INTERSECTING VULNERABILITIES: THE IMPLICATIONS OF DISCLOSURE, STIGMA, AND MENTAL HEALTH FOR INDIVIDUALS LIVING WITH HIV IN SUB-SAHARAN AFRICA

by
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Abstract

Background: Living with HIV entails navigating complex structural, interpersonal, and intrapersonal realities within the healthcare system, peer and family relationships, and the community that can affect one's psychosocial wellbeing. Disclosure of one's HIV status can engender social support, but negative reactions to disclosure can contribute to stigma and poor mental health. These psychosocial aspects of living with HIV impact HIV treatment and overall wellbeing and require further scientific exploration with individuals throughout the life course to inform interventions in contexts where HIV is prevalent, especially sub-Saharan Africa.

Methods: In Chapter Three, we provide a scoping review of the relationship between mental health and the HIV Care Continuum for adolescents living with HIV in sub-Saharan Africa. **In Chapter Four**, we characterize patterns of self-disclosure among adolescents living with HIV in Uganda and assess how choices of to whom to disclose are associated with depression and anxiety symptoms. **In Chapter Five,** we qualitatively explore gossip as a means of labeling people as living with HIV and as a form of HIV stigma in Botswana.

Results: We found that adolescents living with HIV were assessed for mental health along the HIV Care Continuum disproportionately and primarily only at the "Engaged or Retained in Care" step. Adolescents living with HIV in Uganda chose to self-disclose their HIV status to their nuclear family members more often than to extended family or peers. This choice to self-disclose to nuclear family members was mostly associated with non-significant marginally fewer depression and anxiety symptoms compared to adolescents who did not self-disclose to these individuals. HIV gossip in Botswana was gendered and related to the cultural expectations of women and men in Setswana culture. Gossip removed one's choice to self-disclose their HIV status, and both fear of gossip and experiencing gossip could lead to non-adherent behaviors to HIV treatment protocols.

Conclusion: Further understanding of the experience of HIV through a biopsychosocial approach to inform resources and services that promote coping with living with HIV and strengthening social support for people living with HIV is necessary to improve quality of life and end the epidemic.

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Chapter 1: Introduction

1.1 Problem Statement

In 2014, the Joint United Nations Programme on the Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) (UNAIDS) established the 90-90-90 Goals outlining an ambitious set of targets to be achieved in the fight to end the AIDS epidemic: 90% of all people living with HIV (PLHIV) would know their HIV status; 90% of all people diagnosed with HIV would be receiving sustained HIV antiretroviral therapy (ART); and, 90% of those on ART would be virally suppressed by 2020 (1,2). In accordance with these goals, the intention was to make concerted efforts to reach key populations at high risk for HIV/AIDS, including sex workers, men who have sex with men, people who inject drugs, and adolescents. At the time this agenda was set, overall global AIDS-related deaths had decreased by 35%, while deaths among adolescents had risen by 50% (2).

Adolescents, young individuals ages 10-19 (3), remain a hard to reach population (4,5) among whom HIV infections continue to drive the epidemic globally. Pooled estimates from 2016 compiled to assess progress in reaching the 90-90-90 targets for adolescents across three sub-Saharan African (SSA) countries, Malawi, Zambia, and Zimbabwe, demonstrated that less then 50% of adolescents living with HIV/AIDS (ALWH) were aware of their HIV status; approximately 80% of diagnosed ALWH were on ART; and only 79% of ALWH on ART were virally suppressed (6). Comparatively, in these same countries, 78% of adults living with HIV knew their status; 90% of diagnosed adults were on ART; and 90% of adults on ART were virally suppressed (7).

Now that the deadline for the 90-90-90 Goals have passed, focus on meeting new 95-95-95 Goals by 2030 necessitate increased attention to ALWH, who were originally categorized as part of the “missing 10-10-10”, i.e., the 10% of people that were deemed unlikely to be reached in pursuit of the original UNAIDS goals preventing reaching 100% (8). Studies suggest that primary healthcare providers are not testing for HIV among adolescents as much as they need to, and that there is a lack of appropriately developmentally targeted testing services resulting in adolescents not knowing their status (9,10) and severely limiting progress towards 95% of PLHIV knowing their status (5,11). Delayed identification and referral to treatment can lead ALWH to present with worse HIV prognosis complicated by comorbidities (12). Prevalent challenges experienced by adolescents in need of HIV care include a scarcity of youth friendly services in SSA, limited guidelines for providers on how to implement tailored care for them, and conflict between staff and youth stemming from ineffective communication about the various challenges ALWH are facing (13). There is also a paucity of consideration as to the myriad challenges during the developmental period that may create unique challenges to ensuring ALWH receive adequate HIV care to achieve viral suppression (14–16). For instance, as emerging adults, HIV infected adolescents must contend with the transition to adult HIV care, a time during which they are vulnerable to being lost to care (17).

To help build the evidence needed to inform public health interventions that address this gap and facilitate progress towards ending the HIV epidemic, this dissertation serves to assess psychosocial aspects of living with HIV, including stigma and discrimination, across two life course stages: adolescence and adulthood. This research seeks to understand some of the most pervasive challenges that remain for both adolescents and adults living with HIV, with a focus on SSA, as it is the epicenter of the AIDS epidemic (18,19). By examining under-researched psychosocial factors associated with worse HIV prognosis in two life course stages, the findings from each of the aims elucidate the need for a shift from the biomedical to a biopsychosocial approach to HIV that also incorporates targeted developmental approaches.

1.2 Background and Significance

The HIV/AIDS Epidemic in sub-Saharan Africa

HIV/AIDS is recognized as one of the most harmful and enduring public health threats in recent history (18,20). Currently, an estimated 38 million people are living with HIV, of which approximately 36 million are adults and 2 million are children under the age of 15. In 2019, there were 1.7 million new infections globally and 690,000 people died from AIDS related illnesses (21). These figures represent a 40% reduction in annual new HIV infections and a 60% decrease in AIDS-related deaths since their peak in 1998 and 2004 (21,22), respectively. The advent of multiple efficacious treatment and preventative approaches have fundamentally altered the virus' impact and are largely responsible for observed declines. In particular, antiretroviral therapy (ART), pre-exposure prophylaxis (PrEP), and post-exposure prophylaxis (PEP) have created myriad pathways for reducing the risk of contracting HIV and treating the virus (23). The success of ART has extended the lives of PLHIV and has led to HIV now being considered a manageable chronic illness (24,25). The accessibility of ART, PrEP and PEP continues to increase (26,27), and efforts to educate and inform communities about the importance and necessity of using these services to save lives have become widespread (28).

The impact of the epidemic and progress in its control have varied by population and geography. Of the 38 million people living with HIV worldwide (22), SSA bears a disproportionate burden, with over 25 million PLHIV residing there (29). While there is a generalized epidemic in many SSA settings (30), certain populations are more affected by HIV. In particular, adolescent and young adult women in SSA account for 25% of new global HIV infections and are twice as likely to be living with HIV as compared to young men in SSA. Cultural conceptions about HIV also lead to the disease being attributed in many cases to poor morality, sexuality, and contamination, generating stigma and discrimination that act as key barriers to PLHIV seeking treatment in SSA (31). Further, an estimated 40% of PLHIV in SSA are unaware of their status, and access to ART is inconsistent across the region, remaining highly constrained for many. For instance, in Eastern and Southern Africa, where 20.7 million people are living with HIV, over one quarter of adults and more than 40% of children living with HIV are still not receiving ART (32). While prevalence is lower in West and Central Africa (where only 5 million people are living with HIV), more than one third of PLHIV are estimated to not know their status in this region, and rates of ART usage are even lower than in other SSA regions (61% for adults and 33% for children) (33).

Broadening the Biomedical Approach to HIV/AIDS Epidemic Control

While biomedical advancements for HIV have been, and continue to be, fundamental in reducing the global impact of the virus (34), these advancements as described have not fully addressed the myriad factors associated with HIV (35). Broadly, biomedical models define disease as fully stemming from biological factors, without consideration for psychosocial elements of illness; if something cannot be verified on a cellular or molecular level, it tends to be less valued or even ignored within healthcare (36). The biomedical model also concedes to a “mind-body dualism,” in which the mental and somatic are separate entities (37,38).

In contrast, the biopsychosocial model is credited with placing importance on the individual experience of HIV-related illness and how this subjective experience influences diagnosis, treatment, and quality of life (38,39). George Engel conceptualized the biopsychosocial model to provide a framework for clinicians to have a better sense of patients experiences with illness, with the argument that a more holistic approach to care would lead to better overall health outcomes (38). Applying a biopsychosocial lens illuminates how consideration of the psychosocial experience of living with an illness can improve the public health response. UNAIDS and the World Health Organization (WHO) are increasingly calling for initiatives to provide support for PLHIV to navigate disclosure (40), mental health, and stigma, as they help drive the spread of HIV in SSA, and as such, limit what a biological or biomedial approaches alone can achieve (41,42). Each of these factors- disclosure, stigma, and mental health- and their importance to controlling the HIV/AIDS epidemic, is conceptualized in the following sections for the purposes of this dissertation.

