

Contact Information

Presenting Author: Mrs. Nachizya Edith Namukanga
Department of Epidemiology & Biostatistics, School of Public Health, University of Zambia
School of Health and Applied Sciences, UNICAF University

Email: nachizyanamukanga@gmail.com

Executive Summary

This dissemination package accompanies the poster presentation titled:

“Assent, Consent, and Care”: Ethical Reflections on Participatory Research with Adolescents on Primary Dysmenorrhea in Lusaka, Zambia.

The study highlights the ethical complexities of engaging adolescents in sensitive health research. Through participatory visual methods such as DrawingOut workshops and in-depth interviews, the research explored girls’ experiences of primary dysmenorrhea, while critically examining issues of assent, consent, and care.

Key Findings:

Adolescents often felt uncertain about their ‘permission’ to speak on menstruation due to cultural taboos.

Drawing activities created space for some to express menstrual pain for the first time.

Even with consent, stigma and surveillance limited openness.

Ethical clearance alone proved insufficient; true ethics demanded relational engagement and sensitivity.

Conclusion: Ethical adolescent health research requires a paradigm of care honoring agency without exposure, voice without pressure, and participation without assumption.

Title

“Assent, Consent, and Care”: Ethical Reflections on Participatory Research with Adolescents on Primary Dysmenorrhea in Lusaka, Zambia

Presenting Author Mrs. Nachizya Edith Namukanga

Affiliations: Department of Epidemiology & Biostatistics, School of Public Health, University of Zambia, School of Health and Applied Sciences, UNICAF University

Co-Author Prof Joseph Mumba Zulu

Affiliations: Department of Health Policy and Management, Health Promotion and Education, School of Public Health, University of Zambia

Co-Author Dr Margarate N Munakampe

Affiliations: Health Policy and Management Department, School of Public Health, University of Zambia

Co-Author Prof Choolwe Jacobs

Affiliations: Department of Epidemiology & Biostatistics, School of Public Health, University of Zambia

Theme Adolescents Policy, Legal Aspects, Consent, Rights, and Stigma

Abstract

Background

Adolescent health research often grapples with the tensions between protection and participation, particularly when it involves sensitive subjects like menstruation and pain. In Zambia, where menstrual health remains under-prioritized and under-discussed, this study sought to center adolescent girls' lived experiences of primary dysmenorrhea through participatory visual methods. In doing so, it raised critical ethical questions about assent, consent, voice, and care.

Methods

As part of a larger mixed-methods doctoral study, this qualitative phase involved adolescent girls aged 10–19 from public and private schools in Lusaka. DrawingOut workshops and in-depth interviews were used to elicit personal narratives of menstrual pain, stigma, and coping. Ethical protocols included obtaining written informed consent from participants aged 18–19, and dual processes of parental consent and adolescent assent for those under 18. A trauma-informed, gender-sensitive approach guided facilitation and analysis.

Findings

Beyond the data on pain and coping, the research process itself revealed how ethics must move beyond procedural compliance to relational engagement. Younger adolescents expressed uncertainty about “permission to speak” on topics deemed taboo. For some, the act of drawing became their first opportunity to articulate menstrual suffering. Others, despite formal consent, remained guarded due to school surveillance, fear of judgment, or internalized stigma. Facilitators often had to negotiate unspoken boundaries of silence, shame, and duty. These moments underscored that “ethical clearance” alone is insufficient when working with minors on embodied, gendered experiences.

Conclusion

This study illustrates that ethical research with adolescents requires a paradigm of care, not just consent one that honours agency without exposure, voice without pressure, and participation without assumption. As SRHR programs and policies increasingly call for youth engagement, researchers must confront the quiet power dynamics that shape how, when, and whether adolescents are truly heard.

Keywords:

Adolescent research ethics, primary dysmenorrhea, assent and consent, participatory methods, menstrual health, Zambia, SRHR, power dynamics, DrawingOut, feminist research



"ASSENT, CONSENT, AND CARE": ETHICAL REFLECTIONS ON PARTICIPATORY RESEARCH WITH ADOLESCENTS ON PRIMARY DYSMENORRHEA IN LUSAKA, ZAMBIA

220

THEME: ADOLESCENTS POLICY, LEGAL ASPECTS, CONSENT, RIGHTS, AND STIGMA

AUTHORS & AFFILIATIONS

Presenting Author:
Ms. Nachizya Edith Namukanga
Department of Epidemiology & Biostatistics, School of Public Health,
University of Zambia
School of Health and Applied Sciences, UNICAF University

