

#### REVIEW ARTICLE

Data gaps in adolescent fertility surveillance in middle-income countries in Latin America and South Eastern Europe: Barriers to evidence-based health promotion

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### **Abstract**

Adolescent health is a major global priority. Yet, as recently described by the World Health Organization (WHO), increased recognition of the importance of adolescent health rarely transforms into action. One challenge is lack of data, particularly on adolescent fertility. Adolescent pregnancy and childbirth are widespread and affect lifetime health and social outcomes of women, men, and families. Other important components of adolescent fertility include abortion, miscarriage, and stillbirth. Access to reliable, consistently-collected data to understand the scope and complexity of adolescent fertility is critical for designing strong research, developing meaningful policies, building effective programs, and evaluating success in these domains. Vital surveillance data can be challenging to obtain in general, and particularly in low- and middle-income countries and other under-resourced settings (including rural and indigenous communities in high-income countries). Definitions also vary, making comparisons over time and across locations challenging. Informed by the Adolescence and Motherhood Research project in Brazil and considering relevance to the Southern Eastern European (SEE) context, this article focuses on challenges in surveillance data for adolescent fertility for middleincome countries. Specifically, we review the literature to: (1) discuss the importance of understanding adolescent fertility generally, and (2) highlight relevant challenges and complexity in collecting adolescent fertility data, then we (3) consider implications of data gaps on this topic for selected middle-income countries in Latin America and SEE, and (4) propose next steps to improve adolescent fertility data for evidence-based health promotion in the middle-income country context.

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### Introduction

Adolescent health is a major global priority, particularly in the low- and middle-income countries where 90% of the 1.2 billion adolescents (aged 10-19 years) globally live, comprising over 20% of the total population in some countries (1,2). Recent work highlights urgent need for the comprehensive, integrated, and sustained investment in adolescent health (3-5). This can reap immediate rewards, and pay dividends into adult health and future generations (3-5). A major challenge towards this goal is access to reliable surveillance data, which is critical to designing effective policies, programs, and research and then evaluating their impacts across populations (2-5). Data gaps may be one critical reason why the growing recognition of the importance of adolescent health has not transformed into sufficient research, policy, and action (2-5).

Data limitations can be a specific problem in understanding adolescent fertility patterns, trends, and outcomes (6-13). Adolescent pregnancy and childbirth are widespread and affect lifetime health and social outcomes of women, men, and families (6-9). Other

important components of adolescent fertility include abortion, miscarriage, and stillbirth (14-16). Data on these topics can be challenging to obtain given the considerable stigma, measurement complexities, and cultural, demographic, and legal variation across regions and countries (6-16). There is also considerable overlap and variation in the terminology used to describe aspects and outcomes of adolescent fertility (6-13). (For clarity, Table 1 describes key terminology as used in this article.)

Informed by the Adolescence Motherhood Research (AMOR) project in Brazil (17) and considering the relevance to the Southern Eastern European (SEE) region, this article reviews the literature to: (1) discuss the importance of understanding adolescent fertility generally, highlight relevant challenges and complexity in collecting adolescent fertility data, then (3) considers implications of these data gaps for selected middle-income countries (MIC) specifically in Latin America and SEE, and (4) proposes next steps to improve adolescent fertility data for evidence-based health promotion in the MIC context.

Table 1. Key Terminology as used in this article

| Term                         | This Article  |  |  |  |
|------------------------------|---|--|--|--|
| <b>Adolescent Fertility</b>  | We use this term in a general sense to cover any pregnancy-             |  |  |  |
|                              | related experience among those 10-19 years of age,                      |  |  |  |
|                              | including live birth, abortion, stillbirth, or miscarriage. The         |  |  |  |
|                              | live birth could lead to parenting or to adoption. This can             |  |  |  |
|                              | include multiple pregnancies during this time of life.                  |  |  |  |
| <b>Adolescent Pregnancy</b>  | The terms describes a specific physiological state of                   |  |  |  |
|                              | pregnancy among those 10-19 years of age. Includes                      |  |  |  |
|                              | pregnancies ending in births, but also miscarriage and                  |  |  |  |
|                              | abortion*.  |  |  |  |
| <b>Adolescent Live Birth</b> | The term describes a specific outcome from an adolescent                |  |  |  |
|                              | pregnancy among women, specifically the outcome of                      |  |  |  |
|                              | delivering a living child among those 10-19 years of age <sup>†</sup> . |  |  |  |
| Adolescent Parenting         | This term describes one outcome that might follow a live                |  |  |  |
|                              | birth. In contrast to the other definitions that apply to               |  |  |  |



### women only, this term applies to both men and women.

\* http://origin.who.int/healthinfo/indicators/2015/chi\_2015\_37\_fertility\_adolescent.pdf.

