, sexual health

#### Introduction

In 2017, the World Health Organization's (WHO) Global Accelerated Action for the Health of Adolescents (AA-HA!) highlighted the need to determine appropriate and acceptable age limits for adolescents' consent to treatment and access to health services without parental involvement (WHO 2017). There is ample literature in bioethics exploring the ethical issues associated with patient consent and autonomy in healthcare. However, many questions about

the nature of adolescent autonomy and the appropriateness of certain parental consent laws in healthcare are still unresolved and are the subject of ongoing debate (Priest 2019; Salter 2017). Since no biological markers determine when one becomes an adult, determining the age at which a person should be free of the need for parental consent for health-related decisions is ethically complex.

The present article explores aspects of the ethical question regarding the specific case of adolescents' access to sexual and reproductive health services (SRHS). The main argument is that in the exclusive context of SRHS - e.g., abortion, contraceptives, testing and treatment for sexually transmitted infections (STIs) – adolescents' autonomy should be respected if they request to access those services independently, and parental<sup>8</sup> consent should not be automatically required. The principle of autonomy in this context refers to the notion of having one's body integrity, choice and preference respected in healthcare decisions, as is commonly understood in principlism approaches in clinical ethics (Beauchamp & Childress 2001). As developed below, the respect for adolescents' autonomy in this case recognizes the intrinsic ethical value behind the principle of autonomy as the respect of the patient's self-determination. Historically, patients did not always have respected their right to be active participants in healthcare decisions (i.e., medical paternalism). The field of bioethics was critical in advocating for such changes and contributed to a move to patient-physician collaborative decision-making. The reason for choosing SRHS for this article is that they tend to be of sensitive nature for adolescents compared to other types of health services (e.g., dermatology, optometry, physiotherapy). Those services are also usually the primary services provided in sexual health clinics (e.g., Planned Parenthood in the United States, Profamilia in Colombia) and have considerable public health implications.

Three main points are presented to support the argument: 1) Objective evidence is lacking to determine the age at which a person can start to have their autonomy respected in healthcare and also consent to health services while no longer needing their parents to make healthcare

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<sup>&</sup>lt;sup>8</sup> Throughout the article, the expression "parental" consent is used; however, it also applies to legal guardians.

decisions for them; 2) Empirical evidence does not support the claim that parental consent requirements protect adolescents' health and wellbeing when accessing SRHS; and 3) There is no proof that parents (simply as parents) are inherently in a better position (i.e., in possession of relevant competencies) than healthcare professionals or adolescents themselves to determine what is best for an adolescents' sexual and reproductive health.

It is critical to highlight that the purpose of this article is not to advocate for completely eliminating parental consent requirements in adolescent healthcare or to suggest that parental involvement regarding their adolescent children's autonomy is inherently problematic. For example, research in Colombia showed that most adolescent participants appreciated, to varying degrees, the involvement of their parents to access SRHS (Brisson et al. 2021). Some adolescents stated that they wanted their parents to accompany them to a sexual health clinic but wait outside the room to respect the adolescent's privacy with the healthcare professional. Other participants reported wanting the assistance of their parents in choosing a contraceptive option but make the final decisions independently. As such, parental involvement can be beneficial for some adolescents to access SRHS (e.g., as a form of support). Instead, this article discusses the need for greater attention to be given to developing ethically adequate policies to respect adolescents' autonomy in healthcare and respond to an urgent global health problem: adolescents' low use of SRHS (Mazur et al. 2018). The article presents some shortcomings in current parental consent requirements in adolescent healthcare, followed by potential solutions that can promote adolescents' wellbeing, dignity, and protection. Given AA-HA!'s international scope, rooted in the United Nations' Sustainable Development Goals, the present argument is not attached to any specific country and does not address the diverse particularities around parental consent laws for countries across the globe.

## Challenges in Defining Adolescence and the Start of Adulthood

There is no clear, consistent or universal definition of adolescence, which is a recent invention in the history of humankind (Bedin 2011). The term adolescence first appeared in the 15<sup>th</sup> century, from the Latin *adolescere*, meaning "to grow into maturity" (Lerner & Steinberg 2009; Sawyer et al. 2018). However, only in the 19<sup>th</sup> century did adolescence start to become understood as a

distinct life stage (Rozzi 2014). The bourgeoisie and the aristocracy first made this distinction before the term transitioned into the working class in the 20<sup>th</sup> century. Prior to the 19<sup>th</sup> century, European populations did not have a concept for adolescence; individuals went directly from the status of child to adult (Ariès 1960). In the American context, adolescents were simply seen as "inferior adults" as opposed to a separate social category (Moran 2002).

Adolescence emerged as a distinct life stage in the 20<sup>th</sup> century because of industrialization, progress in medicine, improvements in nutrition, advances in public health and, most importantly, greater access to education, which allowed for the period of childhood to be extended by having children depend economically on their parents for longer (Catalano et al. 2012; Frota 2007). It is critical to highlight that the concept of adolescence is foremost a Eurocentric invention, as many cultures worldwide do not have a similar concept of adolescence: people are either categorised as children or adults. For example, there is no tangible concept of adolescence in India, nor is there a word equivalent to 'adolescence' in Indian languages (Burra 2014).

The typical benchmark of 18 years old to define someone as an adult is arbitrary. In bioethics, it is usually agreed that an adult patient (because they are an adult) inherently has autonomy regarding healthcare decisions (Mahowald 2006). In some contexts, the starting age for consent in healthcare is lower, such as 14 years old in the province of Quebec, Canada (Quebec Civil Code 1991). However, there is no consensus in bioethics on the age at which humans can start to consent to healthcare decisions or have their full autonomy respected. Nor are there concrete markers to determine, from an ethical standpoint, when young people can stop having someone else (e.g., parent, legal guardian) make healthcare decisions for them. In other words, in bioethics, there are no clear or widely accepted indicators – whether in terms of chronological age or competency – for when it is unethical to demand parental consent for an adolescent to make healthcare decisions.

In parallel, no objective or specific indicators (i.e., biological markers) exist to define when adolescence ends and adulthood begins (Arnett & Taber 1994; Dahl et al. 2018). This lack of

coherence in defining adolescence and the start of adulthood influenced the introduction of a new definition of adolescence in global health: adolescence is now defined as 10–24 years old (Sawyer et al. 2018). The main reason for extending the definition is to adequately understand the transition from childhood to adolescence and from adolescence to adulthood, making this methodological reason particularly relevant to the field of bioethics when exploring ethical questions around consent and patient autonomy. As shown in neuroscience studies, the adolescent brain is capable of complex problem-solving equal to that of adults, which suggests that adolescents can have decision making capacity in healthcare (Steinberg 2014; Steinberg et al. 2009). It is the reason why adolescents can display high levels of maturity in some areas and situations yet be immature in other instances. Nonetheless, recent neurological studies have also shown that the brain continues to mature well into the mid-20s, which challenges the popular notion in bioethics and law that one is an adult and fully cognitively mature from 18 years old (Drobac 2011).

This lack of coherence and consensus for defining adolescence and specifying a specific chronological age to determine the maturity to make decisions serves as a strong point for the article's argument. If a 23-year-old woman were to ask her healthcare provider for contraceptives and they were to ask for the consent of the patient's parent, this would easily be understood as unethical. It would violate the woman's basic right to bodily autonomy to choose to use contraceptives. However, if a 13-year-old girl were to ask for contraceptives for the same reasons as the 23-year-old (e.g., to prevent an unwanted pregnancy), why should she need her parents' consent to start using contraceptives? Why should it be deemed ethically acceptable to limit part of the adolescent's autonomy in this case because of her age?

It could be argued that the purpose of the parental consent requirement is to protect adolescents. While a valid point in many contexts, as explained in the next sections, empirical evidence is lacking to support the view that parental consent requirements for adolescents to access SRHS actually protect adolescents. On the contrary, data indicate that parental consent requirements can be a serious barrier for adolescents to access needed SRHS (Bortello et al. 2018;

Garney et al. 2021), which represents a serious ethical issue since not accessing needed health services constitutes a form of harm and has considerable public health implications.

# Lack of Empirical Evidence of the Protective Effects of Parental Consent Requirements to Access SRHS

Does having a minimum legal age for waiving parental consent in healthcare best protect adolescents' health and wellbeing? There does not appear to be a clear answer. Worldwide, there are many different minimum legal ages for adolescents to access health services with or without parental consent. For example, in Malawi, the minimum legal age to be tested for HIV without parental consent is 13 years old (McKinnon & Vandermorris 2019), while in Guatemala, one needs to be at least 18 years old (UNICEF 2016). Due to the stricter parental consent requirements, do adolescents in Guatemala have better sexual health and wellbeing than adolescents in Malawi (e.g., are they tested and treated faster after HIV infection)?

Evidently, various factors greatly influence adolescents' access to SRHS beyond the simple question of parental consent requirements (e.g., costs, clinic location and hours, knowledge of available services, cultural perspectives on sex and access to comprehensive sex education), making it challenging to answer the question. Nonetheless, empirical literature on the topic strongly hints that parental consent requirements and lack of respect for adolescent patient confidentiality can be significant factors in preventing adolescents from accessing needed SRHS. This phenomenon has been observed in various cultural contexts – e.g., the UK (Garside et al. 2002), Ethiopia (Muntean et al. 2015), India (Sivagurunathan et al. 2015), the USA (Fuentes et al. 2018; Lehrer et al. 2007) and South Africa (Vujovic et al. 2014). In parallel, however, there appears to be no empirical findings demonstrating that parental consent requirements to access SRHS ameliorate or provide concrete protective effects on adolescents' health and wellbeing. In other words, data do not suggest that because of the need for parental consent, adolescents will be more prone to access SRHS as needed.

As such, if the purpose of parental consent requirements for adolescents to access SRHS is intended to protect adolescents' wellbeing, there should be robust empirical data to support this

position. For example, one would expect to see a greater use of SRHS by adolescents in countries with stricter parental consent requirements compared to countries with more liberal parental consent policies. This lack of empirically based knowledge means that health policies and clinical norms are likely often grounded in particular world views or cultural or religious beliefs; they may, in fact, be ill-suited to provide optimal healthcare for adolescents and promote their wellbeing. This situation is ethically unacceptable and raises issues that should be addressed – i.e., transparency of reasons for particular parental requirements, supported by empirical evidence – in order that policies that directly affect the health and well-being of adolescents be reasoned, evidence-based and ethically justified.

On the one hand, parental consent requirements (and lack of respect for adolescent patient confidentiality) have been empirically shown to prevent adolescents from adequately accessing needed SRHS, meaning that parental consent requirements may have some harmful public health repercussions (Fuentes et al. 2018; Carlisle et al. 2006; Copen et al. 2016). On the other hand, there appear to be no studies that demonstrate concrete beneficial public health effects of parental consent requirements for adolescents to access SRHS; such evidence would allow us to weigh the pros and cons of parental consent requirements for the wellbeing of adolescents to access SRHS and subsequently adopt policies based on the findings. From a consequentialist approach – and particularly from a public health perspective – there is an ethical imperative for policies to be effective in ameliorating the health of populations (Schröder-Bäck et al. 2014). Nonetheless, in the present context, this absence of counterevidence supports the argument for challenging the pertinence of parental consent requirements for adolescents to access SRHS.

### The Question of Protecting Adolescents

One of the main arguments in favour of parental consent requirements for adolescents to access SRHS is to protect adolescents. Indeed, it is a critical point: adolescents constitute a more vulnerable population than adults, and measures are needed for their protection. It is clearly reasonable to require parental consent to decide for adolescents in specific healthcare contexts, especially when it involves high risks (e.g., choosing a treatment option in oncology). However,

in the precise context of SRHS, it is important to recognize that contraceptives, abortions and the testing and treatment of STIs are relatively safe for adolescents (i.e., pose a similar level of risk as for adult patients), and healthcare professionals are normally trained in how to provide these services in an appropriate fashion, given their sensitive nature. Nonetheless, it is critical to reflect on the pertinence of requiring parental consent to protect adolescents for each specific SRHS.

#### **Abortion**

In what context would it be ethically acceptable to force an adolescent to carry a pregnancy to term because her parents do not consent for their daughter to have an abortion? If one is serious about protecting adolescent health, then requests for and access to safe abortion services should be approved, regardless of the parents' views, thus rendering parental consent requirements unnecessary in this specific context. The reasoning behind parental consent requirements in healthcare is to prevent adolescents from making harmful decisions. However, there are no medical benefits for adolescents to carrying to term a pregnancy they want to terminate. Forcing an adolescent to bear a child they do not want to respect a parent's wish is a form of abuse; the same ethical arguments supporting an adult women's choice to terminate a pregnancy apply to adolescent girls. Some might argue that an adolescent may regret having had an abortion, hence the argument for parents to decide for their adolescent if the adolescent should carry the pregnancy. However, the adolescent may also regret not having had an abortion, which renders the "regret argument" impertinent in this context. The question of abortion for adolescents invites us, then, to reflect on the question of adolescents' ability to access contraceptives, notably, to prevent unwanted pregnancies.