Disclosure. HIV testing and counselling are the first steps in engagement with the healthcare system for HIV and the catalyst for PLHIV navigating life with the virus. While testing and counselling are integral to linking PLHIV to care and thus saving lives, there are negative outcomes that can stem from HIV testing. For example, the disclosure of an individual's HIV status by health care workers (HCWs) without their consent is a frequent occurrence in many settings in SSA (43,44). The place where individuals expect to get care for HIV can be a harmful setting given the potential for HCWs to disclose one's status and for community members to see individuals at a clinic and to also disclose to others without a PLHIV's consent (45).

The importance of disclosure as a psychosocial factor to address to achieve better individual and population level HIV outcomes can therefore not be understated. Intentional disclosure is imperative in obtaining social support to cope with HIV and in the reduction of HIV transmission (46,47), via facilitation of informed decision making, e.g., about use of HIV prevention methods during sex (48). As legislation that criminilizes non-disclosure in SSA becomes prevalent, a precedent is being set that situates the act of disclosure as something to be regulated versus a process that can lead to positive outcomes for PLHIV (32,49).

Stigma and Discrimination. An underrecognized goal set forth in conjunction with both the 90-90-90 and 95-95-95 Goals was that of achieving zero discrimination for PLHIV (2). Progress towards achieving zero discrimination will be necessary to make progress with both adolescents and adults to meet the 95-95-95 goals. HIV discrimination broadly is conceptualized to include stigma, denial of care, and violence against PLHIV 5/24/21 10:09:00 PM. Perceived, anticipated, enacted, and internalized stigma are all key risk factors for the onset of mental health conditions for PLHIV as well (53,54). The added complexity of stigma is that of the culturally specific ways it can operate depending on settings. Yet understanding of HIV stigma and its cultural nuances in SSA is limited in approaches to inform evidence-based stigma interventions that are appropriate for various populations living with HIV (55).

The literature on HIV discrimination is extensive and demonstrates that, across the life course, PLHIV are susceptible to multiple forms of discrimination which can fundamentally change an individual's ability to cope with an HIV diagnosis (56,57). Stigma, rejection from others, and abuse derived from actions including seeking clinical care, being seen taking medication, and changes in physical appearance, position PLHIV in highly vulnerable positions (58–60). HIV discrimination in all forms has been found to result in diminished ART adherence, substance use, higher risk for mental health and neurological disorders, and increased mortality 5/24/21 10:09:00 PM. For instance, it has been found in numerous settings in SSA, such as Botswana and Uganda for example, that PLHIV will seek treatment far from their homes due to the associated stigma with being seen receiving care (62–64)5/24/21 10:09:00 PM. Therefore, an

HIV diagnosis can be a major life event that sets off a series of life changes that lead to discrimination and diminished social support (62,65)5/24/21 10:09:00 PM.

Furthermore, ALWH who may have begun facing discrimination from a young age may have diminished social support by the time they are transitioning to adulthood and are responsible for navigating their own healthcare (66,67). It is therefore imperative to address discrimination experienced across the life course as a means to improve resources for the psychosocial wellbeing of PLHIV and ultimately to make progress in epidemic control. Yet for both adolescents and adults, notable reviews have emphasized the limited support structures in place for PLHIV to resist discrimination (68) and that the complexity of stigma and discrimination experienced by PLHIV exacerbates the inadequacy of the public health response to date (69,70).

Mental disorders. Mental health conditions (i.e. depression, anxiety, PTSD) are some of the most common co-morbidities for PLHIV in SSA, and an even larger treatment gap exists for mental health conditions than it does for HIV in SSA. Mental disorders experienced by people living with HIV have been found to lead to declines in CD4 counts, faster progression to AIDS, delayed ART initiation, and poor ART adherence (71,72). ALWH are especially susceptible to psychosocial distress, depression, and anxiety from a developmental perspective as having a strong social network and being accepted by peers is fundamental in developing a sense of self and self-worth as they become adults (73–76).

Interrelationship of Psychosocial Factors. Disclosure, stigma, and mental health in SSA are highly interrelated (77,78). Both HIV stigma and poor mental health are known barriers to HIV status disclosure (56,78). Disclosure of one's HIV status, whether intentional or inadvertent, can lead to subsequent stigma towards PLHIV, which places them at increased risk for poor mental health outcomes (57,79). Studies have found that individuals may even question the value of knowing their HIV status given the subsequent stigma and stressors that can emerge as a result of being HIV positive (65,80). Social isolation, a prevalent result of HIV stigma throughout various settings in SSA (81,82), is a known contributor to the onset of poor mental health as isolation affects one's self-esteem and self-worth.

The interrelationship between these key psyschosocial factors has been specifically demonstrated throughout SSA countries. In Botswana, a country with one of the higest prevalences of HIV in the world and the first SSA country to provide universal access to HIV treatment (83), some individuls have reported believing that mental health conditions stem from the inabiliy to accept one's HIV status and gossip from others about their status (84). Fear of stigma itself has been shown to be a critical deterent of ART adherence in Botswana, as well (85). Similiarly in Uganda, a country that has made ample strides in providing access to ART and that since 2004 provides free access to treatment, the implications of disclosure remains a challenge. Common reasons for non-disclosure in Uganda are fear of rejection and causing stress within one's social network (86). Stigma and disclosure continue to be critical barriers to treatment adherence for PLHIV in Uganda (87), and are key correlates attributed to poor mental health (88).

1.3 Specific Aims

The purpose of this research is to examine under-characterized psychosocial aspects of the HIV/AIDS epidemic: disclosure, stigma and mental health. The research broadly explores how these psychosocial aspects inform the experience of living with HIV within two different life course stages and the ways in which HIV treatment models can be better tailored to address them within these developmental periods. Models for HIV care must address the social dynamics of living with HIV. Integral to addressing these dynamics is understanding the experiences and decision making around disclosure of HIV/AIDS status as a critical event and its intersection with stigma and mental health. Therefore, the larger goal of this research is to inform more effective HIV/AIDS care by fostering understanding of disclosure, stigma and mental health in SSA with implications for both psychosocial support and HIV treatment in regard to both adolescence and adulthood. The first two aims address existing gaps in the adolescent literature while the third aim addresses the salient challenge of stigma for adults living with HIV. Specific aims include:

Aim 1: *To Conduct a scoping review that examines the relationships between mental health and the HIV Care Continuum for ALWH in SSA.* This review will include all studies assessing the mental health of ALWH in SSA in relationship to engagement among all steps of the HIV Care Continuum.

Aim 2: *To Characterize patterns of disclosure and their relationship to mental health among ALWH in Uganda.* A descriptive analysis will examine adolescents' choices around disclosure and how these choices are related to depression and anxiety symptoms.

Aim 3: *To qualitatively assess how gossip eliminates the choice to self-disclose one's HIV status among adults living with HIV in Botswana.* Gossip will be explored as a form of HIV stigma and contextualized as an impetus for diminished mental health and a barrier to HIV treatment.

1.4 References

1. Marsh K, Eaton JW, Mahy M, Sabin K, Autenrieth CS, Wanyeki I, et al. Global, regional and country-level 90–90–90 estimates for 2018: assessing progress towards the 2020 target. AIDS. 2019 Dec 15;33(Suppl 3):S213–26.

2. UNAIDS. 90-90-90: An Ambitious Treatment Target to Help End the AIDS Epidemic [Internet]. 2014 [cited 2021 May 10]. Available from: https://www.unaids.org/sites/default/files/media_asset/90-90-90_en.pdf

3. WHO Adolescent health [Internet]. [cited 2021 May 10]. Available from: https://www.who.int/southeastasia/health-topics/adolescent-health

4. For Every Child, End AIDS: Seventh Stocktaking Report, 2016 [Internet]. [cited 2021 May 9]. Available from: https://www.unicef.org/reports/every-child-end-aids-seventh-stocktaking-report-2016

5. Ajayi AI, Awopegba OE, Adeagbo OA, Ushie BA. Low coverage of HIV testing among adolescents and young adults in Nigeria: Implication for achieving the UNAIDS first 95. PLOS ONE. 2020 May 19;15(5):e0233368.

6. Wong VJ, Murray KR, Phelps BR, Vermund SH, McCarraher DR. Adolescents, young people, and the 90–90–90 goals: a call to improve HIV testing and linkage to treatment. AIDS. 2017 Jul 1;31(Suppl 3):S191–4.

7. Real Progress in the HIV Epidemic: PHIA From Zimbabwe, Malawi, and Zambia [Internet]. CROI Conference. [cited 2021 May 9]. Available from:

https://www.croiconference.org/abstract/real-progress-hiv-epidemic-phia-findings-zimbabwe-malawi-and-zambia/

8. Auerbach JD. Getting to Zero Begins With Getting to Ten. J Acquir Immune Defic Syndr. 2019 Dec 1;82(2):S99–103.

9. Ferrand RA, Munaiwa L, Matsekete J, Bandason T, Nathoo K, Ndhlovu CE, et al. Undiagnosed HIV infection among adolescents seeking primary health care in Zimbabwe. Clin Infect Dis. 2010 Oct 1;51(7):844–51.