## Section 1: Importance of Understanding Adolescent Fertility Patterns and Trends

Three major health risks stem from adolescent fertility. First, pregnancy during adolescence is associated with increased risk of maternal death and disability across a variety of outcomes, with unsafe abortion as one of the foremost contributors (14,16,18-22). Legal and social restrictions on access to safe abortion prompt adolescents to resort to procedures administered by unskilled providers and/or in unsafe conditions (14,16,20,21). Secondly, pregnancy and delivery during adolescence is associated with elevated risks of respiratory diseases, bearing premature birth trauma, and newborns with low birth weight (22). Finally, adolescent pregnancies are correlated with long-term consequences for the mother, including cardiovascular disease, mobility limitations, incontinence, and chronic pain (23,24).

There are also social consequences. Adolescent pregnancies, particularly those resulting in a child, may cause women to miss important life opportunities by dropping out of school and earning less over their lifetimes (1,2,25). Adolescent childbearing can also perpetuate intergenerational poverty through successive waves of adolescent mothers (26,27). It is additionally associated with interpersonal violence and contributes to higher risks of experiencing violence, with a number of negative impacts (28).

Understanding the patterns of adolescent fertility globally and within specific populations is thus vital for regional, national, and international public health. This is particularly true as the critical role of adolescence on health outcomes across the lifespan is increasingly recognized. As highlighted by Vinter et al (2015): "Adolescence is second only to fetal and infant life in the rapidity of growth and pervasiveness of change across body systems" (29).

# Section 2: Adolescent Fertility Data Gaps and Challenges for MIC

Despite the critical importance of this topic, finding relevant data can be challenging and/or have hidden complexities that obscures patterns, trends, and outcomes. Others have documented critical gaps in adolescent fertility data surveillance and management (3,4,6,7,14,30).

Besides adolescent fertility, many other relevant metrics and measures exist around other aspects of adolescent reproductive health (1-8,30). Some relevant examples include: adolescent abortion rate; adolescent marriage rate; access to contraception; use of contraception; use of modern contraception, a SDG (Sustainable Development Goals) target goal for those 15-49 years (31); planning status of adolescent pregnancy (intended, mistimed, unwanted); age at the time of the last pregnancy under 20; age at the time of the first pregnancy; marital status during adolescent pregnancy; and fertility preferences of currently married teenage women (want a child now, within a year, 2 years, later). Other important, related topics include sexual exploitation, sexual preferences, identity, sexually gender (1-8,30).transmitted These diseases

<sup>†</sup> https://data.worldbank.org/indicator/sp.ado.tfrt.



measures share many of the same challenges described in this article but are beyond the scope to discuss in detail.

We highlight some issues with relevance to MIC.

**Research.** First, it is important to note that research on adolescent health generally lags behind research in both child and adult health (1). This may help explain why the decrease in global burden of disease as measured in disability-adjusted life years for adolescents was less than the decrease for adults (3) and why adolescent health gains have been less than those for children (5).

Indicators. There are many relevant indicators in adolescent fertility, which are vital health indicators (30). For instance, rate of adolescent live birth is one of the 12 headline indicators proposed by the Lancet Commission on Adolescent Health and Wellbeing and one of 13 global health target measures for the 2030 SDG (11,31).

A recent paper by Azzopardi et al (2019) provided definitive estimates across many nations for these SDG indicators, including adolescent live birth, and gave a cumulative accounting of 11.7 million live births to adolescents between 15–19 years old in 2016 worldwide (3). While rates of adolescent live birth are decreasing in most countries, patterns vary considerably (3). For instance, Albania was one of only ten countries with an increase in the rate of adolescent live birth between 1990 and 2016 (3).

It is important to note the complexity in the measure of adolescent live birth, including how "adolescent" is defined (11). In the Azzopardi et al (2019) paper, the SDG "annual birth rate per 1000 adolescents aged 10-19 years" metric was measured by "live births per 1000 adolescents in females aged

15-19 years" (3). Of course, across the 10-19 age range many pregnancies occurred that did not result in a live birth, which can have health consequences and are thus also important to measure.