#### **Contraceptives**

Worldwide, one of the leading causes of death for adolescent girls is childbirth and pregnancy complications (Dillon & Cherry 2014; Chandra-Mouli et al. 2014). This reality is completely unacceptable and could be prevented to a great extent if adolescent girls had easier access to contraceptives. Adolescents' lack of access to contraceptives thus constitutes a concrete global health problem. That said, in what context would it be ethically acceptable that an adolescent

girl who could benefit from contraceptives should be forbidden to use them because her parents do not consent? Some may argue that an adolescent girl may not be ready to engage in sexual relations (e.g. in terms of psychological maturity), hence the argument to restrict contraceptive access. However, it is critical to note that even if the parent refuses permission for their daughter to use contraceptives, she could still engage in sexual relations without contraceptives and subsequently be exposed to the risk of an unwanted pregnancy, which can put her in harm's way. As such, if an adolescent girl wishes to use contraceptives, her request should be respected without depending on her parents' approval, hence the argument of not needing parental consent for adolescents who wish to use contraceptives is logical.

#### Testing and Treatment of STIs

What could justify an adolescent not being treated for an STI treated because their parents forbid it? There are no ethically justifiable reasons to not treat an STI. If adolescents require STI treatment, they have an important health problem with both individual and populational implications, and so both as a matter of human dignity and beneficence (individual and population health), they should receive treatment. If parents were to oppose the treatment of an STI for their adolescent children, this would constitute a form of harm, and even parental negligence. Based upon this argument, a parental consent requirement for an adolescent to be tested and treated for an STI is unjustified – adolescents should always be able to be tested and treated for an STI without requiring parental consent.

Abortions, contraceptives and STI treatments can potentially have harmful outcomes for adolescents (e.g., undesirable side effects). Nonetheless, healthcare professionals are arguably in a better position to make the clinical judgment to address those risks than parents, because the former healthcare professionals have the qualifications and experience to make such assessments. As mentioned above, one of the major reasons supporting parental consent requirements is that parents are deemed best placed to make informed decisions on behalf of their adolescents, which can certainly apply in different contexts. However, having the title of

parent does not translate into knowing which treatment would be best to treat an STI or which contraceptive option to choose for the adolescent.

The question of adolescents' sexuality is a true embodiment of the principle of autonomy. Everyone's preferences are unique, and only adolescents themselves can pronounce themselves on the decisions they want to make for their sexual and reproductive health, and it is unethical to coerce others to make decisions regarding their sexuality and reproduction they do not want to make. A parallel can be made with gender. For example, concerning trans youth's ability to make decisions in paediatric transgender healthcare, decisional authority should generally lie in the young patient. The reasoning is that gender uniquely pertains to a person, as such, others (e.g. parents, healthcare professionals) are rarely better positioned to make decisions regarding a youth's true gender than the youth themselves – i.e. others cannot decide what the gender of an adolescent is. The same ethical argument applies to adolescents' access to SRHS; parents are not in a position to decide what is best for the sexual and reproductive health of the adolescent other than the adolescent themselves with their healthcare professional - e.g. an adolescent wanting to start using contraceptives to prevent an unwanted pregnancy. With the objective of protecting adolescents' health and wellbeing, the focus must be on ensuring that adolescents have access to adequate knowledge and resources to make an informed decision regarding their sexual and reproductive health with their healthcare provider.

# **Protection from Abuse**

An adolescent presenting at SRHS could be a victim of sexual abuse. Consequently, healthcare professionals should be trained to address the issue in a sensitive manner and to protect adolescents (e.g., by involving the relevant authorities). Nonetheless, as shown above, parental consent requirements can be a barrier for an adolescent to access SRHS, especially if the adolescent does not feel safe discussing their situation with their parents. It is pertinent to question a reliance on parental consent requirements as a form of protection for adolescents and instead explore alternative measures that could be implemented to protect adolescents who

wish to access SRHS independently. In other words, the parental consent requirement to access SRHS should not be seen as *the* solution to address or prevent the abuse.

# Discussion

Parental consent requirements can be very pertinent in many contexts. For example, in clinical research involving high risks for adolescent participants, parents can help make informed decisions with the adolescent. Nonetheless, as discussed above, there are in some situations, important shortcomings to parental consent requirements for adolescents, notably with regard to access to SRHS. However, removing parental consent requirements is not a magic bullet solution to address the urgent and critical global health issue that adolescents, worldwide, do not access SRHS as needed (WHO 2017). This global health problem is reflected, for example, in the fact that adolescents are the only age group in which AIDS-related deaths are rising instead of decreasing as in the other age groups (Bekker et al. 2015; Bekker et al. 2018). Nonetheless, even if parental consent requirements were removed globally, this measure would not automatically lead to adolescents accessing SRHS; as mentioned above, many factors prevent adolescents from accessing these services. From a bioethics perspective, it is critical to go beyond simply criticizing policies and explore possible solutions.

# Training Adolescent-Competent Health Professionals and Adopting a Decision-Making Capacity Approach

The reasoning of minimum age for parental consent requirements in healthcare is rooted in the logic that once an adolescent reaches a specific chronological age (e.g. 16 years old), they are automatically able to consent independently to healthcare services. However, it is essential to challenge this logic. In order for a patient (adolescent or adult) to be able to consent to healthcare services genuinely, they need to have been presented with all the necessary information to make an informed decision. Reaching a chronological age may mean that one has the capacity to consent to healthcare services; however, it does not lead to instinctively knowing the necessary information to make an informed decision. Hence, instead of naively relying on a chronological age as a marker to determine when an adolescent should have their autonomy respected to

access SRHS, the focus should be on healthcare professionals ensuring patients (adolescents and adults) have the necessary information to make decisions.

In the province of Ontario, Canada, there is no stated age of consent in healthcare. Ontario's (1996) *Health Care Consent Act* suggests that all people (which include adolescents) are presumed to have the capacity to make healthcare decisions, such as having the ability to understand the implications and consequences of a healthcare service. As such, instead of assuming that a patient can automatically start to consent upon reaching a specific chronological age, and then have their autonomy respected by default (the logic with minimum age for parental consent policies), Ontario's *Health Care Consent Act* calls for the healthcare professional to make sure the patient comprehends the risks of a treatment in order to make an informed decision. As such, healthcare workers must be trained to be adolescent-competent (Sawyer & Baltag 2014). This can translate into spending more time with adolescent patients to explain in greater detail the services involved to help the adolescent make an informed decision (e.g. choosing a contraceptive option). Hence, greater efforts must be invested in the training of healthcare professionals on how to attend to adolescent populations, notably, when they are seeking access to SRHS.

# **Training Parents**

While the present article sometimes paints parental consent requirements negatively, it is critical to recognize that parents can be an essential resource to help adolescents access the SRHS they need. For example, some adolescents might erroneously believe that their parents will disapprove of the adolescent's choice to start using contraceptives and as a result avoid accessing a clinic. Parents should have access to the educative resources for discussing sexual and reproductive health with their adolescent children and help them access the SRHS they need and support them in their decisions. For example, clarify to their adolescent that they can schedule and accompany them to their appointment but wait for them in the waiting area to respect their privacy with the healthcare professional.

# **Flexibility**

It is not uncommon during adolescence for the parent-child relationship to experience turmoil (Smeta & Rote 2019). Consequently, the adolescent might be distant from their parents and avoid discussions with them (particularly on a sensitive topic like sexual and reproductive health). This challenging period should not be a reason for adolescents not to access the SRHS they need and want because they do not wish to ask their parents' permission to access such services. However, the adolescent might feel reassurance if another family member (e.g. an aunt, cousin or older sibling) or an adult that they trust (e.g. a school teacher or social worker) helps them access SRHS. Healthcare professionals should welcome the adolescent's choice to involve another adult as a form of support to make informed decisions, even if they are not their parents.

Finally, it is critical to recognize that adolescents who could benefit from SRHS but do not access such services should be framed as a more critical problem than adolescents accessing SRHS without parental consent. If adolescents seek SRHS and request that their parents not be involved, this request should serve as a solid basis for respecting their autonomy in this specific context. Thus, there is a need to challenge the pertinence of parental consent requirements and explore different opportunities to foster adolescents' access to the SRHS they need and want.

There are evident consequentialist reasonings to support the aforementioned arguments (e.g. public health implications) to respect adolescents' autonomy to access SRHS without requiring parental consent. For example, if adolescents do not access STI treatment, there can be STI transmission to others. However, we need to be careful to not root adolescents' access to SRHS on the condition of potential detrimental public health consequences, as doing so neglects the autonomy (e.g. human dignity) adolescents are entitled to. It is essential to recognize the positive side that an adolescent wants to take care of their health (Wenner & George 2021) and must ensure they are given all the necessary tools to make informed decisions when they are asking to access SRHS independently.

# Conclusion

The United Nations' Sustainable Development Goals involving adolescents need to be reached within less than a decade, i.e., by 2030 (UN 2015). This would include creating a world where adolescents can exercise their rights to physical and mental health and wellbeing. However, without robust empirical evidence regarding the protective or harmful effects of parental consent requirements in different healthcare contexts, it will be difficult, if not impossible, to measure and achieve these goals. Researchers should, therefore, develop appropriate methodologies and measures to investigate the question of parental consent in healthcare for adolescents. Only with the resulting robust empirical data will it be possible to effectively guide the development of appropriate and just policies that promote adolescents' wellbeing in healthcare. In the meantime, however, it is still possible to advance with policy change by recognizing the force of the above ethical critiques that show that rarely will it be ethically justifiable to require parental consent for adolescents' access to SRHS. Instead of relying on parental consent as a panacea to protect the health and wellbeing of adolescents accessing SRHS, efforts are needed to create easier access to SRHS for adolescents that want to use those services. Simultaneously, we need to make sure that adolescents possess the necessary tools (e.g. access to adequate information, adolescent-competent health professionals) to make informed decisions and have their autonomy respected regarding their sexual and reproductive health.

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Article VI: Accompagner l'autonomie des adolescents par les Commissariats aux

plaintes et à la qualité de services dans le réseau de la santé

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Résumé

La question de l'autonomie des adolescents dans leurs décisions de santé est un enjeu éthique

complexe, notamment pour les adolescents dans des contextes sociaux précaires. L'autonomie

émergente des adolescents doit être respectée. Néanmoins, les adolescents constituent un

groupe vulnérable nécessitant des mesures de protection et la restriction de leur autonomie est

parfois justifiée. Les exigences en matière de consentement parental peuvent s'avérer un

obstacle sérieux pour certains adolescents qui souhaiteraient accéder à des services de santé

sans l'implication de leurs parents. L'accès aux contraceptifs et le dépistage d'infections

transmises sexuellement sont des exemples communs de cet enjeu. Le présent article de nature

conceptuelle propose que les commissaires aux plaintes et à la qualité de services – tels que

définis par la loi au Québec – puissent accompagner l'autonomie des adolescents dans leurs

démarches vers l'accès aux services de santé, dans des contextes où le consentement parental

se présenterait comme une barrière. Les commissaires, comme entités indépendantes,

pourraient accompagner les intérêts de l'adolescent pour s'assurer qu'il accède aux services

requis. Pour illustrer notre propos, nous présentons deux cas fictifs d'adolescents en situation de

vulnérabilité.

Mots clés: adolescents, autonomie, commissaire aux plaintes, consentement, santé, médiation

Introduction

À l'échelle mondiale, les adolescents sont l'un des groupes qui ont fait le moins de progrès en

matière de santé avec les avancées en développement international en termes de droits de la

personne et en développement économique des pays émergents (Patton et al. 2016). Il existe

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plusieurs raisons derrière ce phénomène. Par exemple, les adolescents ne savent pas comment utiliser les services de santé dans leur communauté et ils se butent à différents obstacles pour accéder à ces services, dont le besoin d'un consentement parental (Mazur et al. 2018 ; Patton et al. 2012 ; Patton et al., 2016). Ces différents enjeux sont intimement liés à l'autonomie des adolescents.

En 2015, les Nations Unies ont introduit les Objectifs de développements durables (ODD) à être atteint pour 2030 (Every Woman Every Child 2015; United Nations 2015). Par rapport aux ODD concernant la santé, les adolescents ont été inclus comme un groupe requérant une attention urgente pour améliorer leur santé et leur bien-être. Ensuite, en 2017, l'Organisation mondiale de la santé (OMS) présenta l'Action mondiale accélérée en faveur de la santé des adolescents (AA-HA!) pour aider à répondre aux ODD reliés à la santé des adolescents (OMS 2017). L'AA-HA! souligne la nécessité de nouveaux moyens pour accompagner l'autonomie des adolescents dans l'accession à des services de santé, pour promouvoir leurs droits (OMS 2017 : 93). Cependant, une certaine ambiguïté demeure au sujet de la manière de mener ce projet (Brisson et al. 2021).

Les disparités d'accès aux services de santé des adolescents causés par la nécessité d'un consentement parental représentent un enjeu éthique important. Par exemple, au niveau mondial, les complications en lien à la grossesse et l'accouchement constituent l'une des causes principales de décès pour les adolescentes (Chandra-Mouli et al. 2014). Ce phénomène pourrait être atténué si les adolescentes avaient une plus grande facilité d'accès aux services de santé reproductive et à la contraception. Il est démontré dans la littérature que le besoin de consentement parental et le manque de respect pour la confidentialité des adolescents sont des barrières critiques pour les adolescents dans l'accès à des services de santé (Bortoletto et al. 2018; Fuentes et al. 2018; Hasselbacher & Truehart 2021; Lehrer et al. 2007). L'objectif de cet article de nature conceptuelle est de présenter une stratégie pour mitiger ces disparités. Plus précisément, il propose que les bureaux d'examen de plaintes ou de médiation (ex. : « ombudsman »), tels que les Commissariats aux plaintes et à la qualité de services (CPQS) au Québec, puissent accompagner l'autonomie des adolescents pour accéder à des services de santé lorsque le besoin de consentement parental se présente comme une barrière. Ce travail ne

se rattache pas à une région géographique particulière, considérant la portée internationale de la recommandation de l'OMS.