10. Riendeau Lazar N, Salas-Humara C, Wood SM, Mollen CJ, Dowshen N. Missed Opportunities for HIV Screening among a Cohort of Adolescents with Recently Diagnosed HIV infection in a Large Pediatric Hospital Care Network. J Adolesc Health. 2018 Dec;63(6):799–802.

11. Khalifa A, Stover J, Mahy M, Idele P, Porth T, Lwamba C. Demographic change and HIV epidemic projections to 2050 for adolescents and young people aged 15-24. Glob Health Action [Internet]. 2019 Sep 12 [cited 2021 May 9];12(1). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6746261/

12. Yi S, Tuot S, Pal K, Khol V, Sok S, Chhoun P, et al. Characteristics of adolescents living with HIV receiving care and treatment services in antiretroviral therapy clinics in Cambodia: descriptive findings from a cross-sectional study. BMC Health Services Research. 2018 Oct 16;18(1):781.

13. Karman E, Wilson KS, Mugo C, Slyker JA, Guthrie BL, Bukusi D, et al. Training Exposure and Self-Rated Competence among HIV Care Providers Working with Adolescents in

Kenya. J Int Assoc Provid AIDS Care [Internet]. 2020 Jun 26 [cited 2021 May 10];19. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7322818/

14. Govindasamy D, Ferrand RA, Wilmore SM, Ford N, Ahmed S, Afnan-Holmes H, et al. Uptake and yield of HIV testing and counselling among children and adolescents in sub-Saharan Africa: a systematic review. J Int AIDS Soc. 2015;18:20182.

15. Organization WH. HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV: recommendations for a public health approach and considerations for policy-makers and managers [Internet]. World Health Organization; 2013 [cited 2020 Aug 17]. Available from: https://apps.who.int/iris/handle/10665/94334

16. Philbin MM, Tanner AE, Duval A, Ellen J, Kapogiannis B, Fortenberry JD. Linking HIV-positive adolescents to care in 15 different clinics across the United States: creating solutions to address structural barriers for linkage to care. AIDS Care. 2014 Jan;26(1):12–9.

17. Wiener LS, Kohrt B-A, Battles HB, Pao M. The HIV Experience: Youth Identified Barriers for Transitioning from Pediatric to Adult Care. Journal of Pediatric Psychology. 2011 Mar 1;36(2):141–54.

18. Kagaayi J, Serwadda D. The History of the HIV/AIDS Epidemic in Africa. Curr HIV/AIDS Rep. 2016 Aug;13(4):187–93.

19. McKinnon LR, Karim QA. Factors Driving the HIV Epidemic in Southern Africa. Curr HIV/AIDS Rep. 2016 Jun;13(3):158–69.

20. SDGs | UNAIDS [Internet]. [cited 2021 May 9]. Available from: https://www.unaids.org/en/SDGs

21. November 25 CSH govDate last updated:, 2020. Global Statistics [Internet]. HIV.gov. 2020 [cited 2021 May 9]. Available from: https://www.hiv.gov/hiv-basics/overview/data-and-trends/global-statistics

22. Global HIV & AIDS statistics — 2020 fact sheet | UNAIDS [Internet]. [cited 2021 May 9]. Available from: https://www.unaids.org/en/resources/fact-sheet

23. Akudibillah G, Pandey A, Medlock J. Maximizing the benefits of ART and PrEP in resource-limited settings. Epidemiology & Infection. 2017 Apr;145(5):942–56.

24. Deeks SG, Lewin SR, Havlir DV. The End of AIDS: HIV Infection as a Chronic Disease. Lancet. 2013 Nov 2;382(9903):1525–33.

25. Wandeler G, Johnson LF, Egger M. Trends in life expectancy of HIV-positive adults on ART across the globe: comparisons with general population. Curr Opin HIV AIDS. 2016 Sep;11(5):492–500.

26. Eakle R, Bourne A, Mbogua J, Mutanha N, Rees H. Exploring acceptability of oral PrEP prior to implementation among female sex workers in South Africa. Journal of the International AIDS Society. 2018;21(2):e25081.

27. Malati CY. Role of pharmacists in improving accessibility of antiretrovirals to support the United States President’s Emergency Plan for AIDS Relief: Impact on the patient, program,

and market. JACCP: JOURNAL OF THE AMERICAN COLLEGE OF CLINICAL PHARMACY. 2020;3(5):980–7.

28. Baggaley R, Doherty M, Ball A, Ford N, Hirnschall G. The Strategic Use of Antiretrovirals to Prevent HIV Infection: A Converging Agenda. Clinical Infectious Diseases. 2015 Jun 1;60(suppl_3):S159–60.

29. HIV/AIDS | WHO | Regional Office for Africa [Internet]. [cited 2021 May 9]. Available from: https://www.afro.who.int/health-topics/hivaids

30. Karim SSA, Baxter C. HIV incidence rates in adolescent girls and young women in sub-Saharan Africa. The Lancet Global Health. 2019 Nov 1;7(11):e1470–1.

31. Mbonu NC, van den Borne B, Vries D, K N. Stigma of People with HIV/AIDS in Sub-Saharan Africa: A Literature Review [Internet]. Journal of Tropical Medicine. 2009 [cited 2017 Nov 4]. Available from: https://www.hindawi.com/journals/jtm/2009/145891/abs/

32. HIV and AIDS in East and Southern Africa regional overview [Internet]. Avert. 2015 [cited 2021 May 9]. Available from: https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/overview

33. HIV and AIDS in West and Central Africa Overview [Internet]. Avert. 2017 [cited 2021 May 9]. Available from: https://www.avert.org/hiv-and-aids-west-and-central-africa-overview

34. HIV: Progress and future challenges in treatment, prevention and cure. [cited 2021 May 2]; Available from: https://www.nature.com/articles/d42473-018-00280-0

35. Greenwood GL, Wilson A, Bansal GP, Barnhart C, Barr E, Berzon R, et al. HIV-Related Stigma Research as a Priority at the National Institutes of Health. AIDS Behav. 2021 Apr 22;

36. Engel GL. The clinical application of the biopsychosocial model. Am J Psychiatry. 1980 May;137(5):535–44.

37. Engel GL. The need for a new medical model: a challenge for biomedicine. Science. 1977 Apr 8;196(4286):129–36.

38. Borrell-Carrió F, Suchman AL, Epstein RM. The Biopsychosocial Model 25 Years Later: Principles, Practice, and Scientific Inquiry. The Annals of Family Medicine. 2004 Nov 1;2(6):576–82.

39. Cohen MA. Biopsychosocial approach to the human immunodeficiency virus epidemic. A clinician's primer. Gen Hosp Psychiatry. 1990 Mar;12(2):98–123.

40. WHO | Opening up the HIV/AIDS epidemic [Internet]. WHO. World Health Organization; [cited 2021 May 9]. Available from: https://www.who.int/hiv/pub/vct/opening/en/

41. Harrison A, Colvin CJ, Kuo C, Swartz A, Lurie M. Sustained High HIV Incidence in Young Women in Southern Africa: Social, Behavioral, and Structural Factors and Emerging Intervention Approaches. Curr HIV/AIDS Rep. 2015 Jun;12(2):207–15.

42. Ortblad KF, Baeten JM, Cherutich P, Wamicwe JN, Wasserheit JN. The arc of HIV epidemics in sub-Saharan Africa: new challenges with concentrating epidemics in the era of 90-90-90. Curr Opin HIV AIDS. 2019 Sep;14(5):354–65.

43. Nyblade L, Stangl A, Weiss E, Ashburn K. Combating HIV stigma in health care settings: what works? J Int AIDS Soc. 2009 Aug 6;12:15.

44. Dapaah JM, Senah KA. HIV/AIDS clients, privacy and confidentiality; the case of two health centres in the Ashanti Region of Ghana. BMC Medical Ethics. 2016 Jul 16;17(1):41.

45. Odeny TA, Penner J, Lewis-Kulzer J, Leslie HH, Shade SB, Adero W, et al. Integration of HIV Care with Primary Health Care Services: Effect on Patient Satisfaction and Stigma in Rural Kenya. AIDS Res Treat [Internet]. 2013 [cited 2021 May 1];2013. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3664481/

46. Chaudoir SR, Fisher JD, Simoni JM. Understanding HIV disclosure: A review and application of the Disclosure Processes Model. Social Science & Medicine. 2011 May 1;72(10):1618–29.

47. Obermeyer CM, Baijal P, Pegurri E. Facilitating HIV Disclosure Across Diverse Settings: A Review. Am J Public Health. 2011 Jun 1;101(6):1011–23.

48. Kalichman SC. HIV Transmission Risk Behaviors of Men and Women Living With HIV-AIDS: Prevalence, Predictors, and Emerging Clinical Interventions. Clinical Psychology: Science and Practice. 2000;7(1):32–47.

49. Eba PM. HIV-specific legislation in sub-Saharan Africa: A comprehensive human rights analysis. African Human Rights Law Journal. 2015;15(2):224–62.

50. Malcolm A, Aggleton P, Bronfman M, Galvão J, Mane P, Verrall J. HIV-related stigmatization and discrimination: Its forms and contexts. Critical Public Health. 1998 Dec 1;8(4):347–70.