Table 2 shows in detail three of the most common ways that relevant constructs in adolescent fertility are actually measured in surveillance, providing calculations for the measure, and targeted critiques for these metrics (adolescent fertility rate, adolescent pregnancy, and adolescent girl pregnancy) (30).

Comparative data. Comparative data is important to understand regional differences cumulative global needs, which time necessitate similar frames and harmonized data (14). Adolescent health data in MIC can be found through national and cross-national surveillance systems. Many MIC publish their own vital statistics reports, but the quality of civil registration and vital statistics systems vary, even across MIC (32).

Many MIC also participate in cross-country surveillance systems toward global consensus indicators, including Demographic and Health Survey (DHS), the Multiple Indicator Cluster Survey (MICS), and Reproductive Health Survey (RHS) (33-36). These are administered by national health systems in conjunction with USAID (DHS & RHS) and UNICEF (MICS) (33-36). They use similar definitions of adolescent fertility, and often, have been administered consistently for many years. International comparison information for adolescent fertility and related measures are also compiled into databases by major organizations, including the United Nations (UN) (37), the World Bank (38), and the Global Health Data Exchange (39). Major international efforts generate point estimates



for country-level comparisons, allowing for cumulative global calculations for key indicators (3,14,21,33,40).

Table 2. Selected definitions for adolescent fertility measures\*

| Source | Indicator name(s)  | Calculation  | <b>Comments Numerator</b>  | <b>Comments Denominator</b>   |
|--------|--|--|--|---|
|        | Adolescent<br>birth rate<br>Adolescent<br>fertility rate | Number of live births to women<br>15-19 years /<br>Total number of women 15 to<br>19 years                           | Excludes very young adolescents (10-14-year-olds)  Excludes miscarriages,  | Requires vital statistics for denominator, which can be challenging in very low income settings   |
| UNFPA  | Age-specific fertility rate                              |  | stillbirths, and abortions.  Measure of adolescent childbearing, not pregnancy                                     | Assumption that all women 15-19 years are <i>at risk</i> of pregnancy and thus, presumably that all women in this age group have already hit puberty. This may not be the case in communities with elevated malnutrition or illness that affect pubertal timing.  |
| UNFPA  | Adolescent<br>pregnancy                                  | Number of women aged 20-24<br>that had a live birth before the<br>age of 18 / Total number of<br>women aged 20 to 24 | Excludes miscarriages, stillbirths, and abortions.  Measure of adolescent childbearing, not pregnancy              | Excludes those who died prior to adulthood, such as those who died in childbirth and/or those living in violent communities. May underestimate adolescent pregnancy/childbirth in the most disadvantaged areas. Requires vital statistics for denominator, which can be challenging in very low income settings |
| UNFPA  | Adolescent<br>girl<br>pregnancy                          | Number of women aged 20-24<br>that had a live birth before the<br>age of 15 / Total number of<br>women aged 20 to 24 | Excludes miscarriages,<br>stillbirths, and abortions.<br>Measure of adolescent girl<br>childbearing, not pregnancy | Similar to above. The issue of deaths before reaching 20-24 is particularly problematic in this group because of the very high risk of maternal mortality in lowincome settings, among adolescents having children.   |

<sup>\*</sup> Loaiza E, Liang M. (2013). Adolescent pregnancy: A review of the evidence. New York, NY: UNFPA.

These readily available metrics are valuable, and provide vital comparative data, but as in the live birth example above, in the background is variation and complexity. Many MIC have incomplete data for adolescent reproductive health outcomes and/or contextual variables (income

inequality, social determinants of health) to better understand variation, patterns, and reasons for those outcomes (12,13). The DHS, MICS, and RHS are not completed yearly, and some countries have not done them recently or at all. For instance, Brazil has not completed a post-2000 DHS (41).



Countries, who have cost sharing for these surveys, have autonomy to add questions and determine sampling frames, which may vary. For instance, many locations did not include unmarried adolescents in questions about sexual activity, use of contraception, or childbearing intentions in past DHS; this continues in a few DHS programs (33,36). Additionally, while many global health indicators seem straightforward presented in tables comparing outcomes across countries, plotted in useful maps (41) included in sophisticated visualizations (43), they are often obtained from very complex statistical models, different time periods, and/or may have missing data generated through sophisticated algorithms (3,14,19,33). In some cases, cross-national comparisons are created where at least some studies have national data extrapolated from smaller studies (14.19). These estimates often do not provide region or focal population specific statistics, which can vary in critical ways within a country. Whatever the indicator, there can be incentives to suppress data for political reasons (5), making the data unreliable in ways that will not be visible in public reports or comparisons.