En raison des particularités légales de chaque pays en lien avec le consentement parental et le régime d'examen des plaintes, il est possible que l'approche proposée nécessite des modulations selon le contexte régional. D'un point de vue éthique, il n'y a pas d'âge précis pour déterminer à partir de quand un adolescent peut consentir à ses propres soins sans l'apport de son parent ou gardien légal. Cette ambiguïté est observable, notamment, par les différents âges minimums légaux de consentement aux soins. Par exemple, dans la province du Manitoba (2022), selon la Loi sur les directives en matière de soins de santé, une personne de 16 ans peut consentir à des soins de manière autonome. Au Québec (2021), selon le Code civil, c'est à partir de 14 ans. Toutefois, il existe des exceptions. Par exemple, au Québec, il faut avoir au moins 18 ans pour faire une demande d'aide médicale à mourir (Lepizerra et al. 2021). En Ontario (2021), selon la Loi de 1996 sur le consentement aux soins de santé, il revient au clinicien de déterminer au cas par cas si un adolescent est apte à consentir à des soins et services.

Il est important de clarifier que nous ne proposons pas que les CPQS doivent consentir à la place des adolescents ou qu'ils puissent remplacer le consentement parental. Toutefois, nous suggérons que les CPQS puissent être une ressource utile pour répondre à ce problème concret qui implique différents enjeux éthiques, particulièrement en lien à l'accompagnement de l'autonomie des adolescents pour accéder à des services de santé.

Pour soutenir notre position, nous étayons en premier lieu les caractéristiques des CPQS au Québec pour démontrer leur applicabilité éthique en matière d'accompagnement de l'autonomie des adolescents pour accéder à des services de santé. Ensuite, nous illustrons la pertinence et la mise en application de notre position à l'aide de deux cas fictifs. Finalement, nous présentons une discussion sur les implications éthiques de ce que nous présentons.

# Caractéristiques éthiques du régime d'examen des plaintes

Les activités des CPQS au Québec sont encadrées par la *Loi sur les services de santé et les services sociaux* (LSSSS). La mise en place des CPQS possède un contexte particulier en matière de respect de l'autonomie des usagers (ex. : patients) de services sociaux et de services de santé. Les CPQS ont été développés dans les années 1980 (LSSSS 2021) afin de permettre aux usagers de services de santé et services sociaux de se prononcer (plaindre) sur les soins et services qu'ils reçoivent (Leblanc 2010). Nous présentons des caractéristiques éthiques des CPQS au Québec comme entité qui pourrait accompagner l'autonomie des adolescents à accéder à des services de santé : indépendance, transparence, centralisation, protection et pragmatique.

# Indépendance

Au Québec, selon la LSSSS, les commissaires doivent être indépendants des établissements pour lesquels ils ont compétence. En d'autres mots, les employés des CPQS ne peuvent occuper d'autres fonctions au sein des établissements. Le but est d'assurer le plus d'objectivité et d'impartialité possible envers les patients dans les fonctions du bureau, ce qui favorise, entre autres choses, la justice épistémique (Lemoine et al. 2022).

Cette quête pour l'indépendance des commissaires a été observée au Québec avec l'entrée en vigueur en juin 2021 du projet de loi 52 (Loi visant à renforcer le régime d'examen des plaintes du réseau de la santé et des services sociaux notamment pour les usagers qui reçoivent des services des établissements privés). Les commissaires des établissements publics sont devenus responsables des plaintes des usagers des établissements privés de leur territoire. Sur le plan de l'éthique, cette nouvelle approche cherche à instaurer une plus grande impartialité du fait que les commissaires ne reçoivent pas de salaire des établissements sur lesquels ils doivent examiner les pratiques. En d'autres mots, avant l'introduction du projet de loi 52, un établissement privé payait un commissaire pour faire l'examen des plaintes de son établissement, d'où un plus grand risque de manque d'impartialité. Toutefois, le but du projet de loi 52 est de limiter les conflits d'intérêts dans l'examen des plaintes, ce qui est une initiative éthique en soi-même, avec l'objectif d'être le plus juste et équitable envers les usagers (Boyce & Davids 2009).

Il est essentiel de noter que même si les CPQS sont des entités indépendantes, les usagers ont aussi le droit de recours au Protecteur du citoyen du Québec. Le Protecteur du citoyen du Québec est également une entité indépendante publique qui a le mandat d'examiner les activités des CPQS et qui peut ensuite émettre des recommandations si cela est jugé nécessaire. Les patients ont recours au Protecteur du citoyen du Québec lorsqu'ils ont déposé une plainte en première instance auprès d'un CPQS et qu'ils ne sont pas satisfaits de la gestion de leur plainte. Ce système d'indépendance à deux instances fait en sorte d'assurer un mécanisme de surveillance accrue et de permettre que les patients aient leur voix entendue, soit en première instance par le CPQS et ensuite en deuxième instance, si nécessaire, avec le Protecteur du citoyen du Québec. Un tel système respecte le principe d'autonomie, tel par l'autodétermination pour les patients (Lemoine et al. 2022). Ainsi, si un CPQS n'a pas des pratiques adéquates envers un patient, celuici peut communiquer avec le Protecteur du citoyen du Québec pour qu'il examine la situation pour s'assurer que les droits du patient sont respectés.

En ce qui concerne la question d'accompagner l'autonomie des adolescents à accéder à des services de santé, l'indépendance du CPQS des établissements de santé fait en sorte de promouvoir le bien-être et les intérêts du jeune patient et non pas ceux des employés ou de l'établissement en question. Le fait d'avoir la mise en place d'une deuxième instance indépendante comme le Protecteur du citoyen du Québec fait en sorte que ce dernier pourrait faire enquête sur les actions des CPQS dans leur accompagnement de l'autonomie des adolescents à accéder à des services de santé.

#### Transparence, centralisation et protection

Toutes les activités des CPQS sont documentées dans le logiciel ministériel *Système d'information de gestion sur les plaintes et sur l'amélioration de la qualité des services* (SIGPAQS), que ce soit un appel téléphonique, un courriel, l'ouverture d'un dossier de plainte ou bien d'une intervention en maltraitance. Les CPQS au Québec sont responsables de prendre les signalements de maltraitance envers les aînés et toute autre personne majeure en situation de vulnérabilité sur leur territoire assigné. Cette structure fait en sorte, entre autres, de centraliser la documentation dans SIGPAQS des plaintes et des cas de maltraitance et d'assurer le suivi de la qualité de services

sur le territoire en identifiant des enjeux systémiques (récurrents) et permettre d'émettre des recommandations aux gestionnaires concernées.

Cette centralisation des services sur un territoire est un effet du projet de loi 10 (Loi modifiant l'organisation et la gouvernance du réseau de la santé et des services sociaux notamment par l'abolition des agences régionales) introduit au Québec en 2015. En ce qui concerne les politiques publiques, ce projet de loi a fait en sorte de fusionner l'administration des services sociaux et de santé sur une région géographique précise. Les CPQS tels qu'ils sont connus aujourd'hui sont une mise en application de cette centralisation. Par exemple, sur l'île de Montréal, il existe cinq territoires géographiques connus sous le nom de CIUSSS (centre intégré universitaire de santé et de services sociaux), pour lesquels chacun possède leur propre CPQS. Chaque CIUSSS est composé de plusieurs établissements de services sociaux et de santé, incluant des hôpitaux, des centres de réadaptations, des centres d'hébergement de soins de longue durée (CHSLD) et centres locaux de services communautaires (CLSC). Une telle structure demande ainsi aux CPQS de bien connaître le réseau de la santé et des services sociaux pour pouvoir accompagner les patients à naviguer dans le système de santé sur le territoire. Cela s'applique notamment pour accompagner l'autonomie des adolescents à accéder à des services de santé. En effet, naviguer un système de santé (en prenant en considération toutes les diverses politiques et processus) peut être très complexe pour des patients adultes, donc encore plus pour les adolescents – d'où l'importance d'avoir des ressources comme des CPQS pour aider les usagers à être accompagnés dans la navigation du système de santé. Tel qu'il sera développé dans la prochaine section, l'obligation des CPQS de tout documenter dans un logiciel s'avère très pratique dans les situations où les CPQS accompagneraient l'autonomie des adolescents à accéder à des services de santé (ex. faire des assistances).

# **Pragmatique**

Bien que les CPQS soient souvent associés aux plaintes, il est important de reconnaître que la très grande majorité des actions effectuées par les CPQS dans le réseau de la santé au Québec consiste en « des assistances » (tel que défini par la LSSSS) (Laliberté et al. 2022). Les assistances

ont pour but principal d'aider les patients en leur fournissant de l'information pertinente et en les accompagnant à naviguer dans le réseau de la santé et des services sociaux.

Par exemple, un patient pourrait communiquer avec un CPQS à la suite d'une conversation avec une secrétaire d'une clinique externe d'un hôpital (ex. : urologie). Le patient explique au CPQS que la secrétaire lui aurait refusé un rendez-vous parce que ça fait plus de cinq ans que le patient aurait vu l'urologue de la clinique et que la secrétaire aurait indiqué qu'une prescription d'un médecin de première ligne est nécessaire pour prendre rendez-vous à nouveau avec l'urologue. Le patient aurait le droit de déposer une plainte officielle auprès du CPQS. Par contre, il serait possible pour le bureau du CPQS de faire une assistance pour clarifier au patient qu'il s'agit de la norme de pratique pour les médecins spécialistes de demander une prescription pour voir à nouveau un patient après une longue période sans suivi. Il pourrait être également ajouté comme explication dans l'assistance du CPQS que les listes d'attentes sont habituellement très longues pour prendre rendez-vous avec un médecin spécialiste. D'où la pertinence que le patient voit un médecin en première ligne (ex. : médecin de famille) pour son problème de santé afin de déterminer s'il est nécessaire de voir un spécialiste et éviter de créer une plus longue liste d'attente pour les autres patients qui aurait besoin d'être vus plus rapidement (principes de justice et efficience).

Les assistances des CPQS servent ainsi d'exemple d'accompagner l'autonomie des patients en servant de point de repère et d'appui pour les patients. Par exemple, si l'enjeu impliquant le patient concerne un établissement ne faisant pas partie de la compétence du CPQS, il sera possible pour le CPQS d'assister le patient en l'orientant vers la bonne instance. Sur le plan de l'éthique publique, cette action représente le respect du principe de justice, notamment, du fait que les assistances sont gratuites et n'importe quel patient en a le droit, peu importe que le patient contribue ou non au financement du système de santé publique au Québec. Tel qu'élaboré dans la prochaine section, l'accompagnement des CPQS pour les adolescents à accéder à des services de santé consisterait en des assistances et non pas des plaintes.

# Accompagner l'autonomie des adolescents pour faciliter leur accès aux services de santé requis

Nous proposons deux cas fictifs pour démontrer comment les CPQS pourraient être une ressource pour accompagner l'autonomie des adolescents à accéder aux services de santé dans leur communauté – plus particulièrement, lorsque le besoin de consentement parental s'avère être une barrière pour que l'adolescent profite des services de santé.

# Cas 1 : Dépistage d'infections transmisses sexuellement

# Présentation du cas

Le partenaire de Jean vient de tester positif au VIH. Jean souhaite donc se faire dépister pour le VIH. Jean se présente à une clinique de santé sexuelle. À l'accueil, la réceptionniste demande à Jean son âge. Jean répond qu'il a 17 ans. La réceptionniste indique que pour passer un test de VIH de manière indépendante, par la loi, il faut avoir au moins 18 ans. La réceptionniste continue en expliquant à Jean que s'il souhaite se faire dépister pour le VIH, il doit revenir avec un parent pour consentir au dépistage. Jean ne souhaite pas demander à ses parents leur consentement pour pouvoir se faire dépister pour le VIH. Il décide donc qu'il attendra un an avant de se faire dépister de manière indépendante, lorsqu'il aura 18 ans.

#### Discussion du cas

Bien que ce cas soit fictif, il s'agit d'une réalité pour plusieurs adolescents. Par exemple, au Guatemala, Mali et Madagascar, il n'est pas possible pour les adolescents de 17 ans ou moins de se faire dépister pour le VIH sans le consentement parental (Barr-DiChiara et al. 2021 ; UNICEF 2016). Cette réalité constitue un sérieux enjeu de santé mondiale, alors que les adolescents constituent le seul groupe d'âge pour lesquels les décès liés au SIDA ne sont pas en décroissance (UNAIDS 2016).

Le cas présenté incorpore plusieurs enjeux éthiques, notamment, la transgression du principe de bienfaisance du fait que si Jean s'avère être séropositif, il bénéficierait de commencer hâtivement son traitement antirétroviral. Il est essentiel de noter qu'aujourd'hui, avec les avancées en traitements antirétroviraux, il est préconisé que les personnes séropositives commencent leur traitement le plus rapidement possible après leur séroconversion (OMS 2015). Les

antirétroviraux permettent de réduire la charge virale à un point tel que les personnes séropositives deviennent indétectables, ce qui se traduit à des bienfaits pour la santé de l'individu séropositif, notamment avec une prolongation de l'espérance de vie (Smiley et al. 2021; Teeraananchai et al. 2017). Mais de manière aussi importante, atteindre une charge virale indétectable a des avantages au niveau de la santé publique puisqu'une personne indétectable ne peut transmettre le VIH à ses partenaires (Cohen et al. 2016; Vernazza et al. 2008). Ainsi, il est possible de comprendre l'importance que Jean puisse se faire dépister rapidement, surtout considérant qu'il y a de fortes chances qu'il ait été exposé au VIH.