51. Abaver DT, Cishe EN. Violence, abuse and discrimination: key factors militating against control of HIV/AIDS among the LGBTI sector. SAHARA J. 2018 Dec;15(1):60–70.

52. Gyamerah AO, Taylor KD, Atuahene K, Anarfi JK, Fletcher M, Raymond HF, et al. Stigma, discrimination, violence, and HIV testing among men who have sex with men in four major cities in Ghana. AIDS Care. 2020 Aug;32(8):1036–44.

53. Chambers LA, Rueda S, Baker DN, Wilson MG, Deutsch R, Raeifar E, et al. Stigma, HIV and health: a qualitative synthesis. BMC Public Health. 2015 Sep 3;15(1):848.

54. M.A MF, Nkomo N, Kafaar Z, Kelly K. Factors associated with prevalence of mental disorder in people living with HIV/AIDS in South Africa. AIDS Care. 2007 Nov 1;19(10):1201–9.

55. Yang LH, Ho-Foster AR, Becker TD, Misra S, Rampa S, Poku OB, et al. Psychometric Validation of a Scale to Assess Culturally-Salient Aspects of HIV Stigma Among Women Living with HIV in Botswana: Engaging "What Matters Most" to Resist Stigma. AIDS Behav [Internet]. 2020 Aug 24 [cited 2021 Jan 27]; Available from: https://doi.org/10.1007/s10461-020-03012-y

56. Mahajan AP, Sayles JN, Patel VA, Remien RH, Ortiz D, Szekeres G, et al. Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. AIDS. 2008 Aug;22(Suppl 2):S67–79.

57. Rueda S, Mitra S, Chen S, Gogolishvili D, Globerman J, Chambers L, et al. Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. BMJ Open. 2016 Jul 1;6(7):e011453.

58. Mills EA. From the physical self to the social body: expressions and effects of HIV-related stigma in South Africa. Journal of Community & Applied Social Psychology. 2006;16(6):498–503.

59. Bond V, Nomsenge S, Mwamba M, Ziba D, Birch A, Mubekapi-Musadaidzwa C, et al. "Being seen" at the clinic: Zambian and South African health worker reflections on the relationship between health facility spatial organisation and items and HIV stigma in 21 health facilities, the HPTN 071 (PopART) study. Health & Place. 2019 Jan 1;55:87–99.

60. Lambert RF, Orrell C, Bangsberg DR, Haberer JE. Factors that Motivated Otherwise Healthy HIV-Positive Young Adults to Access HIV Testing and Treatment in South Africa. AIDS Behav. 2018 Mar 1;22(3):733–41.

61. Stockton MA, Giger K, Nyblade L. A scoping review of the role of HIV-related stigma and discrimination in noncommunicable disease care. PLoS ONE. 2018;13(6):e0199602.

62. Bonnington O, Wamoyi J, Ddaaki W, Bukenya D, Ondenge K, Skovdal M, et al. Changing forms of HIV-related stigma along the HIV care and treatment continuum in sub-Saharan

Africa: a temporal analysis. Sex Transm Infect [Internet]. 2017 Jul 1 [cited 2021 May 1];93(Suppl 3). Available from: https://sti.bmj.com/content/93/Suppl_3/e052975

63. Camlin CS, Charlebois ED, Getahun M, Akatukwasa C, Atwine F, Itiakorit H, et al. Pathways for reduction of HIV-related stigma: a model derived from longitudinal qualitative research in Kenya and Uganda. Journal of the International AIDS Society. 2020;23(12):e25647.

64. Bene M, Darkoh MBK. The constraints of antiretroviral uptake in rural areas: the case of Thamaga and surrounding villages, Botswana. SAHARA J. 2014 Jan 2;11(1):167–77.

65. Sullivan MC, Rosen AO, Allen A, Benbella D, Camacho G, Cortopassi AC, et al. Falling Short of the First 90: HIV Stigma and HIV Testing Research in the 90–90–90 Era. AIDS Behav. 2020 Feb 1;24(2):357–62.

66. Ritchwood TD, Malo V, Jones C, Metzger IW, Atujuna M, Marcus R, et al. Healthcare retention and clinical outcomes among adolescents living with HIV after transition from pediatric to adult care: a systematic review. BMC Public Health. 2020 Aug 3;20(1):1195.

67. Pinzón-Iregui MC, Ibanez G, Beck-Sagué C, Halpern M, Mendoza RM. "…like because you are a grownup, you do not need help": Experiences of Transition from Pediatric to Adult Care among Youth with Perinatal HIV Infection, Their Caregivers, and Health Care Providers in the Dominican Republic. J Int Assoc Provid AIDS Care. 2017 Nov 1;16(6):579–87.

68. Sengupta S, Banks B, Jonas D, Miles MS, Smith GC. HIV interventions to reduce HIV/AIDS stigma: a systematic review. AIDS Behav. 2011 Aug;15(6):1075–87.

69. Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. Soc Sci Med. 2003 Jul;57(1):13–24.

70. Common at its core: HIV-related stigma across contexts [Internet]. ICRW | PASSION. PROOF. POWER. [cited 2021 May 9]. Available from: https://www.icrw.org/publications/common-at-its-core-hiv-related-stigma-across-contexts/

71. Nakimuli-Mpungu E, Bass JK, Alexandre P, Mills EJ, Musisi S, Ram M, et al. Depression, alcohol use and adherence to antiretroviral therapy in sub-Saharan Africa: a systematic review. AIDS Behav. 2012 Nov;16(8):2101–18.

72. Parcesepe AM, Bernard C, Agler R, Ross J, Yotebieng M, Bass J, et al. Mental health and HIV: research priorities related to the implementation and scale up of 'treat all' in sub-Saharan Africa. J Virus Erad. 4(Suppl 2):16–25.

73. Kim MH, Mazenga AC, Yu X, Devandra A, Nguyen C, Ahmed S, et al. Factors associated with depression among adolescents living with HIV in Malawi. BMC Psychiatry. 2015 Oct 26;15(1):264.

74. Laurenzi CA, Skeen S, Gordon S, Akin-Olugbade O, Abrahams N, Bradshaw M, et al. Preventing mental health conditions in adolescents living with HIV: an urgent need for evidence. J Int AIDS Soc [Internet]. 2020 Aug 31 [cited 2021 May 10];23(Suppl 5). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7459172/

75. Vreeman RC, McCoy BM, Lee S. Mental health challenges among adolescents living with HIV. J Int AIDS Soc [Internet]. 2017 May 16 [cited 2020 Feb 18];20(Suppl 3). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5577712/

76. Lee S, Yamazaki M, Harris DR, Harper GW, Ellen J. Social Support and HIV-Status Disclosure to Friends and Family: Implications for HIV-Positive Youth. J Adolesc Health. 2015 Jul;57(1):73–80.

77. The Contextual Environmental Factors Shaping Disclosure of HIV Status across Populations Groups in Sub-Saharan Africa | IntechOpen [Internet]. [cited 2021 May 9]. Available from: https://www.intechopen.com/books/hiv-aids-contemporary-challenges/the-contextual-environmental-factors-shaping-disclosure-of-hiv-status-across-populations-groups-in-s

78. Nabunya P, Byansi W, Sensoy Bahar O, McKay M, Ssewamala FM, Damulira C. Factors Associated With HIV Disclosure and HIV-Related Stigma Among Adolescents Living With HIV in Southwestern Uganda. Front Psychiatry [Internet]. 2020 [cited 2020 Aug 17];11. Available from: https://www.frontiersin.org/articles/10.3389/fpsyt.2020.00772/full

79. Dow DE, Mmbaga BT, Turner EL, Gallis JA, Tabb ZJ, Cunningham CK, et al. Building resilience: a mental health intervention for Tanzanian youth living with HIV. AIDS Care. 2018 Jul 25;30(sup4):12–20.

80. van Dyk AC, van Dyk PJ. “What is the Point of Knowing?”: Psychosocial Barriers to HIV/AIDS Voluntary Counselling and Testing Programmes in South Africa. South African Journal of Psychology. 2003 May 1;33(2):118–25.

81. Kimera E, Vindevogel S, Reynaert D, Justice KM, Rubaihayo J, Maeyer JD, et al. Experiences and effects of HIV-related stigma among youth living with HIV/AIDS in Western Uganda: A photovoice study. PLOS ONE. 2020 Apr 24;15(4):e0232359.

82. Yuh JN, Ellwanger K, Potts L, Ssenyonga J. Stigma among HIV/AIDS Patients in Africa: A critical Review. Procedia - Social and Behavioral Sciences. 2014 Aug;140:581–5.

83. Ramogola-Masire D, Poku O, Mazhani L, Ndwapi N, Misra S, Arscott-Mills T, et al. Botswana's HIV response: Policies, context, and future directions. Journal of Community Psychology. 2020;48(3):1066–70.

84. Becker TD, Ho-Foster AR, Poku OB, Marobela S, Mehta H, Cao DTX, et al. "It's When the Trees Blossom": Explanatory Beliefs, Stigma, and Mental Illness in the Context of HIV in Botswana. Qual Health Res. 2019 Feb 9;1049732319827523.

85. Madiba S, Josiah U. Perceived Stigma and Fear of Unintended Disclosure are Barriers in Medication Adherence in Adolescents with Perinatal HIV in Botswana: A Qualitative Study. BioMed Research International. 2019 Dec 2;2019:e9623159.