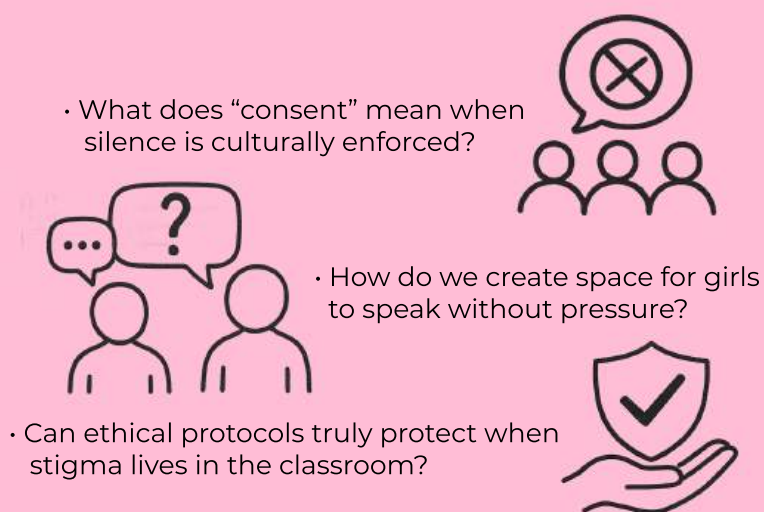
Co-Authors:

Prof Joseph Mumba Zulu
Dept. Health Policy & Management, SPH, UNZA
Dr. Margarate N Munakampe
Dept. Health Policy & Management, SPH, UNZA
Prof Choolwe Jacobs
Dept. Epidemiology & Biostatistics, SPH, UNZA

BACKGROUND

Adolescent health research walks a tightrope, balancing protection with meaningful participation. In Zambia, menstruation remains shrouded in silence and stigma. When researching sensitive topics like primary dysmenorrhea (painful periods), ethical engagement must go beyond paperwork.

This study centered adolescent girls' voices using participatory methods and in doing so, uncovered deeper questions:



METHODS

How We Listened

As part of a mixed-methods doctoral study, we engaged girls aged 10–19 from public and private schools in Lusaka using:

• Drawing Out Workshops;
Visual storytelling to express pain, stigma, coping



• In-Depth Interviews;
Safe-space conversations guided by trauma-informed principles

Ethical Safeguards:

- Written consent (ages 18–19)
- Dual process: Parental consent + adolescent assent (under 18)
- Gender-sensitive, trauma-informed facilitation
- Confidentiality and emotional safety prioritized

KEY FINDINGS

What We Learned — Beyond the Data

The research process itself became a mirror for ethical tensions: Younger girls (10–14) often asked: “Am I allowed to talk about this?”, revealing how taboo silences voice.



For some, drawing was the first time they named their pain, not in words, but in color and shape.

Even with “consent,” many remained guarded, due to fear of teachers, peers, or internalized shame.

Facilitators constantly negotiated invisible boundaries: silence, duty, and cultural expectation.

Takeaway:
Ethical clearance ≠ ethical practice.
True ethics is relational, responsive, and rooted in care.



CONCLUSION & IMPLICATIONS

Rethinking Ethics: From Compliance to Care

Working with adolescents on embodied, gendered experiences demands more than forms, it demands presence, patience, and partnership.

For Researchers: Move beyond “tick-box ethics.” Build trust. Honor silence as much as speech.

For Policymakers: Youth engagement in SRHR must confront power; who speaks, who listens, and who decides.

For Ethics Boards: Review protocols must account for cultural stigma, surveillance, and emotional safety, not just legal consent.

Our Call: Let “care” be the compass, honoring agency without exposure, voice without pressure, participation without assumption.

KEYWORDS & CONTACT

Keywords:

Adolescent research ethics • Primary dysmenorrhea • Assent & consent
• Participatory methods • Menstrual health • Zambia • SRHR
• Power dynamics • DrawingOut • Feminist research

Contact:

Nachizya Edith Namukanga
nachizyanamukanga@gmail.com
University of Zambia | UNICAF University



REFERENCES

- Mangochi, H., Gooding, K., Bennett, A., et al. (2019). How should assent to research be sought in low income settings? Perspectives from parents and children in Southern Malawi. *BMC Medical Ethics*, 20(1), 32. <https://doi.org/10.1186/s12910-019-0369-7>
- Parker, M., & Cheah, P. Y. (2014). Consent and assent in paediatric research in low-income settings. *BMC Medical Ethics*, 15(1), 22. <https://doi.org/10.1186/1472-6939-15-22>
- Folayan, M. O., Haire, B., Harrison, A., Fatusi, O., & Brown, B. (2015). Beyond informed consent: Ethical considerations in the design and implementation of sexual and reproductive health research among adolescents. *African Journal of Reproductive Health*, 18(3), 118–126.
- Loveday, M., Goga, A., Dhali, A., Labuschaigne, M., Roussouw, T., Burgess, T., et al. (2022). Ethically acceptable consent approaches to adolescent research in South Africa. *Southern African Journal of HIV Medicine*, 23(1), a1385. <https://doi.org/10.4102/sajhivmed.v23i1.1385>



Supporting Publications

Full papers related to this study can be accessed at the following links:

1. Journal of Health Research: <https://jhr.ssu.ac.ir/article-1-1073-en.pdf>
2. American Journal of Public Health Research: <https://pubs.sciepub.com/ajphr/13/1/1/index.html>

Acknowledgements

I extend my deepest gratitude to my supervisors Prof Joseph Mumba Zulu, Dr. Margarate N Munakampe, and Prof Choolwe Jacobs for their guidance and commitment to ethical, girl-centered research. I also acknowledge the support of my family, whose patience and encouragement made this work possible. Additionally, I recognize the invaluable contribution from Mawazo Institute and its partners in supporting my research.