Stigma. There are also critical gaps in adolescent fertility data due to underreporting (6). Many adolescents do not want to admit to sexual behavior. These actions and consequences are stigmatized and can be illegal, particularly induced abortion. The implications of these issues for data quality vary by country, and by context within countries (6). School-based youth risk behavior surveys may omit sensitive questions due to stigma and discomfort, exclude younger adolescents, and miss those who are not attending school, but who are particularly vulnerable (44). Informed consent at this age can be complex and parents may refuse to let their children participate in health surveys that include these issues.

Missing populations. Many major yearly public health surveillance instruments (e.g., BRFSS in the US) exclude those younger than 18 as primary respondents. As in school-based settings, adolescent sexuality questions may be deemed too sensitive (or unreliable) respondents. for proxy Population-based telephone surveys may also miss vulnerable communities, including refugee, migrant, homeless and street youth (6,7). School-based surveys miss students who have left school, including those who did so because they are parenting. Thus, many critical communities related to adolescent fertility are excluded from surveillance. There is also a lack of attention adolescent male fathers. This problematic because many assume parenting roles and after doing so, like their female counterparts, become adversely impacted. For example, younger age at birth of first child in men, as well as women, has been associated with greater risk of cardivascular disease (45). However, global data is insufficient on the quantity of adolescent pregnancies fathered by those themselves. Some DHS programs do not survey adolescent men at all (46).

Adolescents less than 15 years of age. Adolescents younger than 15 are often left out of measurement for fertility issues. For instance, much DHS data uses the 15-19 age category to determine adolescent births, excluding the very young and high-risk births. This is a problem because younger girls generally have more complications



with pregnancy and childbirth versus older ones (44,46).

**Repeat births.** Limited guidance exists on repeat birth, especially rapid repeat pregnancy (within 2 years of the index pregnancy). Data on this is particularly limited in MIC, but evidence from higherincome settings indicate that rapid, unwanted repeat pregnancies are relatively common among adolescents (9).

Disaggregated data. There is a critical need to disaggregate data by community, vulnerability, and narrower age groups to identify true needs and risks (6). For instance, while adolescent health data is typically aggregated for 15-19-year-olds in many MIC, the pregnancy rate is higher among 18-19-year-olds than among 15-17-year-olds (14).

Abortions, miscarriages, and stillbirths. Especially given that a large percentage of adolescent pregnancies are unwanted or unintended (82% in a US study) (14), not all adolescent pregnancies end in a live birth. While birth data are generally complete, collection and evaluation of abortion data and estimation of miscarriages globally and by country are limited (14). Miscarriage among adolescents may go unrecognized (14). Stillbirths, a major issue in many MIC, can be hard to definitively quantify (47,48). These issues can vary greatly by location and reporting laws (voluntary or required, sanctions), and the role of the public and private health sectors; where abortion is legally or logistically restricted may be both the least likely to have relatable data on abortion as well as most likely to have unsafe abortions (14,16,20,21). Abortion policies can vary greatly in a short time period, impacting data reporting patterns, validity, and completeness over time (14). In places were abortion is illegal, there are clandestine clinics unknown to the health system and that do not provide information to national registries or researchers resulting in underestimates of true prevalence.

Cross-Sectional Data. The cross-sectional nature of data typically collected on adolescent fertility also impacts research consequences of adolescent into the related issues, pregnancy socioeconomic characteristics are measured at the time of the survey, not at birth or during pregnancy (49). In retrospective surveys, a woman's situation may have changed considerably. She may have experienced a socioeconomic downturn subsequent to the delivery; for instance, some adolescents are kicked out of their homes if they become pregnant. Cohort effects can also be an issue; yet, little longitudinal research exists on this topic, especially cross-cultural from large, populations (50).

Good Sexual Health. Most adolescent fertility surveillance metrics focus on risk and danger (pregnancy, sexually transmitted disease), treating all adolescent sexuality as negative (51,52). We know little about childbearing desires (6) or positive sexual health. In some communities, childbearing and marriage at this age are common and surveillance systems might build distrust by taking a completely negative perspective on this issue (7,53).