86. Ssali SN, Atuyambe L, Tumwine C, Segujja E, Nekesa N, Nannungi A, et al. Reasons for Disclosure of HIV Status by People Living with HIV/AIDS and in HIV Care in Uganda: An Exploratory Study. AIDS Patient Care STDS. 2010 Oct;24(10):675–81.

87. Nabukeera-Barungi N, Elyanu P, Asire B, Katureebe C, Lukabwe I, Namusoke E, et al. Adherence to antiretroviral therapy and retention in care for adolescents living with HIV

from 10 districts in Uganda. BMC Infect Dis [Internet]. 2015 Nov 14 [cited 2021 May 1];15. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4647509/

88. Kiene SM, Dove M, Wanyenze RK. Depressive Symptoms, Disclosure, HIV-Related Stigma, and Coping following HIV Testing among Outpatients in Uganda: A Daily Process Analysis. AIDS Behav. 2018 May;22(5):1639–51.

Chapter 2: Literature Review

This dissertation specifically focuses on three psychosocial aspects of HIV within SSA: disclosure, stigma and mental health. The purpose of this chapter is to demonstrate the relevant literature that informs the subsequent aims and questions they explore. A critical element in presenting a broad overview of this literature is to also emphasize the difference in terms of the existing evidence that speaks to these psychosocial factors among adult PLHIV compared to ALWH. We present evidence in this chapter from various settings in SSA to provide a sense of the broad landscape of addressing HIV in this setting, with specific examples from Botswana and Uganda as they are the settings for chapters 4 and 5.

2.1 Disclosure

For the purposes of this dissertation, disclosure of HIV status refers to: "self-disclosure", i.e., when an individual decides whether, when, and how to reveal their HIV status to others; and, to instances in which someone else reveals another individual's status with or without that person's consent (e.g., via gossip)(1,2). The contexts in which a PLHIV chooses to reveal their status varies greatly across demographics and culture. Estimates of HIV status disclosure within SSA are highly variable ranging from 16%-86% of PLHIV having disclosed to anyone across regions and countries (3). Men and women living in urban areas are more likely to self-disclose than those living in rural areas. In addition, both men and women describe a desire to gain social support as a key motivation for disclosing their HIV status (1).

Self-Disclosure

Research on disclosure practices in SSA has disproportionately focused on women (4), who have been found to be more likely to disclose their status than males living with HIV (5).

HIV testing during antenatal care creates a dynamic in which women are often the first to learn their status within a relationship, which results in the onus of disclosure falling more commonly on them as compared to men (6,7). Variation has been demonstrated across different SSA settings, however, with men being found to be more likely to disclose than women in some studies (8).

Predictors of non-disclosure of HIV status among adults are well known in the literature: stigma, rejection, the inability to marry, and limited economic opportunities are all documented impediments (9–11). Further, being single, having a lower education status, and not having a dedicated support group were found to be correlates of non-disclosure in studies in Nigeria and Mozambique (12,13). Challenges with navigating safe sexual practices, the inability to accept one's HIV status, and desire for acceptance are also common reasons. Subsequent relationship conflicts, fear of violence, and enacted intimate partner violence are prevalent outcomes of disclosure that are also often not addressed through HIV treatment and services as found in settings such as Nigeria, South Africa, and Zimbabwe (14–16).

Significantly less research has been conducted on self-disclosure by ALWH as compared to adults (17,18). The World Health Organization recommends counselling and support for ALWH on self-disclosure, but only a limited number of studies have evaluated the effectiveness of these programs in SSA (18,19). The predominant focus of literature on disclosure with ALWH focuses on if, when, and how caregivers discloe to a child or adolescent that they are living with HIV (20). Of the few studies that examine self-disclosure by an ALWH of their HIV status, 18% of ALWH (n=582) were found to have disclosed to a friend, classmate, or partner in a study from Uganda and Kenya (21); 67% to family compared to 43% to non-family members (n=97) in a second study from Kenya (22); and over half disclosed only to their immediate family in a study of ALWH from South Africa (n=29) (23).

Disclosure of HIV Status by Others

Inadvertent disclosure is a common experience for PLHIV that is feared and descried to generate subsequent stigma from community members (24–26). Disclosure without one's consent by HCWs is a well-studied phenomenon throughout the continent (1,27). It is also well documented that many HCWs believe it is their right to know whether a patient is living with HIV and that they can refuse treatment to PLHIV (28). Studies from Ethiopia and Tanzania demonstrate the differential treatment of clinicians towards PLHIV in clinical settings including not providing care and the practice of testing and disclosing one's HIV status without consent (28,29). In some countries there is even momentum to have mandatory premarital HIV testing and to allow health care workers to disclose the results with or without consent to the other party (1).

2.2 Benefits and Limitations of Disclosure

Currently, debate exists as to whether disclosure of HIV status should be as promoted as it currently (30). There are scarce programs and resources to aid PLHIV in this process, placing undue burden on them to navigate disclosure alone. One critique of the promotion of disclosure is that, in the absence of other programs and supports, it does not account for the negative outcomes that may result for PLHIV. Particularly in SSA, ample literature demonstrates mixed results of disclosing one's status (30,31). This scarcity of programming remains against the backdrop of global recognition (e.g., by organizations such as UNAIDS, WHO, and UNICEF) of the need for and benefits of HIV status disclosure (32,33). At the structural level, multiple countries within SSA criminalize sex work; same-sex relationships,; and HIV exposure, non-disclosure and transmission (34). Some of the most marginalized individuals in SSA are therefore placed at increased risk for legal consequences given their identities or behaviors being commonly associated with high rates of HIV (35). Often these laws are broad in scope which only exacerbates numerous ways to punish PLHIV whether they disclosed their status themselves or not (34,36).

Another reason that supportive disclosure programs are needed is that there has been an increase in early initiation to ART. Early initiation has been found to lead to increases in disclosure and social support as PLHIV seek adherence support (37) and the ability to openly take medications (38,39). The counselling that coincides with ART initiation, including hopeful messaging about adherence to ART lowering risk for transmission and increasing one's ability to lead a healthy life (40), is widely credited with increasing self-disclosure. However, early initiation may therefore also create pressure on PLHIV to disclose without proper support and resources, especially in the absence of healthcare provider training to support PLHIV in the longer term (21).

A main challenge with improving programs to support disclosure is that there is a lack of knowledge on what key individuals a PLHIV may want or need to disclose to (22). A majority of studies on disclosure from countries in SSA focus exclusively on disclosure to one's sexual partners (5,41,42). Fewer studies focus on disclosing to other parities, such as family members. In South Africa, community support initiatives such as counselling from community health workers was found to lead to increased disclosure to families. Yet, who PLHIV specifically disclosed to in their families was only categorized as being either one's parents or other family members(43) . A similar phenomenon was also observed in a study from Mozambique that did not characterize which family members PLHIV were specifically disclosing their HIV status to when they chose to disclose within the family (44). Limited emphasis on support for disclosing to the parties different communities of PLHIV want and feel the need to disclose to may undermine public health HIV prevention initiatives to promote disclosure. Ultimately, PLHIV may be more willing and efficacious in disclosing their HIV status if support is provided for disclosing to all individuals who are seen as essential sources of support.

2.3 Disclosure of HIV Status in Botswana

Botswana is one of many countries with laws that criminalize the transmission, non-disclosure or exposure of another to HIV (45). The recent Public Health Act is considered to be a violation of the rights of PLHIV (46) given three stipulations that lawfully allow HCWs to disclose a patient's HIV status: 1) to a sexual partner or caregiver if the PLHIV has not disclosed after a reasonable amount of time, 2) after the death of a PLHIV, and 3) when disclosing to other HCWs involved with treating a PLHIV. Mandatory HIV testing is also allowed if an individual is unconscious and unable to give consent, a clinician deems it in the interest of the patient, and before any dental or surgical procedure. This law positions PLHIV to be vulnerable to their status being disclosed without their consent (47).

Ample support is needed in order to increase HIV status disclosure in Botswana (48), as perceived stigma and disclosure without one's consent have been found to hinder this process for PLHIV. Acceptance of gender norms that women should be subservient and have less decision-making power even in matters of sexual and reproductive health also promotes non-disclosure to maintain relationships. Further, one study in Botswana also found that clinic staff actively did not encourage self-disclosure given the potential outcome of stigma for PLHIV (49). While anxiety, rejection from partners, and general fear of reprisal from others have been found to lead to limited disclosure in Botswana, reasons for disclosure include the desire to protect others from

HIV, getting financial support (50), and being able to have positive social support when it comes to HIV treatment (49). Few studies in Botswana specifically examine disclosure among ALWH. Of those that do, the focus is on the impact of disclosure to adolescents that they are HIV positive 5/24/21 10:09:00 PM.

2.4 Disclosure of HIV status in Uganda

The transmission and non-disclosure of HIV is also criminalized in Uganda. Vague definitions of intentional and attempted transmission allow courts to assume defendants living with HIV in court cases are at fault (36). There were also mandates included in Uganda's HIV and AIDS Prevention and Control Act that allow the disclosure of one's HIV status without their consent to: 1) a guardian if a minor is being treated; 2) HCWs involved in treatment; 3) anyone who had exposure to the bodily fluids of a person who was tested for HIV; and, 4) individuals with whom the PLHIV comes into close contact.

