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Research Participation and Feedback: Perception of Adolescents and Young Adults Living with HIV in Lagos, Nigeria

Participation à la Recherche et Retour d'Information : Perception des Adolescents et Jeunes Adultes Vivant Avec le VIH à Lagos, Nigeria.

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ABSTRACT

BACKGROUND: Evidence-based research remains the cornerstone in changing the narrative of wholesome health among Adolescents and Young Adults Living with HIV (AYALHIV). However, little is known about the perceptions of AYALHIV in research participation and outcomes, in low- and middle-income countries, especially in sub-Saharan Africa. This study describes the perception of AYALHIV in research participation and outcome in Lagos, Nigeria

METHODS: The study population was drawn from a cohort of participants in a cross-sectional study at the Nigerian Institute of Medical Research. The survey questions were on perceptions of the importance of research participation, the frequency, understanding of participation in research, the interest in the outcome, the knowledge of the interpretation of the outcome and the willingness to participate in future studies. Data obtained was analyzed using SPSS version 26.0.

RESULTS: The mean age of the AYALHIV was 15.7(\pm 3.1) years, with a male-to-female ratio of (0.8:1), and 85.7% on antiretroviral drugs for at least five years. Seventy-two percent (46/63) have been involved in previous studies at least once, with only 27% (17/63) informed on the outcome of the research they have ever participated. Only 30% (19) of participants understood they were involved in research, with 92% interested in the study outcome. 87.3% (55) will request more information before participating in future research activities.

CONCLUSION: Educating AYALHIV on research participation is important in promoting concerted efforts by researchers towards improving engagement, patient-centred care, and research dissemination. *WAJM 2024; 41 (7): 748 - 754*

KEYWORDS: HIV, Adolescent, Young Adults, Perception, Research

RÉSUMÉ

CONTEXTE: La recherche fondée sur des données probantes reste la pierre angulaire du changement du discours sur la santé saine chez les adolescents et les jeunes adultes vivant avec le VIH (AYALHIV). Cependant, on sait peu de choses sur les perceptions de l'AYALHIV dans la participation et les résultats de la recherche, dans les pays à revenu faible et intermédiaire, en particulier en Afrique subsaharienne. Cette étude décrit la perception d'AYALHIV dans la participation et les résultats de la recherche à Lagos, au Nigéria.

METHODES: La population m'étudiée a été tirée d'une cohorte de participants à une étude transversale menée à l'Institut nigérian de recherche médicale. Les questions de l'enquête portaient sur les perceptions de l'importance de la participation à la recherche, la fréquence, la compréhension de la participation à la recherche, l'intérêt pour les résultats, la connaissance de l'interprétation des résultats et la volonté de participer à des études futures. Les données obtenues ont été analysées à l'aide de SPSS version 26.0

RESULTATS: L'âge moyen des AYALHIV était de 15,7 (\pm 3,1) ans, avec un ratio hommes/femmes de (0,8 : 1) et 85,7 % prenaient des médicaments antirétroviraux depuis au moins cinq ans. Soixante-douze pour cent (46/63) ont participé à des études antérieures au moins une fois, et seulement 27 % (17/63) sont informés des résultats de la recherche à laquelle ils ont déjà participé. Seulement 30 % (19) des participants comprenaient qu'ils étaient impliqués dans la recherche, et 92 % d'entre eux étaient intéressés par les résultats de l'étude. 87,3 % (55) demanderont plus d'informations avant de participer à de futures activités de recherche.

CONCLUSION: Éduquer AYALHIV sur la participation à la recherche est important pour promouvoir les efforts concertés des chercheurs en vue d'améliorer l'engagement, les soins centrés sur le patient et la diffusion de la recherche. *WAJM 2024; 41 (7): 748 - 754*

MOTS CLES: VIH, Adolescent, Jeunes adultes, Perception, Recherche

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ABBREVIATIONS: **AIDS:** Acquired Immunodeficiency Syndrome; **ART:** Anti-Retroviral Therapy; **AYA:** Adolescent and Young Adults; **AYALHIV:** Adolescents and Young Adults Living with HIV **CSD:** Clinical Sciences Department; **HAART:** Highly Active Anti-Retroviral Therapy; **HIV:** Human Immunodeficiency Virus; **IRB:** Institutional Review Board; **LMIC:** Low and Middle-income Countries; **NIMR:** Nigerian Institute of Medical Research; **PLWH:** People Living with HIV and AIDS; **SD:** Standard Deviation; **SEPT:** September; **SPSS:** Statistical Package for Social Sciences; **WHO:** World Health Organization