Consequences of these gaps and challenges. Many adolescent pregnancies and the negative consequences are preventable, but inconsistent and unreliable



data can make it hard to design effective solutions across all populations. Ignoring inequality between specific groups can hide critical disparities, including a fundamental cause of intergenerational cycles of poverty. There can be considerable variation in data quality across regions within countries, across countries, and across regional groupings of countries. This complexity (not always acknowledged) to comparisons, international and makesevidence-based policy and the evaluation of those policies challenging (4,5,54,55). Yet, better surveillance may bring unwelcome or unexpected findings as key metrics may increase, impacting funding priorities or political momentum. Without nuanced, meaningful, consistent including data sensitive to subtle and incremental change, it is challenging to design programs, policies, and research to address adolescent fertility issues and hard to measure intervention effects (49).

## Section 3: Data Challenges in the MIC Context

We now specifically consider these adolescent reproductive health data challenges from experiences in the AMOR project in a Latin America context, followed by a consideration of these issues in the SEE context.

The Adolescence and Motherhood Research (AMOR) Project. The AMOR project (17) is a research initiative with two complementary study aims of improving quantitative health research capacity in a low-income rural area of Northeast Brazil, while completing a pilot project towards the long-term objective of building sustainable infrastructure for research to elucidate pathways between adolescent childbirth and

adverse health conditions across the lifecourse (23). As part of this study, a pilot cohort of adolescents, pregnant for the first time, was recruited in the first trimester of pregnancy and followed over time.

Measurement/Regional Data. Brazil is a large MIC with substantial socioeconomic regional divides. Many states in Northeast Brazil, such as Rio Grande do Norte, rank last for income, education and social services, while other states in the south of the country, such as São Paulo, are relatively well off (56). In Brazil, the National Information System on Live (SINASC), implemented gradually in all states since 1990 (57), receives live birth information from all maternity hospitals and other health units.

Although there is increasing coverage of SINASC across the states, scale-up has occurred differentially across Brazil. For example, it was estimated that the coverage rate of SINASC reached almost 100% for the South, Southeast and Midwest regions in 2011, but it was between 70-90% for most of the poorer Northern and Northeastern states (58). Although SINASC provides useful data about rates of live birth for women of specific age-groups and regions over the years, incomplete data in some registers, particularly in the less advantaged regions, and the lack of information about miscarriages or abortions, limits its use for the understanding of adolescent pregnancies. The Brazilian Institutes of Geography and Statistics (IBGE) performs a demographic census in Brazil every decade and provide information about adolescent childbirth rates, but its use is limited given the large time lag between surveys. During the years between the censuses, the IBGE performs an annual National Household Sample Survey.



However, because data is collected on a sample of households for each state, information about the levels and patterns of adolescent fertility, as well as any spatial disaggregation generated by such estimates are limited by small sample sizes. Moreover, questions about adolescent fertility are directed only for girls aged 15 or older.

Study Recruitment. Planning the AMOR project recruitment was difficult due to such data gaps. Our target sample included adolescents in the first pregnancy aged between 13-18 years-old from the Trairi region of the Rio Grande do Norte state. Using information from SINASC, we identified the number of live births from adolescents in the target towns during the previous years, but the data regarding adolescents from 13-18 vears aggregated into the 10-19-year age group. In particular, the number of adolescent pregancies increases dramatically when age 19 is included, showing the importance of relevant data disagregation.

Once the project was underway, we also needed adolescent birth rate for our focal location to understand the scope, representation, and success of our study recruitment. Again, aggregated information by age groups from SINASC prevented us from being able to do these estimates. We also were unable to estimate miscarriages, which were not included in the SINASC data, but were ultimately seen in 8% of our adolescent sample after baseline evaluation.

Latin America Context. Regional relevance and knowledge are important for consideration of these data gaps in Brazil. Adolescent fertility rates in the WHO Latin American and Caribbean region are the second highest in the world, much higher than in other regions with similar levels of development (49). While total fertility has dropped in recent decades, adolescent fertility rates have dropped much less sharply (46). The high rates of adolescent fertility can be seen in the Latin American Table 3.