L'une des raisons derrière le principe du besoin de consentement parental est que les parents sont considérés comme étant dans une meilleure position que l'adolescent pour prendre des décisions – donc l'objectif du besoin de consentement parental étant de protéger le bien-être de l'adolescent dans l'éventualité que l'adolescent prendrait une mauvaise décision en lien à des soins et services de santé (Katz et al. 2016). Ainsi, l'autonomie des adolescents est perçue comme n'étant pas complète en soi comme serait le cas pour un patient adulte (Mahowald 2006 : 140). Toutefois, comme mentionné plus haut, les recherches démontrent que le besoin de consentement parental peut s'avérer être un obstacle important pour les adolescents qui souhaiteraient accéder à des services de santé sans que leurs parents soient impliqués, d'où le besoin de développer d'autres mesures pour protéger les adolescents et accompagner leur autonomie.

Dans les cas comme celui présenté – où un adolescent ferait la demande de services sans le consentement parental – nous proposons qu'un CPQS puisse venir en aide en « accompagnant » l'autonomie de l'adolescent via une assistance. Par exemple, dans un tel cas, il serait possible pour la clinique de faire appel au CPQS comme entité indépendante pour examiner et documenter la situation pour accompagner l'autonomie du jeune patient, au lieu de simplement rejeter la demande de services de l'adolescent.

Le CPQS pourrait rencontrer en premier lieu le professionnel de la santé (ex. : infirmière) pour que des explications de la situation soient présentées. Dans le cas présent, l'infirmière pourrait

clarifier qu'il y a de fortes indications que le patient serait séropositif et qu'il est nécessaire pour le bien-être de l'adolescent de passer un test pour le VIH (pour ensuite commencer un traitement antirétroviral si nécessaire), mais que le besoin de consentement parental s'avère être une barrière pour que le patient passe le test. Il pourrait ainsi être déterminé avec le professionnel de santé que l'absence d'utilisation du service de santé constitue un plus grand tort que de passer le test de dépistage sans le consentement des parents. Le rôle du CPQS ici ne serait pas de rendre (ex. confirmer) une décision clinique, mais de s'assurer que le professionnel de la santé a effectué un raisonnement éthique pour justifier le choix de vouloir dépister l'adolescent à sa demande sans le consentement de ses parents. Il serait aussi possible de documenter par le CPQS les mesures entreprises par le professionnel de la santé pour protéger le bien-être de l'adolescent, soit en offrant des ressources qui seront offertes pour assurer la protection du jeune patient (ex. faire la liaison avec un travailleur social ou psychologue si nécessaire). En d'autres mots, le CPQS s'assure qu'il y a un plan mis en place par le professionnel de santé pour la prise en charge, l'accompagnement et le suivi du patient adolescent pour s'assurer que ce dernier n'est pas « oublié » à la suite du test de dépistage.

Ensuite, il serait possible pour le CPQS de rencontrer le patient adolescent seul. Le premier but serait d'expliquer au patient le rôle des CPQS et clarifier qu'il s'agit d'une entité indépendante qui a pour objectif d'accompagner les patients en promouvant leurs intérêts (et non pas ceux de l'établissement). Ainsi, le CPQS pourra clarifier que si le patient fait face à des enjeux dans l'accès à ses services de santé (ex. discrimination de la part de professionnels), le jeune patient pourra communiquer avec le CPQS pour répondre à la situation et protéger les intérêts du patient.

Le CPQS pourrait ainsi documenter dans SIGPAQS : 1) les raisons pour lesquelles le jeune patient ne souhaite pas que ses parents soient impliqués, 2) la motivation derrière son choix de vouloir se faire dépister (pour s'assurer qu'il s'agit d'un choix éclairé), et 3) les démarches et mesures misent en place par l'établissement pour protéger le jeune patient. Cette approche protectrice ferait en sorte d'accompagner l'autonomie du jeune patient nécessitant un accès à un service de santé au lieu de « rejeter » l'autonomie du patient dû à son âge.

# Cas 2 : Programme de santé mentale

# Présentation du cas

Marie a 14 ans. Après l'école, en attendant l'autobus de ville, elle remarque une publicité à l'arrêt de son autobus promouvant un programme de services en santé mentale et dépendance dans un centre communautaire offrant des services sociaux dans son quartier. Marie a commencé à expérimenter des drogues illicites avec ses amies. Elle reconnait qu'elle commence à avoir un problème de consommation, particulièrement en observant son propre comportement et celui de ses amies (ex. : mentir à leurs parents pour sortir à la cachette pour consommer). Marie aimerait consulter les services offerts de ce programme pour pouvoir arrêter de consommer et l'aider à gérer ses relations compliquées avec ses amies qui ont des comportements problématiques.

Plus tard cette semaine, après l'école, Marie se présente au centre qui offre le programme en dépendance. La réceptionniste lui demande de remplir un formulaire dans la salle d'attente et lui indique de le partager avec la travailleuse sociale une fois qu'elle l'appellera. À voir les questions du formulaire, Marie décide de ne pas répondre à certaines des questions. Par exemple, elle ne veut pas indiquer son adresse ni son numéro de téléphone à la maison par crainte que ses parents soient mis au courant qu'elle souhaite utiliser des services en santé mentale pour aider à arrêter de consommer des drogues.

La travailleuse sociale appelle Marie et elles vont dans une salle privée pour faire une préévaluation. En observant le formulaire, la travailleuse sociale indique à Marie qu'il manque beaucoup d'information, notamment sa date de naissance. Marie explique que la confidentialité est un enjeu important pour elle parce qu'elle ne veut pas que ses parents soient au courant qu'elle a un problème de consommation; d'où le fait qu'elle n'a pas répondu à certaines questions. La travailleuse sociale demande à Marie quel âge elle a. Marie lui répond qu'elle a 14 ans. Suite à cette réponse, la travailleuse sociale explique que par la loi, à cause de son âge, il n'est pas possible d'offrir des services à Marie sans l'accord de ses parents. La travailleuse sociale continue en clarifiant qu'elle peut remettre à Marie un formulaire de consentement parental que ses parents devront remplir pour donner leur accord que leur adolescente reçoit des services du programme de santé mentale concernant son problème de consommation.

Marie est très déçue de la réponse de la travailleuse sociale. Elle prend le formulaire de consentement parental et quitte le centre. À l'extérieur, elle jette le formulaire de consentement parental dans les poubelles parce qu'elle sait qu'elle ne demandera pas le consentement de ses parents. Ses parents lui ayant déjà mentionné qu'ils l'expulseraient de la maison s'ils apprenaient qu'elle consomme des drogues. Marie risquerait ainsi de faire face à un contexte de vulnérabilité encore plus sévère si ses parents sont impliqués dans sa demande d'accès à des services de santé. Marie abandonne donc l'idée d'obtenir les services du programme de santé mentale considérant que le risque de l'implication de ses parents ne vaut pas la peine.

# Discussion du cas

Il est essentiel de noter que la santé mentale des adolescents constitue un enjeu de santé mondiale critique (Patel et al. 2007). De manière générale, les enjeux de santé mentale, telles les dépendances, ne commencent pas seulement à l'âge adulte (ex. à partir de 18 ans), mais très souvent à l'adolescence (Johnson et al. 2018). D'où l'importance que les adolescents peuvent avoir un accès précoce aux services de santé mentale adéquats pour assurer une transition saine à l'âge adulte.

Dans le cas présent, les mêmes démarches pourraient être entreprises que celles mentionnées précédemment : le CPQS pourrait rencontrer en premier le professionnel de santé, suivi de l'adolescente seule. Dans le cas de Marie, en comparaison au cas précédent, il est anticipé que les services en santé mentale auront lieu à plusieurs reprises et dureront sur une longue période. Dans le but d'accompagner l'autonomie de l'adolescent, il serait pertinent pour le CPQS de faire des suivis réguliers avec Marie pour s'assurer que les services offerts sans le consentement de parents ne causent pas de tort à l'adolescente. Dans l'éventualité que les services ne soient pas adéquats pour l'adolescente, le CPQS pourra intervenir pour protéger les intérêts de la patiente et s'assurer de la qualité de services, soit en orientant la patiente vers des services mieux adaptés.

Cela dit, comme mentionné dans l'introduction, nous n'argumentons pas que les CPQS pourraient remplacer le consentement des parents. Toutefois, les CPQS pourraient intervenir dans des cas problématiques, tel qu'il serait attendu d'un parent (selon la logique des lois de consentement parental) dans des situations qui compromettraient le bien-être de l'adolescent.

# Discussion

L'autonomie des adolescents constitue un enjeu éthique complexe, particulièrement dans le milieu de la santé (Zagouras et al. 2021). D'un côté, il est impératif de respecter l'autonomie émergente des adolescentes. D'un point de vue éthique, il est nécessaire de permettre une certaine liberté aux adolescents pour honorer leurs souhaits — dépendamment de la situation. Par exemple, une adolescente qui refuse de participer à un essai clinique doit voir son choix respecté, indépendamment de ce que ses parents souhaitent. Toutefois, les adolescents constituent simultanément un groupe vulnérable et il est éthiquement justifiable de restreindre leur autonomie dans un certain contexte dans le but de les protéger. Dans le cadre de cet article, nous argumentons que l'accompagnement des CPQS en santé pourrait être une solution qui permettrait à la fois de respecter l'autonomie émergente des adolescents, tout en offrant une mesure de protection pour ceux-ci lorsque le consentement parental se présenterait comme une barrière.

Chaque pays possède ses particularités légales en matière de consentement parental et de soins et services de santé, et comme mentionné précédemment, il n'existe pas de marqueur objectif en bioéthique pour déterminer concrètement à partir de quel âge un humain peut commencer à consentir pour des soins sans le besoin de consentement parental. Considérant cette lacune, il est difficile, en matière d'éthique publique, argumenter de réduire (ou augmenter) l'âge minimum pour qu'un adolescent puisse commencer à consentir à des soins et services de manière autonome. Cependant, il serait possible d'inclure dans les politiques publiques les CPQS comme ressource pour appuyer le bien-être des adolescents, tel que les exemples précédents ont pu démontrer. Nous suggérons qu'une telle initiative aurait le potentiel d'aider à augmenter

la prévalence d'accès de services de santé par les adolescents, au lieu de rester indifférent face à l'enjeu de santé mondiale qui est le manque d'accès aux services de santé dont les adolescents nécessitent.

Toutefois, il existerait des exceptions éthiquement justifiables pour un CPQS de ne pas toujours appuyer les choix des patients adolescents dans l'obtention de services de santé. Par exemple, un adolescent de 15 ans qui ferait une demande de changement de sexe par opération chirurgicale. Un CPQS ne devrait pas être une autorité à se prononcer sur une décision médicale d'un tel poids. Néanmoins, dans ces cas complexes, il serait possible pour le CPQS d'accompagner l'autonomie des adolescents par des assistances en impliquant les professionnels pertinents pour répondre aux besoins du jeune patient (ex. : orientation vers des services spécialisés sur le sujet). Il serait ainsi pertinent de développer des barèmes pour orienter les CPQS à accompagner l'autonomie des patients adolescents dans différents types de services de santé. Par exemple, l'accès à des services de santé sexuelle et reproductive (ex. : contraceptifs, dépistage d'ITS) serait adéquat pour impliquer les CPQS. Par contre, les soins et services qui requerraient des actes médicaux plus sérieux (ex. : intervention médicale de la part d'un médecin) ne devraient pas faire partie de la responsabilité des CPQS.

Au Québec, comme dans plusieurs autres endroits dans le monde, il existe des politiques publiques en matière de protection des personnes âgées. Toutefois, il serait nécessaire de développer, autant au Québec qu'à l'échelle internationale, des politiques publiques pour protéger les jeunes dans leurs accès à des services de santé qu'ils requièrent. Il est essentiel de reconnaitre que la suggestion que nous proposons est très paternaliste envers les jeunes patients, notamment, du fait que l'on argumente pour des mesures qui s'impliquent directement avec l'autonomie des jeunes (ex. demander d'expliquer leur choix de ne pas vouloir demander le consentement de leur parent). Une telle approche paternaliste serait facilement perçue comme étant éthiquement problématique pour les patients adultes. Cependant, dans le cas présent, il s'agit d'un paternalisme éthiquement justifié concernant l'objectif de protéger et promouvoir l'autonomie des adolescents dans des contextes vulnérables. Par exemple, le phénomène des

jeunes sans-abris constitue un enjeu public critique (Morton et al. 2020). Les jeunes sans-abris sont dans des contextes de vulnérabilités extrêmes; leurs relations avec leurs parents étant souvent très complexes, tel par leur absence (Heerde & Patton 2020; McCann & Brown 2019). L'utilisation des CPQS ne serait pas une fin en soi pour adresser l'enjeu de santé mondiale qui est la faible prévalence d'accès à des services de santé par les adolescents. Toutefois, les CPQS sont une ressource sous-utilisée pour répondre aux enjeux des groupes vulnérables, au-delà des adolescents, tels par exemple les immigrants et réfugiés.

# Conclusion

Il n'existe pas de consensus en bioéthique pour déterminer à partir de quel âge un patient a le droit d'avoir son entière autonomie respectée et ne requerrait pas le consentement d'un parent pour prendre des décisions en lien à sa santé. Il est important de reconnaître que les adolescents ont une autonomie émergente, d'où l'importance de trouver des moyens pour accompagner leur autonomie croissante, tout en protégeant ce groupe démographique vulnérable.