Common reasons for non-disclosure in Uganda include being in a relationship for less than a year, having lost a family member to AIDS, and diminished social support from others who already knew of one's HIV status (53–55). Pregnant women have also reported challenges of disclosure given economic dependence on men, the potential for experiencing violence, and being blamed for the spread of HIV within their family (56). Yet, there are also various studies demonstrating critical reasons why PLHIV choose to disclose in Uganda. Initiating ART, receiving counselling, and seeing role models who have disclosed publicly are all key factors associated with self-disclosure (57). Furthermore, with HIV as a risk factor for IPV in Uganda, there are efforts to provide more counselling and resources for disclosing HIV in ways that would mitigate violence and that are demonstrative in resulting in increases in self- disclosure (58).

Few studies have focused on self-disclosure among ALWH in Uganda. Among the studies that exist, there are mixed results in which self disclosure has been associated social support, with self-disclosure leading both social support and rejection (21,59). Of additional importance are studies with HCWs and caregivers of ALWH who express the need for more programmatic support and training to aid ALWH in self-disclosure (60).

2.5 Stigma

Stigma is an especially salient challenge for PLHIV Studies characterizing predictors of internalized stigma and programs to address this type of stigma in SSA are limited (61,62). There are mixed results as to what demographics are predictive of internalized stigma as both being older and younger have been found to be related to internalized stigma (63), as well as being a woman or man (64), and having either higher or lower education. While studies on ART adherence are inconsistent in terms of whether this leads to internalized stigma, challenges with HIV-related illness and poor treatment outcomes were confirmed predictors of stigma in settings including Uganda, Malawi, South Africa, and Tanzania (65,66). In addition, depression has been found to lead to internalized stigma in Kenya and Uganda (67,68), as well as to alcohol use in South Africa (42).

As disclosure is a demonstrated catalyst for stigma, various studies convey gossip following disclosure and subsequent discrimination as a common form of stigmatizing behavior. Anticipated stigma commonly stems from fear of gossip and challenges with navigating sexual behavior (69). In addition, avoidance of voluntary counselling and testing may derive from anticipated stigma given a positive result, including fear of being treated like a pariah and being ousted from social networks (70).

There is a dearth of evidence-based stigma interventions for enacted and other forms of stigma in SSA. While stigma is recognized as a multidimensional process, few interventions exist to reduce the harms of all types of stigma for PLHIV. Of those that do, the majority are found in South Africa, with a predominant focus on interpersonal and intrapersonal stigma and mixed results on efficacy (71,72). An intervention in Zambia focused on home-based testing and counselling and community awareness for HIV led to decreases in individuals having stigmatizing beliefs and attitudes about PLHIV, yet reductions in perceived stigma were not observed (73). There is also a scarcity of measures specifically conceptualized, adapted, and validated for assessing stigma in SSA (74), especially considering the diverse cultural and contextual settings in which PLHIV live across the region (75). This impedes progress in assessing the effectiveness of stigma mitigation efforts in SSA.

2.6 Addressing HIV Stigma in SSA

HIV stigma in Uganda is cited as a pervasive challenge for PLHIV (66,76,77). Internalized and anticipated HIV stigma have been found to be increasing in some settings in Uganda, as access to HIV treatment and services has expanded (78). Stigma is also known to be a correlate of masculinity in Uganda and threatens the norms expected of men such as respectability and independence. HIV thus has been attributed to reducing men in Uganda’s likelihood of seeking clinical care for HIV and disclosing their HIV status (79). Pregnant women in Uganda have been found to face HIV stigma from HCWs which has been attributed to challenges navigating health care for themselves and their unborn children (80). Support groups for PLHIV in Uganda are being touted as an integral mechanism for resisting stigma in this setting. Support groups have enabled collective action among PLHIV to create social change and work together to dispel HIV stigma while also being integral in reducing the self-stigma that is common among PLHIV in Uganda (81). The impact of stigma in Uganda requires increased attention and conceptualization of valid measures, as only recent studies have yielded measures that have been validated for Uganda specifically around measurement of internalized HIV stigma (66).

The recent development of a scale of cultural conceptions of HIV stigma in Botswana represents one of the first efforts to measure stigma and how it impacts the daily lives and treatment seeking for PLHIV within a specific SSA setting (75). This study and related work focused on the manifestations of cultural HIV stigma in Botswana can pave the way for further exploration as to the operationalization of stigma in specific sociocultural settings. Findings highlighted that despite legal protections being in place to protect PLHIV from discrimination, particularly among men, the negative connotations of HIV threatened masculine ideals and contributed to stressors associated with employment insecurity (82,83). Men living with HIV expressed experiencing both direct and indirect forms of employment discrimination as the mechanisms for protecting PLHIV from discrimination were not abundantly clear. Concealing one's status was also critical to maintaining their employment, thus decreasing the likelihood that men would seek support for HIV discrimination despite protections in place (9).

Among women in Botswana, structural policies such as mandated HIV testing during antenatal care positioned them to be the first diagnosed with HIV versus their partner, resulting in disproportionate HIV stigma and being blamed for its transmission (10). Botswana exemplifies how protections being put in place to mitigate stigma may not be sufficient to address the ways that stigma impacts the daily lived experience of HIV. Even policies that are meant to promote the health and wellbeing of PLHIV can cause unintentional harm given the social and cultural dynamics of HIV.

2.7 The Burden of Mental Health among PLHIV in SSA

Extant literature from SSA has demonstrated that PLHIV are at higher risk for mental disorders, reduced quality of life, and diminished emotional wellbeing compared to individuals not living with HIV(84). Psychological distress, anxiety and depression have also been demonstrated as risk factors for increased morbidity (85). Studies have additionally found that poor social support, the presence of life stressors, and stigma were associated with an increase in the likelihood of depression among PLHIV and that PLHIV who screened positive for anxiety were also found to have avoidant coping behavior and be high risk for substance use (86). A high prevalence of HIV is therefore a population level dynamic that leads to increased rates of mental disorders, which in turn can limit HIV treatment adherence (87,88). In Botswana, it was found that depression was highly prevalent in the five districts in the country with the highest HIV prevalence rates, with over 30% of men and 25% of women in these districts having high rates of depressive symptoms (89). Anxiety disorders among PLHIV in SSA Nigeria have been found to be associated with lack of social support, unemployment, and not being married, all of which can be potentiated by experiencing stigma (90).

Few countries in SSA have comprehensive mental health policies and programming in place, let alone dedicated initiatives for PLHIV (91,92). Most mental policies call for the provision of treatment and protection for individuals living with mental health conditions (91,93). Although, many are limited in their human rights-based approaches to the protections and implementation of comprehensive services for mental disorders. Countries within SSA that are recognized for their mental health policies include both Uganda and South Africa; they are known for their comprehensive mental health legislation that recognize the need for service quality, advocacy, human rights, and research (94). Despite only a few settings in SSA having existing mental health policies, the underdiagnoses and undertreatment of mental disorders for PLHIV remains prevalent (92). Many HIV treatment providers have little training in the screening and treatment of mental health conditions and SSA has a scarce cadre of mental health professionals. Globally the annual rate of visits for mental health is 1,051 per 100,000 while in SSA it is 14 per 100,000. There even countries in SSA in which the mental health treatment gap is over 90% (95).

2.8 Specific Population Burden of Mental Disorders in SSA

Specifically, among adult's living with HIV, there is high psychiatric co-morbidity experienced by both women and men in SSA. Extant literature demonstrates that adult PLHIV are more likely to be diagnosed with depression compared to people who are not living with HIV (96), and depression is the most common mental disorder among adult PLHIV (97). Estimates across SSA countries place the prevalence of depression between 14-64% with particularly high rates in Uganda and South Africa (87,92). Anxiety is also prevalent among adults living with HIV with various studies suggesting a prevalence between 19%-37% (98). Psychiatric multimorbity is also common with co-occurring mood and anxiety disorders, and the co-occurrence of mood and substance use disorders (92).

Adolescents are disproportionately at higher risk for mental health conditions given this being the typical onset for disorders, regardless of HIV status (99,100). However, ALWH have been found to have 1.68 times the odds of depression, 1.77 times the odds of anxiety, and 1.59 times the odds of conduct disorder compared to peers who are uninfected (101). Studies within SSA have also suggested an estimated prevalence of depression among ALWH to range from 18.9% (102)-46% (103). The prevalence of anxiety was estimated to be as high as 32% among ALWH in this context as well (104). ALWH are also more likely to be hospitalized for mental illness compared to their peers who are uninfected with HIV (105). In addition, only 27% of countries in SSA have dedicated adolescent mental health beds and in the majority of countries there is approximately 1 child psychiatrist for 4 million people (106).