Table 3. Adolescent birth rate (births per 1,000 women ages 15-19) available by selected countries in Latin America and South Eastern Europe by source\*

| Indicator   | Latin America Examples |          |          | South   | South Eastern European<br>Examples |        | Notes  |
|---|------------------------|----------|----------|---------|------------------------------------|--------|--|
|   | Brazil                 | Colombia | Honduras | Albania | Romania                            | Serbia |  |
| Azzopardi et al,<br>2019, Lancet<br>article (data from<br>2016) <sup>†</sup>  | 66.8                   | 41.6     | 72.6     | 21.8    | 32.2                               | 16.1   | Data is "Birth rate (live<br>births per 1000<br>population per year) in<br>females aged 15–19<br>years." Representing<br>SDG Metric: "Annual<br>birth rate per 1000<br>adolescents aged 10–19<br>years." |
| World Bank<br>database<br>adolescent fertility<br>rates (data from<br>2016) ‡ | 62.7                   | 49.5     | 72.1     | 20.7    | 33.7                               | 19.3   | Yearly adolescent<br>fertility rate since 1960<br>by countries with<br>regional benchmarks.  |
| Adolescent Birth<br>Rate Map  | 65                     | 85       | 99       | 18      | 36                                 | 22     | Map with comparisons by countries. Per   |



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| Adolescent Health<br>UNICEF <sup>¶</sup>   |                |                |                |                |      |      | website "Most recent<br>estimates for each<br>country taken from<br>2015 Update for the<br>MDG Database:<br>Adolescent Birth Rate<br>(UNFPA/UN<br>Population Division)." |
|--|----------------|----------------|----------------|----------------|------|------|--|
| United Nations<br>age-specific<br>fertility rates<br>(2010-2015) <sup>§</sup>                                  | 67.0           | 57.7           | 77.8           | 20.7           | 36.4 | 21.0 | 5-year average age-<br>specific fertility rates<br>from 1950-1955 with<br>regional benchmarks.   |
| WHO Adolescent<br>birth rate by WHO<br>region, 2005-<br>2016**   | 60.8           | 71.6           | 101.0          | 18.9           | 35.3 | 16.4 | Data visualization with<br>comparisons by<br>countries within WHO<br>regions and global and<br>regional benchmarks.  |
| Demographic and<br>Health Survey<br>(DHS) <sup>††</sup> (date of<br>most recent DHS<br>included on<br>website) | 87.9<br>(1996) | 85.1<br>(2010) | 99.0<br>(2011) | 19.6<br>(2008) | N/A  | N/A  | Adolescent birth rate information by country. Subnational information available by income quartiles and rural/urban.   |

<sup>\*</sup> As Shown by Source as of March 15, 2019.

Though abortion and contraception are heavily restricted in this region, many occur nonetheless, often unsafely (46,49,59). Adolescent fertility is considered to be high with little use of modern contraceptives; there are an estimated 600,000 unplanned pregnancies in adolescents, and about half of women giving birth for the first time are in their teens (50). Many Latin American nations have adolescent pregnancy and health inequalities by population or region, but these disparities are hidden by

aggregated national-level data (46). Gender-based violence is a significant problem in Latin America, though sexual coercion and abuse from adult males are not reliably or consistently recorded in adolescent health surveillance data (46).

Examples. To demonstrate an example of the general data complexity mentioned in section 2 applied to the Latin American context, Table 3 provides comparative data specifically for one metric (adolescent fertility rate) for three Latin American

<sup>&</sup>lt;sup>†</sup> Azzopardi PS, Hearps SJC, Francis KL, et al. Progress in adolescent health and wellbeing: tracking 12 headline indicators for 195 countries and territories, 1990–2016. Lancet 2019; published online March 12. http://dx.doi.org/10.1016/S0140-6736(18)32427-9.

<sup>\*</sup> SP.ADO.TFRT from World Bank Website downloaded https://data.worldbank.org/indicator/sp.ado.tfrt 3.14.2019.

<sup>¶</sup> https://data.unicef.org/topic/maternal-health/adolescent-health/ -- Adolescent birth rate by country (number of annual births per 1000 adolescents aged 15-19).

https://population.un.org/wpp/Download/Standard/Fertility/ FERT/7: Age-specific fertility rates by region, subregion and country, 1950-2100 (births per 1,000 women).

<sup>\*\*</sup> http://apps.who.int/gho/data/node.sdg.3-7-viz-2?lang=en SDG Target 3.7 World Health Statistics data visualizations dashboard SDG Target 3.7 | Sexual and reproductive health; Adolescent birth.

<sup>††</sup> http://apps.who.int/gho/data/view.main.vURBADOBIRTHTOTv Adolescent birth rate Data by country; Per website: Last updated: 2016-03-23.