Les Nations Unies demandent que les ODD soient atteints d'ici 2030, ce qui inclue de trouver des moyens pour augmenter l'utilisation des services de santé auxquels les adolescents ont besoin. C'est la raison pour laquelle l'OMS argumente que l'on doit trouver des moyens pour accompagner l'autonomie des adolescents pour accéder à des services de santé. Notre article démontre comment les CPQS pourraient être une ressource utile pour accompagner l'autonomie des adolescents à accéder à des services de santé lorsque le consentement parental se présente comme étant une barrière. Notre article est de nature conceptuelle, il serait ainsi important d'explorer de manière empirique les implications de ce que nous proposons.

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Article VII: How Bioethics and Sex Education Can Help Address the Question of

**Consent in Sex for Adolescents** 

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Education.

<u>Abstract</u>

Determining when adolescents can consent to sexual relations is ethically complex: there are no

concrete objective or biological markers to accurately determine when a person can start to

consent to make decisions. In this paper, we argue that educating adolescents about core

bioethical concepts, like free and informed consent, is a critical part in helping determine when

adolescents should be able to consent to engage in sexual relations. Adolescents must, we argue,

know the foundations of consent, just like patients or research participants need to understand

what consent entails in order to genuinely consent (e.g., that they are entitled to withdraw their

consent at any time without needing justifications). Ultimately, we argue for teaching bioethics

concepts to adolescents starting at a young age, as a part of comprehensive sex education, to

help them develop healthy consensual relationships.

**Keywords**: adolescent, autonomy, bioethics, consent, sex, sex education

Introduction

The question of adolescent consent in sex is a highly complex and controversial ethical topic,

notably as there is no consensus on the age at which adolescents can or should be allowed to

consent to sexual relations (Fischel 2016; Petroni, Madhumita and Sawyer 2019; Steutel 2009;

Tellings 2009; Waites 2005). This diversity of positions is particularly evident in the variation in

laws establishing minimum age for consent, across states in the United States (U.S.) or even

between countries around the globe. There are also marked differences in laws regarding how

gender is treated, in some instances even within the same location (Butler 2011; Fischel 2016).

Adolescents engaging in heterosexual relations can, in some cases, consent sooner than their

peers engaging in homosexual relations. For example, in Chile, the age of consent for

heterosexual sex is 14 years old whereas it is 18 years for homosexual sex (Chilean Penal Code,

Art. 362; Art. 365).

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The structure of consent laws often seems to imply that the ability to consent to sex becomes evident when people reach a certain chronological age, because this age is concordant with having the intellectual capacity (e.g., cognitive maturity) to consent. However, it is important to question this logic by asking if reaching a specific chronological age *automatically* means knowing instinctively how to consent to sexual relations. We challenge this logic by arguing that it is necessary to engage in measures (e.g., educative initiatives) with adolescents to provide them with the necessary knowledge and understanding about consent in order for them to be able to consent to sexual relations. Said differently, it should be a public responsibility to teach the basis of consent to sex to adolescents (i.e., knowledge to be provided), rather than perceiving the ability to consent in sex as an aptitude that adolescents "naturally" obtain upon reaching a particular chronological age. How can a person (e.g., an adolescent) consent to something if they do not know the meaning of consent and its application?

In this article, we argue that core notions in bioethics related to respect for individual autonomy can help answer part of the question of sexual consent for adolescents. First, in the same way that a patient or research participant needs to understand what consent entails to be able to authentically consent to treatment or research, adolescents must have a clear and coherent understanding of the basis of consent and its application in the context of sexual relations (e.g., the right to withdraw consent at any time without needing to justify themselves). If an individual does not understand what consent is, they technically cannot consent to sexual relations, to health services, or to participation in research.

The first part of the article highlights the difficulty of defining the adolescent subject. Here we underline how this difficulty in concretely delineating when one can start to consent to sexual relations necessitates developing measures to protect this vulnerable population, such as teaching adolescents bioethical concepts from a young age – which can be pertinent for other types of relationships beyond questions of sex (e.g., romantic relationships, friendships). Then, we present the relevant canonical bioethics concepts that should be taught to adolescents and their pertinence for how to have consensual relationships. Ultimately, we advocate for

comprehensive sex education that includes discussions about consent and its application in sex. The objective is for adolescents to possess all the necessary knowledge and resources to engage in healthy and consensual relationships.

# **Challenges in Defining Adolescence**

First, it is crucial to recognize that there is no biological or objective marker to determine when a person becomes an adult (Arnett 1994; Dahl et al. 2018). The entry into adulthood is predominantly socially defined – and by default, adults are perceived and defined as individuals capable of independently consenting to make choices because of their adult status (Mahowald 2006: 140). For example, to highlight the plasticity of the definition of adolescence, at the beginning of the 20<sup>th</sup> century in the U.S., adolescents were simply seen as "inferior adults" instead of a separate group (Moran 2000: 1). Such a conceptualization of adolescents is quite different from recent international development and global health initiatives that call for recognizing adolescents as their own unique category instead of simply being labeled as "older children" or "young adults" (UN 2015; WHO 2017).

It is now generally agreed that age does not automatically equate to the same level of maturity for all persons (Le Breton 2012; Mahowald 2006). For example, in some contexts, 13-year-olds can possess the necessary maturity to understand the severity of the risks and threats to humankind posed by climate change (Lee et al. 2020). In other instances, 19-year-olds can make immature decisions, such as driving under the influence of alcohol or drugs, due to peer pressure (Keyzers, Lee and Dworkin 2020) or display impulsivity towards risk taking (Romer 2010). Neurological studies indicate that the brain continues to mature into the mid-twenties, which challenges the popular notion in law (and often in bioethics) that one is an adult, and fully cognitively mature, starting at 18 years old (Drobac 2011).

This evident inconsistency in determining when people can start to consent to participate in activities that involve risks (e.g., sex) calls for the development of measures to protect this vulnerable population. While there are different consent laws across the globe, it is critical to

recognize that adolescents will engage in sexual activities regardless of the law. Consent laws do not prevent adolescents from partaking in sexual relations. As such, we build our argument from the premise that there is a social responsibility to proactively provide young people with knowledge on how to consent to sex, such as through comprehensive sex education – notably, to protect them from potential harm by giving them tools and resources (e.g., information). In parallel, we also start from the premise that being an adult (e.g., over 18 years old), does not translate into an automatic understanding on how to engage in consensual relationships if one has not learned the meaning of consent and its application. Hence, it is essential to provide adolescents with some of the foundational tools to engage in consensual relations throughout their life, such as educating them on core bioethics concepts such as respect for autonomy and free and informed consent.

# **Free and Informed Consent**

For people (e.g., adolescents) to be able to consent to sexual relations, they must first have a clear and coherent understanding of the concept of free consent and its application. This application translates into teaching adolescents the following notions: autonomy, agency, power relations. It also involves educating adolescents of available protective resources (e.g., local authorities, ombudsperson office).

# **Autonomy**

First, the adolescent must be invited to reflect on *why* they wish to engage in a sexual relationship. It is perhaps a challenging question to ask oneself. Nonetheless, it is critical for the adolescent to recognize if their decision is truly voluntary (i.e., autonomous). If a research participant (or patient) recognizes that they are being coerced to engage in a study (or clinical intervention) because of undue pressure, this self-awareness will constitute the first step to recognizing that their participation would not be consensual and by default, signals an important ethical problem in the research (or clinical) context. The same applies to engaging in sexual relations.

Through self-reflection, an adolescent might recognize that they are looking to engage in a sexual relation because of indirect peer pressure (e.g., the adolescent's friends are sexually active, and the adolescent feels inadequate), or the adolescent's partner is pressuring or coercing them to engage in sexual relations (e.g., making threats). In any case, it needs to be explained that to engage in a sexual relation consensually, the adolescent must genuinely want to, and any doubt indicates that they are not yet ready to consent to engage in sexual relations.

In tandem, it must be made unquestionably clear that it is always acceptable to decline to engage in a sexual activity; and it must be explained that even if one has agreed to partake in sexual activity, the adolescent is still entitled to withdraw their consent at any moment. Subsequently, it must be clarified to adolescents that no reasons are needed to justify oneself from refusing to engage in sexual activity. On this topic could be expanded as a conversation with adolescents that there are different reasons why someone may decline to partake in sexual activities — and all reasons are valid.

Arguably the most popular ethical principle in Western bioethics is respect for autonomy (O'Neil 2008). The ethical principle can represent various concepts – e.g., independence, volition, maturity. As framed within the principlism framework of Beauchamp and Childress (2019), a common understanding of autonomy is respecting one's choice, bodily integrity, and self-determination. For example, a woman's wish to be sterilized so as not to have children should be respected, regardless of her healthcare provider's opinions and beliefs; the importance of respecting such autonomy has gained attention in light of the recent U.S. Supreme Court overturning of the *Roe v Wade* and subsequent state prohibitions of abortion.

Sexuality, both as behaviour and as an issue for public policy, embodies all the tensions surrounding how, when and for whom autonomy should be respected. Humans have diverse preferences and in general, in liberal, democratic societies these choices are respected unless they infringe on the liberties of others. But sexuality is also intimately tied to notions of pleasure and desires, and shaped by cultural and social norms of what is considered acceptable (and which

are often contested). Further, sexuality is a topic for which adolescents and adults may be uncomfortable discussing, particularly when it involves marginalized adolescents, such as adolescent girls and LGBT+ adolescents (Fine 1988; Lamb, Lustig and Graling 2013). Yet, it is critical to include discussions of pleasure and desires as these relate directly to consent, since it involves partners' respect of each other's choices or preferences (i.e., autonomy) (Kulwicki 2008). Sexual relations involve others, and adolescents generally have sex for pleasurable purposes (instead of for reproductive goals), which also then points to the importance of discussions regarding agency and power relations.

# **Agency and Power Relations**

To truly comprehend the meaning of consent, adolescents must be taught about the notion of agency, which involves understanding power relations. Sexual interactions involve someone else; as such, all the parties involved need to have a common understanding of consent. It must be made unmistakably clear to adolescents, from a young age, that sexual relations without free and explicit consent constitute an assault: "Yes means Yes, No means No... and without a Yes, it's a No!" As such, it is critical that adolescents learn that they can and must talk with their partners about what they would each like to do, i.e., their desires and preferences, and agree on what they are each comfortable with, and thus consent to these prior to engaging in any sexual activities. If an adolescent does not feel comfortable explicitly discussing with their partner which sexual activities they wish to engage in (e.g., because of shyness), this signals that they are not yet ready to partake in sexual activities. Obtaining consent needs to be active and ongoing (as in research ethics or clinical care). If a partner consented once to engage in a specific sexual activity, it does mean they cannot change their mind, nor that they have consented for future sexual activities.

Adolescents should also be encouraged to reflect on their own preferences and social position, and how these may or may not align with those of their partner. Bay-Cheng (2017: 344) proposes that school-based sexuality education should engage young people in critical analysis of social structures that surround their sexual wellbeing, which includes discussions about agency and

power relations. If the partner makes threats to coerce participation in sex, there is clearly no free consent. On that topic, there should be discussions about power relations (which also applies in research ethics and clinical care). For example, a family doctor inviting their patient to participate in their study in which they are an investigator creates problematic conflicts of role and interest. Since there is a relationship of dependence or differential power dynamics, the patient might feel obligated to participate in the study; and they might also assume that the study is in their own best interests (i.e., therapeutic misconception). As such, clinician-researchers need to be self-reflective about their own motivations and their social position with regards to patients/participants. The same applies to sexual relations: adolescents need to ask themselves whether their partner has sufficient agency to freely consent to a sexual activity and how to ensure an enabling context in which each can voice their preferences. If a (clinician) researcher observed that a (patient) participant displayed a lack of enthusiasm to continue with a study but was shy to voice their disinterest, it is the duty of the researcher to explicitly raise this issue for discussion and participant validation.

#### **Protection**

Patients and research participants have access to ombudsperson offices as recourse in cases of misbehaviour or misconduct by a health professional or researcher. The availability of and access to this office is not dependent upon a complaint but can be a resource to inform patients and participants of their rights. This information is usually included in the consent form for research. Ombudsperson offices serve as independent bodies that advocate for the rights of patients and research participants, notably, to prevent them from potential exploitation by health professionals and researchers. The same sorts of measure should be provided to adolescents as part of comprehensive sex education (e.g., promotion of the availability of resources like local public health authorities, community centers, helplines, social workers, psychologists) so that they are informed of the different available resources if, for example, they were to victims of sexual abuse or would want information regarding their rights.

#### **Information**

In order for someone (e.g., patient, research participant) to be able to consent to partake in an activity (e.g., medical treatment, research), they must possess all the necessary information (e.g., aims of the activity, potential risks involved, measures to prevent these risks) in order to be capable of making an informed decision as to whether they wish to participate - and such information is usually presented in a consent form and/or information sheet. The same principle should apply to sexual relations. For someone to consent to a sexual relation that would entail possible consequences (e.g., physical or psychological discomfort, unwanted pregnancy, exposure to sexually transmitted infections), they must be informed of all the possible risks involved, and subsequently, the measures to prevent and address these risks (e.g., explanation of how contraceptives work and the steps on how to access them, clarifications of where to obtain testing for sexually transmitted infections). Following this logic, in order for someone to consent to sexual relations, they should have received comprehensive sex education rooted in accessible and scientific knowledge and be able to discuss these issues in a meaningful way with their partner. If an adolescent (or adult) does not know the risks involved in the sexual activity they are to partake in, they cannot consent since they do not have all the necessary information to make an informed decision. As a consequence, preventing adolescents from accessing or not providing scientifically based comprehensive sex education impedes their ability to be informed and so engage in consensual sexual relations.