2.9 Addressing Mental Health in the Context of HIV

Exploring the ways in which stigma and stressful life events, such as disclosure, contribute to poor mental health (92,107)5/24/21 10:09:00 PM, is key to addressing the co-occurrence of mental health and HIV. Calls for the integration of mental health screening and treatment into HIV services are increasing as many countries in SSA are beginning to recognize diminished advancements in curbing the HIV epidemic due to co-morbid mental disorders (87,108). Efforts to measure the impact of stigma and disclosure as means of informing mental health interventions are scaling up in settings with high rates of HIV including Botswana and South Africa (109). A recent review used the term “intersecting vulnerabilities” to describe the plight of living with both HIV and mental health conditions as it emphasized the structural, sociocultural, and intrapersonal dynamics of HIV that are associated with mental health (88). Especially for sustained engagement and retention in HIV treatment, mental health and the stressors of living with HIV substantially decrease the likelihood of remaining in care (110,111).

2.10 References

1. Obermeyer CM, Baijal P, Pegurri E. Facilitating HIV Disclosure Across Diverse Settings: A Review. Am J Public Health. 2011 Jun;101(6):1011–23.

2. Stutterheim SE, Bos AER, Pryor JB, Brands R, Liebregts M, Schaalma HP. Psychological and Social Correlates of HIV Status Disclosure: The Significance of Stigma Visibility. AIDS Education and Prevention. 2011 Aug 1;23(4):382–92.

3. Longinetti E, Santacatterina M, El-Khatib Z. Gender Perspective of Risk Factors Associated with Disclosure of HIV Status, a Cross-Sectional Study in Soweto, South Africa. PLOS ONE. 2014 Apr 17;9(4):e95440.

4. Iwelunmor J, Sofolahan-Oladeinde Y, Airhihenbuwa CO. Sociocultural Factors Influencing HIV Disclosure Among Men in South Africa. Am J Mens Health. 2015 May;9(3):193–200.

5. Maeri I, Ayadi AE, Getahun M, Charlebois E, Akatukwasa C, Tumwebaze D, et al. "How can I tell?" Consequences of HIV status disclosure among couples in eastern African communities in the context of an ongoing HIV "test-and-treat" trial. AIDS Care. 2016 Jun 2;28(sup3):59–66.

6. Colombini M, James C, Ndwiga C, Integra team, Mayhew SH. The risks of partner violence following HIV status disclosure, and health service responses: narratives of women attending reproductive health services in Kenya. J Int AIDS Soc. 2016;19(1):20766.

7. Ramlagan S, Matseke G, Rodriguez VJ, Jones DL, Peltzer K, Ruiter RAC, et al. Determinants of disclosure and non-disclosure of HIV-positive status, by pregnant women in rural South Africa. SAHARA J. 2018 Oct 16;15(1):155–63.

8. Hallberg D, Kimario TD, Mtuya C, Msuya M, Björling G. Factors affecting HIV disclosure among partners in Morongo, Tanzania. International Journal of Africa Nursing Sciences. 2019 Jan 1;10:49–54.

9. Misra S, Mehta HT, Eschliman EL, Rampa S, Poku OB, Wang W-Q, et al. Identifying "What Matters Most" to Men in Botswana to Promote Resistance to HIV-Related Stigma. Qual Health Res. 2021 Mar 25;10497323211001360.

10. Yang L, Poku O, Misra S, Mehta H, Rampa S, Eisenberg MM, et al. Stigma, Structural Vulnerability, and "What Matters Most" Among Women Living with HIV in Botswana, 2017. American Journal of Public Health. 2021;

11. Yonah G, Fredrick F, Leyna G. HIV serostatus disclosure among people living with HIV/AIDS in Mwanza, Tanzania. AIDS Res Ther. 2014 Jan 22;11:5.

12. Ao I. Rate and correlates of HIV serostatus disclosure among HIV positive pregnant women in Nnewi southeastern Nigeria. Journal of Medicine and Medical Science. 2010 Sep 1;1:296–301.

13. Taylor, K., Lamb, M., Lahuerta, M., Ahoua, L., Abacassamo, F., & Elul, B. Patterns and Predictors of HIV Status Disclosure in the 12 Months After Diagnosis in Mozambique. J Acquir Immune Defic Syndr. 2020 Jul 1;84(3):242–52.

14. Iliyasu Z, Abubakar IS, Babashani M, Galadanci HS. Domestic violence among women living with HIV/AIDS in Kano, Northern Nigeria. Afr J Reprod Health. 2011 Sep;15(3):41–9.

15. Hatcher AM, Woollett N, Pallitto CC, Mokoatle K, Stöckl H, MacPhail C, et al. Bidirectional links between HIV and intimate partner violence in pregnancy: implications for prevention of mother-to-child transmission. J Int AIDS Soc. 2014;17:19233.

16. Shamu S, Zarowsky C, Shefer T, Temmerman M, Abrahams N. Intimate partner violence after disclosure of HIV test results among pregnant women in Harare, Zimbabwe. PLoS One. 2014;9(10):e109447.

17. Adzordor P, Avoka C, Bawontuo V, Agbesi S, Kuupiel D. Mapping evidence on adolescents' HIV-positive status disclosure in sub-Saharan Africa: a protocol for a scoping review. Systematic Reviews. 2020 Dec 4;9(1):278.

18. Toska E, Cluver LD, Hodes R, Kidia KK. Sex and secrecy: How HIV-status disclosure affects safe sex among HIV-positive adolescents. AIDS Care. 2015 Nov 2;27(sup1):47–58.

19. MacCarthy S, Rasanathan JJK, Ferguson L, Gruskin S. The pregnancy decisions of HIV-positive women: the state of knowledge and way forward. Reproductive Health Matters. 2012 Jan 1;20(sup39):119–40.

20. Britto C, Mehta K, Thomas R, Shet A. Prevalence and Correlates of HIV Disclosure Among Children and Adolescents in Low- and Middle-Income Countries: A Systematic Review. J Dev Behav Pediatr. 2016;37(6):496–505.

21. Nöstlinger C, Bakeera-Kitaka S, Buyze J, Loos J, Buvé A. Factors influencing social self-disclosure among adolescents living with HIV in Eastern Africa. AIDS Care. 2015 Nov 2;27(sup1):36–46.

22. Mugo C, Seeh D, Guthrie B, Moreno M, Kumar M, John-Stewart G, et al. Association of experienced and internalized stigma with self-disclosure of HIV status by youth living with HIV. AIDS Behav [Internet]. 2021 Jan 3 [cited 2021 Apr 27]; Available from: http://link.springer.com/10.1007/s10461-020-03137-0

23. Petersen I, Bhana A, Myeza N, Alicea S, John S, Holst H, et al. Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: a qualitative investigation. AIDS Care. 2010 Aug;22(8):970–8.

24. Giovenco D, Gill K, Fynn L, Duyver M, O'Rourke S, Straten A van der, et al. Experiences of oral pre-exposure prophylaxis (PrEP) use disclosure among South African adolescent girls and young women and its perceived impact on adherence. PLOS ONE. 2021 Mar 5;16(3):e0248307.

25. Gadisa T, Tymejczyk O, Kulkarni SG, Hoffman S, Lahuerta M, Remien RH, et al. Disclosure History Among Persons Initiating Antiretroviral Treatment at Six HIV Clinics in Oromia, Ethiopia, 2012–2013. AIDS Behav. 2017 Jan;21(1):70–81.

26. Kulkarni S, Hoffman S, Gadisa T, Melaku Z, Fantehun M, Yigzaw M, et al. Identifying Perceived Barriers along the HIV Care Continuum: Findings from Providers, Peer Educators, and Observations of Provider-Patient Interactions in Ethiopia. J Int Assoc Provid AIDS Care. 2016;15(4):291–300.

27. Nyblade L, Stockton MA, Giger K, Bond V, Ekstrand ML, Lean RM, et al. Stigma in health facilities: why it matters and how we can change it. BMC Medicine. 2019 Feb 15;17(1):25.

28. Olalekan AW. Conflicts in Rights of Disclosure of HIV Status in South Western Nigeria: the Health Care Provider's Perspective. Mater Sociomed. 2012;24(1):21–5.

29. Feyissa GT, Abebe L, Girma E, Woldie M. Stigma and discrimination against people living with HIV by healthcare providers, Southwest Ethiopia. BMC Public Health. 2012 Jul 13;12(1):522.

30. Greeff M, Phetlhu R, Makoae LN, Dlamini PS, Holzemer WL, Naidoo JR, et al. Disclosure of HIV Status: Experiences and Perceptions of Persons Living With HIV/AIDS and Nurses Involved in Their Care in Africa. Qual Health Res. 2008 Mar 1;18(3):311–24.

31. Ssali SN, Atuyambe L, Tumwine C, Segujja E, Nekesa N, Nannungi A, et al. Reasons for Disclosure of HIV Status by People Living with HIV/AIDS and in HIV Care in Uganda: An Exploratory Study. AIDS Patient Care STDS. 2010 Oct;24(10):675–81.

32. WHO | Opening up the HIV/AIDS epidemic [Internet]. WHO. World Health Organization; [cited 2021 May 9]. Available from: https://www.who.int/hiv/pub/vct/opening/en/

33. WHO adolescents living with HIV: developing and strengthening care and support services [Internet]. WHO. World Health Organization. [cited 2021 May 9]. Available from: https://www.childrenandaids.org/developing-and-strengthening-hiv-care

34. Eba PM. HIV-specific legislation in sub-Saharan Africa: A comprehensive human rights analysis. African Human Rights Law Journal. 2015;15(2):224–62.