Countries (Brazil, Colombia, and Honduras) taken from current online resources or recent, influential publications from reliable sources.

Data is also provided for three SEE countries (Albania, Romania, and Serbia). This table demonstrates inconsistent results, timing differences of data collection, and the importance of these issues on demonstrated

trends. While some variation is to be expected over time, there are large differences across measures. For instance, measures for Honduras vary from 72.1 to over 100 per 1000 women. Table 4 summarizes some key challenges in the Latin America context in adolescent fertility surveillance.

Table 4. Some Important data gaps by region for South Eastern Europe and Latin America

| Location                         | What is missing for surveillance?   | Context specific challenges   | Specific areas in the country where there are data gaps and challenges   |
|----------------------------------|---|---|--|
| South Eastern Europe<br>Examples | Pregnancies Teen pregnancies which end in abortion Adolescent births outside the marriage Teen pregnancies which end in miscarriages  | Despite some standardized instruments there are differences in indicators used to monitor the problem.  Different indicators used by EU (Eurostat) and UN  DHS is not carried out by all SEE countries. It is not planned for the future and needs to be substituted by good surveillance data  | Important discrepancies especially in abortion rates among surveillance and DHS/RHS. Limited studies in Serbia, Bulgaria and Albania show very high risk among Roma population compared to general. Most surveillance data do not allow specific monitoring of this ethnic group.  |
| Latin American Examples          | Data about abortion: According to the most recent estimate, about 99% of abortions in Colombia are performed outside the law (impossible to obtain direct data about these) Data on interpersonal violence in pregnancy Information relevant to infectious diseases such as Zika, which may have influenced abortions Stillbirths | Abortion in Brazil and Colombia are legal only in very specific circumstances. In Colombia this includes the following circumstances since 2006: The continuation of the pregnancy constitutes a danger to the life or health of the mother; The existence of life-threatening fetal malformations; The pregnancy is the result of rape, non-consensual artificial insemination or incest. Vulnerability is hidden and patterns of risk or illness may not reflect facts. | Northeastern Brazil has lower surveillance, with relevance to Adolescence and Motherhood Research study planning and recruitment evaluation, and to other studies on similar populations.  While the rich in many Latin American countries may have access to abortions, this is not the case for the poor. Thus, more cases of microcephaly may have occurred from Zika that were not reported as those who were rich could have received abortions that were never recorded. This can impact regional estimates as well as surveillance generally. |

Southern Eastern European context. The SEE region is mostly made of MIC transitioning from ex-communist societies to European Union (EU) associates, including Albania, Bosnia and Herzegovina, Bulgaria,

Croatia, Northern Macedonia, Moldavia, Montenegro, Romania, Serbia, and Ukraine. This context has both similar and unique adolescent reproductive health data gaps to those discussed above (60,61). These



countries have a very different historical and economic background from the Latin American context.

While this region has some of the lowest rates of adolescent-girl pregnancies among all LMIC (31), rates remain higher than the EU average. Some Eastern European EU members in the SEE region, notably Romania and Bulgaria, have high rates of adolescent pregnancy relative to peer states (62). Also, although the SEE region is rated relatively high in terms of equality as measured by Gini index, the trends of 'adolescent-girl pregnancies' rates disproportionally unfavorable among the poorest (31,62,63).Usage rates contraceptive methods, including modern methods, remain very low in SEE (63). Abortion has dropped significantly in the region, since the 1990s, but reliance on abortion as a means of fertility control remains high in some countries (62,63).

Variation and measurement challenges are demonstrated in Table 3 for the SEE counties. Misinterpretation of indicators or in data can cause significant gaps inconsistencies in reporting of adolescent fertility rates across sources for the same country in the region (63,64). When comparing adolescent fertility rates among SEE countries, Albania appears to be the only one showing a reverse of the general decreasing trend during the last decade. Romania has one of the highest adolescent birth rates in the region. The three major surveillance instruments (DHS, RHS, and MICS) have been implemented in Albania, in consecutive rounds, with the most recent published on December 2018. The latest DHS or RHS reports from other SEE countries are from more than 10 years ago. Besides the metrics in Table 3. Albania also has official administrative data from birth registration. Accordingly, the adolescent fertility rate is 15.96 (65), considerably lower than estimates from other survey-based surveillance sources.