#### Discussion

This article underscores the need for educative initiatives that provide knowledge for adolescents to engage in free, informed and consensual relationships – and this teaching would benefit from an explicit grounding in an understanding of core bioethics concepts, such as respect for autonomy, and how they can be applied in practice. When people (including adults) engage in sexual practices without adequate understanding of consent, this signals a problem since they may have their rights violated (e.g., not knowing they can refuse to engage in sex) or may violate the rights of others. One approach to address the issue would be through science-based comprehensive sex education initiatives, for example, as advocated in UNESCO's *International* 

technical guidance on sexuality education: An evidence-informed approach. UNESCO's guideline already integrates essential modules related to consent (e.g., bodily integrity). However, our article provides an explicit ethical justification – grounded in respect for autonomy – to support the teachings of consent in sex education programs like UNESCO's guideline.

It is worth remembering that advocacy for the promotion of accessible sex education, that includes discussion of consent, is not new. Feminist activists around the world have, for decades, played a critical role in disseminating knowledge about consent, fighting against violence in sex, and lobbying for greater accessibility to sexual education as well as sexual health services more generally. Recent notable examples include online movements like #MeToo that seek to denunciate rape culture (Mendes et al. 2018; Rentschler 2014), which have had an impact in increased online searches about consent and thus showed the motivation of many people to obtain more information on the matter (Kaufman et al. 2021). Given the expertise of bioethics in clearly articulating these concepts in the areas such as research and clinical care, we argue for the pertinence of teaching these concepts, in similar ways, as part of comprehensive sex education starting from a young age, in school and at home.

As already stated, it should not be the responsibility of adolescents to intuitively know how to consent upon reaching a particular chronological age (e.g., 18 years old). Consent laws that present a minimum age at which one *can* start to consent to sex are structured on the logic that the ability is based on an intellectual competency. Yet, as we noted earlier, there is no reliable or concrete marker (e.g., biological sign) that is widely accepted to determine the moment that a person can or should start to consent, in terms of intellectual capacity. The result is thus laws based on arbitrary categories, such as age; and these invariably are disconnected from discussions about capacity or the necessary resources with which individuals can learn how to consent and so be able to actualise this capacity. We argue that it is a social obligation to provide such knowledge to young people so they can build their capacity to make free and informed decisions and participate in healthy and respectful sexual relations with their partners. A further ethical argument to support our position is rooted in social justice. When only some adolescents

are provided with comprehensive sex education and knowledge about consent (i.e., their rights and duties), they have started from a more privileged position than adolescents who have had such essential knowledge withheld - e.g., adolescents who do not know where to access contraceptives or do not know they have the right to refuse to engage in sex and that there are resources to help them in cases of abuse.

# **Unanswered Ethical Questions**

While we addressed some of the ethical basis of adolescents' consent in sex, there remain important unanswered ethical questions. One such question is determining a reliable minimum age at which an adolescent could *potentially* start to be able to consent to sex. For example, data shows that some adolescents start becoming sexually active at 12 years old (e.g., Cavazos-Rehg et al. 2009; Halkitis et al. 2021). That said, can a 12-year-old actually consent to partake in a sexual activity (e.g., in terms of psychological maturity)? We do not here provide an answer, but it would be reasonable to suggest that most 12-year-olds cannot consent to engage in sexual relations because of obvious developmental and psychological factors. Nonetheless, given that studies show that some 12-year-olds (or younger individuals) start engaging in sexual activities, there is an urgent need to provide them with the necessary information as part of sex education – such as that presented above – so that they at least have the tools and resources to help orient and protect themselves (e.g., have the knowledge of the right to refuse to engage in sex, knowing to which authority to signal abuse, learn how to have more respectful discussion with their sexual partners).

Another important ethical question to ask is the acceptable age gaps between adolescents who have sexual relations. It might be seen as acceptable in certain contexts that a 14-year-old and 17-year-old who go to the same school can have consensual sexual relations given that they are social peers. Nonetheless, if it is a 14-year-old and a 19-year-old, the age gap may become problematic because the 19-year-old is legally defined as an adult whereas the 14-year-old is a minor, and so this relationship might be prohibited (e.g., defined as statutory rape). It may not be possible to clearly define acceptable age differences where adolescents are concerned

regarding consensual sexual behaviour. This situation again points to the need for honest discussion, supported by sex education, that is adapted to both younger and older adolescents (as well as young adults), in order to examine the ethical and legal ramifications of such relations, explore how to respectfully acknowledge (and manage) the different responsibilities associated with different ages, etc.

From a consequentialist perspective, teaching comprehensive sex education at a young age has been shown to contribute to delaying the start of sexual activities (Ekrut et al. 2013; Kirby 2008; Mueller, Gavin, and Kulkarni 2008). It would be logical to suggest that teaching the basis of consent to adolescents could also help in delaying or diminishing the number of problematic sexual activities at a population level. Being taught that sex without consent constitutes an aggression and that there are resources available for people who have experienced sexual abuse would help adolescents understand the seriousness of consent requirements and hopefully encourage them to reconsider engaging in problematic sexual relations. Hence, teaching adolescents about consent could potentially have beneficial public health ramifications.

#### Conclusion

The topic of adolescents' consent in sexual relations can be a highly uncomfortable topic, for both adolescents and adults, particularly as it touches upon questions of pleasure, desire, and sexual and reproductive autonomy. Nonetheless, instead of avoiding the question, with the correlate that no progress is made, the field of bioethics can contribute by addressing this question head-on and mobilizing its expertise regarding respect for autonomy and consent. Throughout the years, there has been many polarizing debates about sex education for young people: some pushing to limit as much as possible the information presented (e.g., abstinence-only education), with others advocating provision of as much knowledge as possible (e.g., comprehensive sex education). At the core of the debate is the common goal of protecting young people. Our article demonstrates the pertinence of teaching adolescents core bioethical concepts, notably respect for autonomy as articulated by free and informed consent, as a means to empower them to make

choices about their sexuality that are respectful of their desires and preferences, as well as those of their sexual partners.

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# **Chapter 7: Discussion & Conclusion**

The Discussion chapter returns to the four main thesis objectives, presented in the Introduction, in line with Kon's (2009) main categories for empirical bioethics research. The Discussion synthesizes the research findings in relation to the WHO's call to foster adolescents' autonomy to access health services (see **Table 16**), and concludes by exploring directions for future research on the topic of adolescents' autonomy.

# Objective 1: Clarify how adolescents understand the concept of autonomy

The first objective of the research was of exploratory nature. The goal was to document the understanding and experiences of Colombian adolescents as it relates to questions of their autonomy — more particularly, concerning their access to SRHS. In line with Kon's (2009) framework, the purpose of this first category of empirical bioethics work is to get an initial sense of the participants' reality (i.e., *Lay of the land*). This first step in the research was critical as it enabled the development of an initial foundation of the research problem, which then oriented the subsequent stages of the research project and achievement of the stated objectives.

Recognizing that adolescents have different understandings of the principle of autonomy was a critical finding as it highlighted an important problem: when some adolescents have a more accurate understanding of the basis of autonomy (e.g., rights) in healthcare access, they start from a more privileged position than their peers. For example, an adolescent taught about their rights and how, in practice, to access local SRHS will most likely have easier access to such services compared to an adolescent who does not know the existence of those services nor know how to access them. Such disparities signal an important inequity. In line with the WHO's call to foster adolescents' autonomy to access health services, and from the perspective of a reproductive justice framework, the data demonstrates that one of the ethical arguments to support such an initiative is through challenging an important injustice: when all adolescents are presented with the same knowledge regarding the basis of autonomy in healthcare, this balances out some inequalities between adolescents on their access to SRHS.

# Objective 2: Examine the preferences and experiences of adolescents

The main objective for this second part of the thesis was to explore whether the preferences of Colombian adolescents are being met concerning their autonomy to access SRHS. An important result of the empirical study to acknowledge is that many participants expressed having various preferences. While this finding might not be a surprising, it is nevertheless a critical point to recognize because it adds important nuance to a topic that is often treated in a black/white or bimodal fashion. The fact that adolescents reported having various preferences calls for the need to pay attention to the details of those differences and to examine, from a justice perspective, whether all have their preferences equally met regarding access to SRHS.

A much higher proportion of participants had their preference met than expected (which is a good thing). However, what unexpectedly emerged from the results was the participants' strong appreciation for and desire to have their parents involved (and at times, others like friends) in supporting their autonomy to access SRHS (e.g., to be accompanied to the clinic). When developing the research project, I took into consideration the previous literature on the subject of adolescents and their access to SRHS. The overwhelming majority of research on the topic showed that adolescents want to access SRHS independently and the lack of respect for confidentiality was a critical barrier for them – i.e., adolescents tend to not have their preferences met. Hence, from the existing literature, I started from the premise that the involvement of parents might be problematic for Colombian adolescents' autonomy and access to SRHS. Nonetheless, the majority of participants reported in the survey and interviews an appreciation for the implication of their parents regarding access to SRHS (e.g., to accompany to the clinic, help choose a contraceptive option). These findings force us to reconsider the conceptualisation of autonomy as it is commonly understood in terms of independence and self-sufficiency in bioethics (particularly in North America), which led me to explore a relational autonomy approach.

Based on the research findings, a relational autonomy perspective is an appropriate approach to address the question of Colombian adolescents' autonomy to access SRHS. Instead of aiming for

autonomy as self-sufficiency and perceiving independence as a goal in healthcare, a relational autonomy approach can help parents, health professionals, and decision makers better recognize the way that patients may wish to have others (e.g., parents) involved in assisting healthcare decisions; or in the case of this research, at times, simply accompanying the adolescent patient to the clinic without having to help them make a decision.

# Objective 3: Explore how adolescents wish for their autonomy to be fostered

A critical question asked of participants was their stance regarding the WHO's advocacy to foster adolescents' autonomy to access health services. There is a paternalistic undertone to the WHO's call, and it would be justifiable for a group to reject a global health measure advocating to foster their autonomy to access health services – it would be unethical to endorse an initiative for which the targeted groups were not in agreement. Nonetheless, there was an overall appreciation by participants of the idea that there would be public efforts to help them gain greater access to SRHS. The main reason was an acknowledgment that participants experience challenges regarding their access to SRHS – e.g., lack of adequate knowledge on how to access a clinic. Participants saw measures to foster their autonomy to access SRHS as a potential solution to address the issue. During the interviews, participants agreed that one way to foster their autonomy would be to provide parents with comprehensive sex education. The goal would be for parents to have the appropriate scientific knowledge on the subject so that they could then help their adolescent make informed decisions regarding sexual and reproductive health, and ultimately assist them access needed SRHS. This finding connects to the previous point on the relevance of adopting a relational autonomy approach concerning Colombian adolescents' autonomy to access SRHS.

# Objective 4: Identify the ethical issues and propose ethically informed solutions

This fourth objective was influenced by the results of the research and the overall experience of the PhD as a reflective process, which led to the development of conceptual papers. The multiyear time frame of the doctoral project made it possible to explore different ethical reflections regarding adolescent autonomy, which in dialogue with the empirical results, led to the proposition of different recommendations.

The question of consent was not initially central to the doctoral research as it is a highly complex ethical subject where adolescents are concerned. However, given that the thesis revolved around adolescents' autonomy to access healthcare services, it become evident that the question of consent had to be addressed. The subsequent analysis of the issue highlighted the need to make available different resources for adolescents to protect them in their access to SRHS. One way to do so would be through the development of ombudsperson offices (as independent agencies) that could help adolescents access the health services they need in cases where parental consent requirements could be a barrier. Overall, a key element to help foster the autonomy of adolescents resides in education, both for adolescents themselves and their parents. Without access to adequate information needed to make informed decisions (e.g., know where to get STI/HIV testing and treatment), it will be impossible for adolescents to have their autonomy actualized to access needed SRHS.

Table 16. Synthesis of main doctoral research questions

Questions	Answers
Should we endorse or reject the WHO's call to foster adolescents'	Yes, we need to endorse the WHO's call.
autonomy to access health services, such as SRHS?	
What are the main categories to	1. Education: provide the resources to help adolescents
foster adolescents' autonomy to access health services?	develop the necessary skills (e.g., teach adolescents the basis of autonomy in healthcare).
	2. Policy: creating enabling environments in which the
	autonomy of adolescents can be supported in healthcare.
What is the main ethical	Principle of justice
justification to endorse measures to	The results show discrepancies between adolescents
foster adolescents' autonomy to	regarding their autonomy to access SRHS (i.e., some will
access SRHS?	have easier access than others), which is unjust. Hence, the need to develop measures that will create greater equality in access for adolescents (e.g., through education and policies).

What is one strategy to help foster	As voiced by participants, one approach to have their
adolescents' autonomy to access	autonomy fostered to access SRHS would be through
SRHS?	providing comprehensive sex education to parents so that
	they can help their adolescents access needed SRHS (e.g., to
	make informed decisions, accompany the adolescent to the
	clinic).

# **Directions for Future Research**

I would argue that one of the most important elements to take away from the research is that most participants voiced wanting their parents involved as it concerns adolescents' autonomy and sexual and reproductive health (e.g., helping choose a contraceptive option, accompany adolescent to clinic for STI/HIV testing). More concretely there was an enthusiastic response to the idea of providing comprehensive sex education to parents, as a public health initiative, with the goal of helping parents discuss the topic with their adolescents and help them access needed SRHS. Based on these findings, future research should be conducted with parents to: 1) determine if parents wish to receive comprehensive sex education to be able to then discuss the topic with their adolescent; 2) explore how such a public health measure could be implemented (e.g., through online learning, with mobile applications); 3) measure the effects of providing comprehensive sex education to parents on the health and wellbeing of adolescents. An empirical investigation of the effects of such a project could be done through a prospective cohort study where parents of adolescents in one community would be provided comprehensive sex education (exposed group), whereas another community (without such education) could serve as the comparison group. This would make it possible to measure, over time, whether providing comprehensive sex education to parents leads to positive outcomes for adolescents (e.g., more frequent HIV/STI testing, higher contraceptive use, lower adolescent maternal mortality rate).

As mentioned, previous research on the topic of adolescents' use of SRHS has tended to frame parents as potential barriers for adolescents' use of such services. As a result, parents and parental consent requirement policies are framed as having possible negative health impacts on adolescents' health. This doctoral research helps bring a different outlook to the question, and

suggests that parents could be a key positive resource to help foster the autonomy of adolescents to access SRHS, but only if they are given the tools to do so.

Overall, I would argue that it is critical to continue research on adolescents' autonomy and consent in healthcare. I hope that my research findings can encourage others in bioethics to pursue empirical and conceptual research to examine the ethical issues associated with adolescents' autonomy and access to SRHS — and healthcare more generally. Historically, bioethics played an important role in denouncing ethically problematic policies and conduct of healthcare professionals (e.g., doctors). If a policy is shown to lead to inequitable health ramifications for certain groups of people (e.g., barriers to access health services), it would be reasonable for bioethics researchers and professionals to advocate for and collaborate in the development of more ethical practices. With the present research, it is possible to observe that in some instances parents can be a barrier for adolescents to access SRHS, just as some parents can be a positive enabling factor to help adolescents access the SRHS that they need. Should the field of bioethics comment on the practices and values of parents that have repercussions on the health of their children? My doctoral research does not provide an answer but opens the way for the field to continue exploring ethical questions involving adolescents and their parents.

# **Conclusion**

The main objective of this doctoral research was to address ethical questions about the WHO's call to foster adolescents' autonomy to access sexual and reproductive health services. There is no consensus in bioethics and science concerning adolescents' autonomy in healthcare – e.g., determining when a person's full autonomy should be respected to make decisions, or establishing at what age it is (un)ethical to demand parental consent. Adolescents are in a transition stage between childhood and adulthood, and they face many and diverse barriers to accessing health services tailored to their particular life stage. The ambiguity surrounding this period of human development is precisely what makes it critical for the field of bioethics to investigate the associated socio-ethical and policy implications.

An empirical bioethics approach was used to explore the ethical question of the WHO's call to foster adolescents' autonomy to access health services. More specifically, the case of Colombian adolescents' access to sexual and reproductive health services was used because most research conducted with adolescents is performed in high-income countries. Thus, there is a need to do research with adolescents in low- and middle-income countries, so that they too have their voices heard on subjects that concern them. The case of sexual and reproductive health services was chosen because they are types of health services that are of a sensitive nature for both adolescents and parents.

One of the broader aims of my doctoral research was to demonstrate that I have different methodological skills, i.e., quantitative, qualitative and conceptual. By mobilizing these various approaches to conducting bioethics research, I was able to investigate the ethical question of adolescents' autonomy from diverse angles and propose analyses that were grounded in both robust empirical data and rigorous conceptual work. I sincerely hope I did justice to the contribution of the young Colombian participants who so generously shared their experiences with me. And I hope that my publications will be helpful in bringing positive changes (e.g., policies) regarding adolescents' well-being and health.

On a concluding personal note, through my PhD in bioethics I have found my true calling and wish to continue to explore ethical issues involving adolescents in healthcare. I plan to keep doing research on the topic, such as conducting a postdoctoral work with parents of adolescents to investigate their interest in receiving comprehensive sex education (as my participants expressed in their interviews). My long-term goal is to develop a research program on "Adolescence, Bioethics and Global Health." The objective would be to conduct a diversity of research with adolescents in low- and middle-income countries and offer a platform for them to be heard on health subjects that concern them. As such, my PhD in bioethics was the first step in what will hopefully be more research on ethics and adolescence.

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# **Appendix 1: Recruitment Information for Surveys (English)**

# A STUDY ON ADOLESCENTS AND YOUNG ADULTS' AUTONOMY TO ACCESS SEXUAL AND REPRODUCTIVE HEALTH SERVICES IN COLOMBIA

**PURPOSE OF RESEARCH:** We are inviting adolescent and young adult patients at Profamilia to answer a short anonymous questionnaire (approximately 5-10 minutes) on the subject of autonomy to access sexual and reproductive health services. You can answer the questionnaire while you wait for your appointment in the waiting area. We are looking for a sample size of approximately 250 participants.

WHO IS RUNNING THIS PROJECT? WHO IS FINANCING THIS PROJECT? A PhD student researcher (Julien Brisson-Morales) from the Bioethics Program at the University of Montreal's School of Public Health, in Canada, is running this project, which is financed by the Canadian Institutes of Health Research.

**WHAT DO I HAVE TO DO?** You are invited to fill out a survey. The survey has 25 questions (plus demographic questions) and takes about 5-10 minutes to complete. It asks questions about topics related to the autonomy of adolescents and young adults in accessing sexual and reproductive health services.

**DO I HAVE TO ANSWER THIS SURVEY? WILL MY PARTICIPATION AFFECT THE SERVICES I RECEIVE AT PROFAMILIA?** You do not have to answer the survey. You are free to choose to participate or not, and your choice will in no way affect the quality of the services you will receive today or in the future at Profamilia.

**IF I START ANSWERING THE SURVEY, DO I HAVE TO COMPLETE IT?** No. You do not need to complete the survey, you can stop answering the survey at any time without having to give a reason.

WHY AM I BEING INVITED TO PARTICIPATE IN THIS RESEARCH? All the adolescents and young adults (10-24 years old) visiting this clinic are presented with the opportunity to answer this survey, as a way to document their perceptions about topics (access to health services) that affect them directly.

**IS THE SURVEY ANONYMOUS?** The survey is anonymous. You will not be asked to share your name.

WHAT WILL HAPPEN TO THE DATA? WILL THE DATA REMAIN CONFIDENTIAL AND PROTECTED? The data will be used for presentations in scientific conferences and in scientific articles, and to advocate for changes to help young people to access sexual and reproductive health services. The data will remain confidential and only the principal researcher will have access to the data that will be password protected.

**IS THERE A COMPENSATION FOR ANSWERING THE SURVEY?** No. Answering the survey is done on a voluntary basis.

**ARE THERE ANY RISKS INVOLVED IN ANSWERING THE SURVEY?** There are no major risks involved. Due to the nature of the study (e.g., sexual health), there might be some questions that you could find uncomfortable to answer.

**ARE THERE ANY BENEFITS INVOLVED IN ANSWERING THE SURVEY?** There are no direct benefits from answering the survey. Your participation will contribute to better understanding the ethical challenges related to adolescents accessing sexual health services.

**IF I HAVE QUESTIONS ABOUT THIS STUDY, WHO CAN I CONTACT?** You can contact the researcher Julien Brisson-Morales. His contact information is at the bottom of the following page.

\*\*\* IF YOU ARE <u>NOT</u> INTERESTED IN ANSWERING THE SURVEY, SIMPLY DISCARD OF THE PAPER IN A RECYCLING BIN IN THE WAITING AREA.

\*\*\* If you already answered this survey, please do not answer it again.

#### IF YOU ARE INTERESTED IN ANSWERING THE SURVEY, FOLLOW THE FOLLOWING STEPS:

#### **PROCEDURES**

There are <u>2 options</u> to answer the survey (you choose whichever option you prefer):

You can either go to the following address on your cellphone and answer the survey online: https://es.surveymonkey.com/r/Profamilia

Or, you can fill out the survey on paper by following these steps:

- Go see the receptionist who gave you this piece of paper and tell her you want to fill out the survey.
- The receptionist will give you the survey with a pencil.
- Fill out the survey in the waiting area.
- In the waiting area, there will be a locked box where you can put the survey once you are done.

# **Appendix 2: Consent Form Interviews (English)**

# A STUDY ON ADOLESCENTS AND YOUNG ADULTS' AUTONOMY TO ACCESS SEXUAL AND REPRODUCTIVE HEALTH SERVICES IN COLOMBIA

Principal investigator: Julien Brisson-Morales
PhD student in bioethics, Department of Social & Preventive Medicine
School of Public Health, University of Montreal, Canada
Whatsapp

Email

Directors: Bryn Williams-Jones
Vardit Ravitsky

This project is financed by: the Canadian Institutes of Health Research (CIHR)

You are invited to participate in an audio-recorded interview for a research project. Before you agree, please take the time to read through this document explaining the conditions of this research. Do not hesitate to ask any questions you may have.

#### **INFORMATION FOR PARTICIPANT**

#### 1. RESEARCH PROJECT DESCRIPTION

Studies have shown that young people are a group of the population that do not frequently use sexual and reproductive health services despite having important health needs to be addressed. Different reasons exist to explain this phenomenon, such as young people being unfamiliar on how to use healthcare services in their community. To answer this problem, public health experts argue that it is important to promote the autonomy of young people to access healthcare services. The objective of this research is to explore the ethical issues around the promotion of adolescents and young adults' autonomy in accessing sexual and reproductive health services in Colombia.

#### 2. PURPOSE OF THIS INTERVIEW

The purpose of this interview is to gather information from young people on their opinions and experiences about their autonomy to access healthcare services related to sexual and reproductive health in Colombia.

#### 3. VOLUNTARY PARTICIPATION

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. Whether you choose to participate or not, this choice will not affect the quality of services you receive today or in the future at Profamilia.

#### 4. PROCEDURES

The researcher will ask you a few demographic information (e.g., age, level of education). Then the researcher will start the audio-recording device and ask you open-ended questions on the topic of young people's autonomy to access sexual and reproductive health services.

#### 5. DURATION

The interview should last <u>approximately one hour</u>. The length of the interview may be shorter or longer depending on how much information you wish to share throughout the interview.

#### 6. CONFIDENTIALITY

Your personal information will remain private. The interview will be transcribed on a computer by the researcher. The audio-recorded interview will be kept in password protected file on the researcher's computer that is also password protected with a different password. A pseudonym will be given to you to protect your identity. Any information that could potentially directly identify you will be altered.

#### 7. HANDLING AND DISPOSAL OF DATA

The data from the interviews will be analysed and used for presentation at scientific conferences and in scientific articles, and to help Profamilia with the services they offer to young people. The transcription and audio-recorded interview will be kept for 7 years and will then be destroyed.

#### 8. POTENTIAL RISKS

There are no major risks involved with this research. However, due to the nature of the themes that will be discussed during the interview, such as the topic of sex, it is possible you may feel uncomfortable or that the interview may raise unpleasant emotions. If during the interview you need immediate emotional support, you may let the researcher know and he will get you a health professional in the clinic.

#### 9. POTENTIAL BENEFITS

There are no guarantees that participating in this interview will yield you direct benefits. Your participation will contribute to better understanding the ethical challenges related to adolescents accessing sexual health services.

#### 10. REMUNERATION

There are no remunerations for participating in this interview. Participating in this interview is done on a voluntary basis.

#### 11. RIGHT TO REFUSE OR WITHDRAW

You do not have to take part in this research if you do not wish to do so. You may stop participating in the interview at any time that you wish without having to give a reason. You can simply tell the researcher you'd like to stop. Also, you do not need to answer a question if you do not want to. You can simply tell the researcher you do not want to answer the question without having to give a reason.

#### 12. SAMPLE SIZE

The objective is to have between 10 - 30 participants participating in an interview for this part of the research.

#### **CONTACT INFORMATION**

You will be given a copy of this consent form for your records. If at any time, either now or later, you have a question, please feel free to ask it. If you have questions or concerns regarding your rights as a participant in this study, please contact Profamilia's coordinator of research, Marcela Sánchez at msanchez@profamilia.org.co, teléfono: (57+1) 3390900 ext.650.