According to some estimations, Romania has one of the highest "young adolescent" birth rates in the world (14). Data from the 2005 Romanian RHS, which could be outdated, show regional variation with the rate of young adolescent births per 1000 to be 10 in urban areas compared to 46 in rural areas (66). Similarly, some data from the Serbian MICS 2014 allows detailed analyses of adolescent fertility indicators among settlements where rates exceptionally high compared to general population (67,68).In some Roma settlements, 32.8% of adolescents are having children (23.8% given birth; 9% pregnant) (68). As in Latin America, most SEE lack reliable country-level data on abortion (14). When they do, the data conflict. For instance, 2017 Albanian estimates of the adolescent abortion rate were 2.1 per 1000 live births among those 15-19 years from abortion surveillance data (69), while an estimate based on DHS is lower at 1 per 1000 women for those 15-19 years (70). Data from Romania is from 2005, which estimates the adolescent abortion rate (for three years prior to survey) at 10 per 1000 women 15-19 years, which is a decrease from 26 per 1000 women 15-19 in the RHS 2000.

One additional interesting issue is that this region is defined differently by various international organizations (60,61). Many other locations have similar benchmark/comparator issues. Table 4 also summarizes some key challenges for SEE region in adolescent fertility surveillance.



# Section 4: Ideas for Solutions and Conversations

In order to design targeted interventions to improve adolescent health, there is a need to better understand data and needs around critical metrics of relevance to these population groups. Darroch et al (6) provide some excellent solutions. These include: using creative analyses of existing data to consider reporting by those over 15 of their experiences before 15, though this is subject to limitations in report and recollection, particularly over time; broadening existing national surveillance to better include excluded groups (younger women, nevermarried women); and creating focused, youth-targeted surveys especially including vulnerable communities. Harmonized data needed systems also consensus/standardization of various instruments used in various MIC, with buyin from relevant organizations, including WHO, UNICEF, UNFPA, World Bank, USAID, and Eurostat (1,71-73). Shared goals (such as SDG targets) can provide momentum to achieve these goals. Indeed, there are critical new movements towards health data collaboratives (1,71-73), though these have many challenges (74,75). Engaging the health system may help fill in some data gaps, such as increasing the stimuli for the health units/ providers to provide the information properly, to fill out the forms, making them understand its importance or giving some credits for who does. This should be a priority especially in countries where population surveys have failed to overcome stigma and produced lower rates than surveillance systems. Other options include using specific studies to represent larger regions, but these do not solve issues where there is no data or where it has critical gaps for underreported or missing groups. In fact, this could obscure these issues even more dramatically. Also, for better data, more longitudinal studies are needed with data about teen pregnancy and the consequences over time, physically, emotionally, and situationally.

One way to address these issues is to have conversations across settings. We invite interested readers with similar, or different, challenges to share their concerns to be compiled in future work. The survey will be open from April 1, 2019 to January 1, 2020: http://hawaiidphs.co1.qualtrics.com/jfe/form/SV 7UTmvPGiFHiQ5KJ.

### **Conclusions**

Adolescent health is increasingly recognized as a major global priority, necessitating comprehensive, integrated, and sustained investment to allow this population to achieve their full potential and most optimal wellbeing (1,3). This investment can reap rewards. As the Lancet Commission on Adolescent Health and Wellbeing highlighted, this time period is foundational to physical, cognitive, emotional, social, and resources, concluding economic "Investments in adolescent health and wellbeing bring benefits today, for decades to come, and for the next generation" (5). Variation in the measures, and the absence of other important metrics, may contribute to misleading conclusions about who is at risk, trends in rates, and the success or lack thereof of interventions. With improved collection of this health data, governments are better equipped and informed to prioritize health challenges, develop policies, deploy resources, and measure success (6,7,73-77). In the absence of this information, it is challenging to develop appropriate adolescent reproductive health programs and interventions.



While this paper focused on adolescent pregnancy, these data collection challenges could be relevant to many other adolescent health issues that are preventable but also neglected, such as mental health, drug abuse, intentional and unintentional injuries, or sexually transmitted infections (2). Other sexual and reproductive health problems, including HIV/AIDS, remain a major concern for adolescent health, particularly in some regions. Collecting substance use data

and adolescent violence have related issues and also relationships with adolescent sexual choices and behaviors. These all share stigma. Yet these all appear in adolescence with considerable consequences to adolescent immediate and future health as well as their future families (2), and connect back to the recognition that adolescent health generally, and adolescent fertility specifically, are critical parts to a life-course perspective on adolescent health (1,5,9-11).

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