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#### AGREEMENT OF PARTICIPANT

- I understand that I can take my time to decide whether I want to participate in this interview or not.
- I understand that by participating in this research I am not renouncing any of my rights and I also understand that the researchers are not withheld from their responsibilities.
- By signing this document, I am stating that the nature of the interview has been explained to me. s

I, the undersigned, hereby consent to be a participant in the portion of the project described above
First and last name in print:
Signature of participant:
Date:
RESEARCHER'S COMMITMENT I explained the conditions of participation in the research project to the participant. I responded to the best of my knowledge to the questions asked and made sure of the participant's understanding. I agree with the research team to respect what has been agreed to in this information and consent form.
First and last name in print:
Signature of investigator:
Date:

# **Appendix 3: Survey Questions (English)**

1. What is the main reason you are in Profamilia today?			
a. To access information/education related to sexual and/or reproductive health.			
b. Vaccination (e.g., HPV, hepatitis B).			
c. Contraceptives			
d. Testing or treatment for HIV and/or sexually transmitted infection (STI).			
e. Counseling			
f. Abortion/Voluntary Termination of Pregnancy (VTP)			
g. Sterilization			
h. Pregnancy-related (e.g., ultrasound)			
<ul><li>i. Fertility problem (e.g., assisted reproduction)</li></ul>			
j. Others (specify):			
2. What other services are you looking for at the clinic today? (more than one possible choice	e'		
a. None	٠,		
b. Accessing information related to sexual and/or reproductive health.			
c. Vaccination (e.g., HPV, hepatitis B)			
d. Contraceptives			
e. Testing or treatment for HIV and/or sexually transmitted infection (STI)			
f. Counseling			
g. Abortion/Voluntary Termination of Pregnancy (VTP)			
h. Sterilization			
i. Pregnancy-related (e.g., ultrasound)			
j. Fertility problem (e.g., assisted reproduction)			
3. Are there any services (related to sexual/reproductive health) that you would like to acce	c		
today but are not available here?	J.		
a. No/Not applicable			
b. Yes (specify):			
5. (open.)			
4. Did you come alone today at the clinic?			
a. Yes			
b. No			
5. If you were accompanied to the clinic today, who came with you? (more than one possible)	١L		
choice, check all that apply)			
a. Mother			
b. Father			
c. Friend			
d. Partner (e.g., boyfriend/girlfriend or sexual partner)			
(0.) 1 0			

e. Other person (specify):

6. How did you know to come to Profamilia today? (more than one possible choice)
a. I searched the Internet
b. I asked a friend
c. I asked my mother
d. I asked my father
e. I asked a relative
f. I saw an advertisement
g. I learned at school
h. Other(especifica):
7. What do you think is the minimum age for an adolescent to see a healthcare
professional without a parent in Colombia?
a. 12
b. 13
c. 14
d. 15
e. 16
f. 17
g. 18
h. No minimum age
i. I do not know
8. Today, if you could have chosen, would have you preferred to come alone or
accompanied to the clinic?
a. I wanted to come alone
b. I wanted to come accompanied
c. Does not matter to me
9. When seeing a healthcare professional for your sexual/reproductive health, do you
prefer being alone with the healthcare professional or accompanied?
a. I prefer being alone
b. I prefer being accompanied by a parent
c. I prefer being accompanied by a relative
d. I prefer being accompanied by a friend
e. I prefer being accompanied by a partner
f. Does not matter
10. When seeing a healthcare professional for your sexual/reproductive health, does the
presence of a parent makes you avoid disclosing certain information or avoid asking

certain question?
a. Yes
b. No

c. Maybe/don't know

- 11. If you could choose, in relation to your sexual and reproductive health, would you prefer to go to a clinic that is strictly reserved for young people (25 years old and under) or do you prefer clinics for all ages that are welcoming of young people
  - a. Clinics reserved for young people
  - b. Clinics of all ages
  - c. Doesn't matter to me
- 12. When seeking healthcare services related to your sexual/reproductive health, do you prefer your healthcare provider to be the same gender as you:
  - a. Yes
  - b. No
  - c. Does not matter
- 13. Do your parents or other relative know you are at Profamilia today?
  - a. Both my parents
  - b. My mother
  - c. My father
  - d. Other relative (specify):
  - e. No, my family does not know I am here today
- 14. Did you receive sexual health education in school?
  - a. Yes
  - b. No
  - c. Don't know
- 15. If you received sexual health education in school, did they teach you how to use healthcare services? (e.g. where and how to get tested for a sexually transmitted infection)
  - a. Yes
  - b. No
  - c. Don't remember
- 16. If you received sexual health education, did they teach you the laws and rights of minors to access and use healthcare services? (e.g., issues of confidentiality for minors)
  - a. Yes
  - b. No
  - c. Don't remember/does not apply
- 17. According to you, how important is it for adolescents to be taught how to use health services in their community?
  - a. Very important
  - b. Important
  - c. Not important

- 18. How interested would you be to have access to YouTube videos and/or content online explaining in detail how to use sexual and reproductive health services in your community?
  - a. Very interested
  - b. Interested
  - c. Not interested
- 19. How confident do you feel on your knowledge related to the rights of minors to access health services in Colombia?
  - a. I feel very knowledgeable on the topic
  - b. I feel somewhat knowledgeable
  - c. I have limited knowledge on the topic
- 20. Would you like information on the rights of adolescents to access and use sexual health services to be made more accessible? (e.g. taught in school, explained on the Internet)
  - a. Very interested
  - b. Yes
  - c. Maybe/indifferent
  - d. No
- 21. Previous studies have shown that there exist different factors preventing adolescents and young people from accessing sexual and reproductive health services. Have any of those factors applied to you (today or in the past): (more than one option)
  - a. Cost
  - b. Fear of being judged
  - c. Hours of clinic
  - d. Confidentiality
  - e. Location
  - f. Length of waiting time
  - g. Other:
  - h. None/Not applicable
- 22. In relations to the reason you came in for today in the clinic, do you prefer the healthcare professional to tell you what to do (e.g., decide what s/he believes is the best choice for you) or you prefer to make your own decision without the opinion of the healthcare professional?
  - a. I want the health professional to tell me what to do
  - b. I want to make the decision by myself without the opinion of the healthcare professional
  - c. I want to make my own decision but also hear the opinion of the healthcare professional
  - d. I only want the opinion of the person I came with
  - e. I want the opinion of the person I came with and the opinion of the healthcare professional

- 23. When seeing healthcare professionals today at the clinic, do you want them to interact with you the same way they would do with an older adult (e.g., talk to you as if you were an adult):
  - a. I want healthcare professionals to interact with me the same way they would do with an older adult
  - b. I want healthcare professionals to interact with me as a young person
- 24. Have you ever been tested for HIV?
  - a. Yes
  - b. No
  - c. Don't know
- 25. Have you ever been tested for a sexually transmitted infection (e.g., chlamydia, gonorrhea, syphilis)?
  - a. Yes
  - b. No
  - c. Don't know
- 26. Is there anything you would like to add on the topic of adolescents' autonomy to access sexual and reproductive health services:

(open space to write)

# **DEMOGRAPHICS:** Age: **Estrato:** a. 1 b. 2 c. 3 d. 4 e. 5 f. 6 g. Don't know Gender: a. Male b. Female c. Transwoman d. Transman e. Other: **Sexual orientation:** a. Heterosexual (attracted to gender different than yours): b. Homosexual (attracted to the same gender as yours): c. Bisexual d. Other e. Don't know

# **Highest level of education:**

- a. Elementary school
- b. High school
- c. College
- d. University
- e. Other:
- f. None

# **Currently in school:**

- a. Yes
- b. No

# Remunerated work in the last year:

- a. Yes
- b. No

# **Relationship status:**

a. Married

- b. Single
- c. In a serious relationship
- d. Other:

# Do you currently live with your parent:

- a. Live with both parents
- b. Live with mother
- c. Live with father
- d. Live with other relative, specify:
- e. Living on my own

# Do you have health insurance:

- a. Yes
- b. No
- c. Parent's insurance
- d. Partner's insurance
- e. Other

# Are you a Venezuelan migrant:

- a. Yes
- b. No

# If you are a Venezuelan migrant, when did you first migrate to Colombia (year):

# Are you a displaced person?

- a. Yes
- b. No

# Do you have any children:

- a. Yes
- b. No

# If you have children, how many:

If you have children, age of oldest child:

Age you started becoming sexually active:

Do you have a family doctor:

- a. Yes
- b. No
- c. Don't know

# **Appendix 4: Interview Guide (English)**

Gender:

Age:

Estrato:

Highest level of education:

Currently in school or working:

Who you live with:

Venezuelan migrant:

If Venezuelan migrant, when did you migrate to Colombia:

Did you receive sex education in school:

#### **QUESTIONS:**

- 1. Is there a particular reason why you wanted to participate in this interview today?
- 2. How would you define the concept of autonomy?
- 3. Have you ever sought health care services related to your sexual/reproductive health?
  - How old were you? First time? More than one occasion?
  - Where were you? Family doctor? Specialty clinic?
  - How did you know how to access those services? (e.g., asked a parent, friend)
- 4. Studies show that adolescents/youth do not frequently use sexual and reproductive health services, even though they have important health needs that should be addressed. Studies explain that there are different reasons / barriers for this phenomenon.
  - From your own experience, does this apply to you?
  - What are some of the barriers you might have experienced in accessing sexual and reproductive health services?
  - What did you find that helped you access health services?
- 5. When you visited a health professional for your sexual/reproductive health, did you go alone or accompanied?
  - Was it important for you to be alone or accompanied? Did that influence how you interacted with the health professional?
- 6. Public health experts argue for more autonomy for adolescents/young people to access sexual and reproductive health services.
  - Do you agree?
  - How do you define/interpret the concept of "empowering" adolescents to access health services?

- 7. What does autonomy represent/imply to you as a young person in accessing sexual health services?
- 8. If you could make one change to policies related to adolescent access to health services, what would it be?
- 9. Do you think it would be a great idea to have accessible online content (e.g., YouTube videos) that explains to teens how to access sexual health services? What type of content would you like to be present?
- 10. Is there anything else you would like to add on the topic?

<sup>1</sup> Shah, S. K., Essack, Z., Byron, K., Slack, C., Reirden, D., van Rooyen, H., ... & Wendler, D. S. (2020). Adolescent barriers to HIV prevention research: are parental consent requirements the biggest obstacle?. *Journal of Adolescent Health*, 67(4), 495-501.



# Comité d'éthique de la recherche en sciences et en santé (CERSES)

#### **CERTIFICAT D'APPROBATION ÉTHIQUE**

Le Comité d'éthique de la recherche en sciences et en santé (CERSES), selon les procédures en vigueur, en vertu des documents qui lui ont été fournis, a examiné le projet de recherche suivant et conclu qu'il respecte les règles d'éthique énoncées dans la Politique sur la recherche avec des êtres humains de l'Université de Montréal.

"Fostering Autonomy" for Adolescents to Access Sexual &

Reproductive Health Services: The case of Colombian & Venezuelan

Migrant Adolescents in Colombia

Étudiant requérant

Julien Brisson, Candidat au PhD, Ecole de santé publique

Sous la direction de:

Bryn Williams-Jones, Professeur titulaire, Ecole de santé publique & Vardit

Ravitsky, Ecole de santé publique

Financement		
Organisme	Instituts de recherche en santé du Canada	
Programme	Doctoral Award - Frederick Banting and Charles Best Canada Graduate Scholaships	
Titre de l'octroi si différent		
Numéro d'octroi	201610GSD-385545-283387	
Chercheur principal		
No de compte		

#### MODALITÉS D'APPLICATION

Tout changement anticipé au protocole de recherche doit être communiqué au Comité qui en évaluera l'impact au chapitre de l'éthique.

Toute interruption prématurée du projet ou tout incident grave doit être immédiatement signalé au Comité.

Selon les règles universitaires en vigueur, un suivi annuel est minimalement exigé pour maintenir la validité de la présente approbation éthique, et ce, jusqu'à la fin du projet. Le questionnaire de suivi est disponible sur la page web du Comité.

Marie-Josee Bernardi, vice-presidente Comité d'éthique de la recherche en sciences

et en santé (CERSES) Université de Montréal 17 juin 2019 Date de délivrance **1er juillet 2020** Date de fin de validité

1er juillet 2020 Date du prochain suivi



# Comité d'éthique de la recherche en sciences et en santé (CERSES)

17 juin 2019

Objet: Approbation éthique – « "Fostering Autonomy" for Adolescents to Access Sexual & Reproductive Health Services: The case of Colombian & Venezuelan Migrant Adolescents in Colombia »

M. Julien Brisson,

Le Comité d'éthique de la recherche en sciences et en santé (CERSES) a étudié le projet de recherche susmentionné et a délivré le certificat d'éthique demandé suite à la satisfaction des exigences précédemment émises. Vous trouverez ci-joint une copie numérisée de votre certificat. Nous vous invitons à faire suivre ce document au technicien en gestion de dossiers étudiants (TGDE) de votre département.

Notez qu'il y apparaît une mention relative à un suivi annuel et que le certificat comporte une date de fin de validité. En effet, afin de répondre aux exigences éthiques en vigueur au Canada et à l'Université de Montréal, nous devons exercer un suivi annuel auprès des chercheurs et étudiants-chercheurs.

De manière à rendre ce processus le plus simple possible, nous avons élaboré un court questionnaire qui vous permettra à la fois de satisfaire aux exigences du suivi et de nous faire part de vos commentaires et de vos besoins en matière d'éthique en cours de recherche. Ce questionnaire de suivi devra être rempli annuellement jusqu'à la fin du projet et pourra nous être retourné par courriel. La validité de l'approbation éthique est conditionnelle à ce suivi. Sur réception du dernier rapport de suivi en fin de projet, votre dossier sera clos.

Il est entendu que cela ne modifie en rien l'obligation pour le chercheur, tel qu'indiqué sur le certificat d'éthique, de signaler au CERSES tout incident grave dès qu'il survient ou de lui faire part de tout changement anticipé au protocole de recherche.

Nous vous prions d'agréer, Madame, Messieurs, l'expression de nos sentiments les meilleurs,

Marie-Josée Bernardi, vice-présidente Comité d'éthique de la recherche en sciences et en santé (CERSES) Université de Montréal

c.c. Gestion des certificats, BRDV
Bryn Williams-Jones, Professeur titulaire
Vardit Ravitsky, Ecole de santé publique

p.j. Certificat #CERSES-19-049-P

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