35. HIV and AIDS in East and Southern Africa regional overview [Internet]. Avert. 2015 [cited 2021 May 9]. Available from: https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/overview

36. HIV criminalisation laws around the world [Internet]. aidsmap.com. [cited 2021 May 10]. Available from: https://www.aidsmap.com/about-hiv/hiv-criminalisation-laws-around-world

37. Haberlen SA, Nakigozi G, Gray RH, Brahmbhatt H, Ssekasanvu J, Serwadda D, et al. Antiretroviral Therapy Availability and HIV Disclosure to Spouse in Rakai, Uganda: A Longitudinal Population-Based Study. J Acquir Immune Defic Syndr. 2015 Jun 1;69(2):241–7.

38. Suzan-Monti M, Kouanfack C, Boyer S, Blanche J, Bonono R-C, Delaporte E, et al. Impact of HIV Comprehensive Care and Treatment on Serostatus Disclosure among Cameroonian Patients in Rural District Hospitals. PLoS One [Internet]. 2013 Jan 31 [cited 2021 May 2];8(1). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3561392/

39. King R, Katuntu D, Lifshay J, Packel L, Batamwita R, Nakayiwa S, et al. Processes and Outcomes of HIV Serostatus Disclosure to Sexual Partners among People Living with HIV in Uganda. AIDS Behav. 2008 Mar 1;12(2):232–43.

40. Fiorentino M, Nishimwe M, Protopopescu C, Iwuji C, Okesola N, Spire B, et al. Early ART Initiation Improves HIV Status Disclosure and Social Support in People Living with HIV, Linked to Care Within a Universal Test and Treat Program in Rural South Africa (ANRS 12249 TasP Trial). AIDS Behav. 2021 Apr 1;25(4):1306–22.

41. Alemayehu M, Aregay A, Kalayu A, Yebyo H. HIV disclosure to sexual partner and associated factors among women attending ART clinic at Mekelle hospital, Northern Ethiopia. BMC Public Health. 2014 Jul 23;14(1):746.

42. Simbayi LC, Kalichman SC, Strebel A, Cloete A, Henda N, Mqeketo A. Disclosure of HIV status to sex partners and sexual risk behaviours among HIV-positive men and women, Cape Town, South Africa. Sex Transm Infect. 2007 Feb;83(1):29–34.

43. Wouters E, van Loon F, van Rensburg D, Meulemans H. Community Support and Disclosure of HIV Serostatus to Family Members by Public-Sector Antiretroviral Treatment Patients in the Free State Province of South Africa. AIDS Patient Care and STDs. 2009 May;23(5):357–64.

44. Pearson CR, Micek MA, Pfeiffer J, Montoya P, Matediane E, Jonasse T, et al. One Year After ART Initiation: Psychosocial Factors Associated with Stigma Among HIV-Positive Mozambicans. AIDS Behav. 2009 Dec;13(6):1189–96.

45. 2019 UNAIDS Data [Internet]. UNAIDS. 2019 [cited 2021 May 9]. Available from: https://www.unaids.org/sites/default/files/media_asset/2019-UNAIDS-data_en.pdf

46. Oduetse OK, Nkomo B, Majingo N, Mashalla Y, Seloilwe E. Perceptions and attitudes towards acceptability of HIV self-testing among female sex workers in Selibe Phikwe, Botswana. African Journal of AIDS Research (AJAR). 2019 Sep;18(3):192–7.

47. Sarumi RO, Strode AE. New law on HIV testing in Botswana: The implications for healthcare professionals. South Afr J HIV Med [Internet]. 2015 Sep 11 [cited 2021 May 10];16(1). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5843220/

48. Madiba S, Josiah U. Perceived Stigma and Fear of Unintended Disclosure are Barriers in Medication Adherence in Adolescents with Perinatal HIV in Botswana: A Qualitative Study. BioMed Research International. 2019 Dec 2;2019:e9623159.

49. Midtbø V, Daniel M. Disclosure as a Positive Resource: The Lived Experiences of HIV-Positive Adolescents in Botswana. In: Liamputtong P, editor. Children and Young People Living with HIV/AIDS: A Cross-Cultural Perspective [Internet]. Cham: Springer International Publishing; 2016 [cited 2021 May 2]. p. 321–38. (Cross-Cultural Research in Health, Illness and Well-Being). Available from: https://doi.org/10.1007/978-3-319-29936-5_17

50. Masupe TK, van Rensburg GH, Human SP. Factors Influencing Disclosure of Hiv Status to Sexual Partners in Botswana. Africa Journal of Nursing & Midwifery. 2012 Sep;14(2):18–32.

51. Okatch H, Morales K, Rogers R, Chapman J, Marukutira T, Tshume O, et al. Trends in HIV Treatment Adherence Before and After HIV Status Disclosure to Adolescents in Botswana. J Adolesc Health. 2020 Oct;67(4):502–8.

52. Midtbø V, Shirima V, Skovdal M, Daniel M. How disclosure and antiretroviral therapy help HIV-infected adolescents in sub-Saharan Africa cope with stigma. Afr J AIDS Res. 2012 Oct;11(3):261–71.

53. Bulterys MA, Sharma M, Mugwanya K, Stein G, Mujugira A, Nakyanzi A, et al. Correlates of HIV Status Nondisclosure by Pregnant Women Living With HIV to Their Male Partners

in Uganda: A Cross-Sectional Study. J Acquir Immune Defic Syndr. 2021 Apr 1;86(4):389–95.

54. Naigino R, Makumbi F, Mukose A, Buregyeya E, Arinaitwe J, Musinguzi J, et al. HIV status disclosure and associated outcomes among pregnant women enrolled in antiretroviral therapy in Uganda: a mixed methods study. Reproductive Health. 2017 Aug 30;14(1):107.

55. Osinde MO, Kakaire O, Kaye DK. Factors associated with disclosure of HIV serostatus to sexual partners of patients receiving HIV care in Kabale, Uganda. Int J Gynaecol Obstet. 2012 Jul;118(1):61–4.

56. Rujumba J, Neema S, Byamugisha R, Tylleskär T, Tumwine JK, Heggenhougen HK. “Telling my husband I have HIV is too heavy to come out of my mouth”: pregnant women’s disclosure experiences and support needs following antenatal HIV testing in eastern Uganda. Journal of the International AIDS Society. 2012;15(2):17429.

57. Kadowa I, Nuwaha F. Factors influencing disclosure of HIV positive status in Mityana district of Uganda. African Health Sciences. 2009 Mar 20;9(1):26–33.

58. Wagman JA, Gray RH, Campbell JC, Thoma M, Ndyanabo A, Ssekasanvu J, et al. Effectiveness of an integrated intimate partner violence and HIV prevention intervention in Rakai, Uganda: analysis of an intervention in an existing cluster randomised cohort. The Lancet Global Health. 2015 Jan 1;3(1):e23–33.

59. Ashaba S, Cooper-Vince CE, Vořechovská D, Rukundo GZ, Maling S, Akena D, et al. Community beliefs, HIV stigma, and depression among adolescents living with HIV in rural Uganda. African Journal of AIDS Research. 2019 Sep 27;18(3):169–80.

60. Mutumba M, Mugerwa H, Musiime V, Gautam A, Nakyambadde H, Matama C, et al. Perceptions of Strategies and Intervention Approaches for HIV Self-Management among Ugandan Adolescents: A Qualitative Study. J Int Assoc Provid AIDS Care. 2019 Jan 1;18:2325958218823246.

61. Stangl AL, Lloyd JK, Brady LM, Holland CE, Baral S. A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: how far have we come? J Int AIDS Soc. 2013 Nov 13;16(3 Suppl 2):18734.

62. Pantelic M, Shenderovich Y, Cluver L, Boyes M. Predictors of internalised HIV-related stigma: a systematic review of studies in sub-Saharan Africa. Health Psychol Rev. 2015;9(4):469–90.

63. Sorsdahl KR, Mall S, Stein DJ, Joska JA. The prevalence and predictors of stigma amongst people living with HIV/AIDS in the Western Province. AIDS Care. 2011 Jun 1;23(6):680–5.

64. Nattabi B, Li J, Thompson SC, Orach CG, Earnest J. Factors Associated With Perceived Stigma Among People Living With HIV/AIDS in Post-Conflict Northern Uganda. AIDS Education and Prevention. 2011 Jun 1;23(3):193–205.

65. Holzemer WL, Uys LR, Chirwa ML, Greeff M, Makoae LN, Kohi TW, et al. Validation of the HIV/AIDS Stigma Instrument—PLWA (HASI-P). AIDS Care. 2007 Sep 1;19(8):1002–12.

66. Tsai AC, Weiser SD, Steward WT, Mukiibi NFB, Kawuma A, Kembabazi A, et al. Evidence for the Reliability and Validity of the Internalized AIDS-Related Stigma Scale in Rural Uganda. AIDS Behav. 2013 Jan 1;17(1):427–33.

67. Cuca YP, Onono M, Bukusi E, Turan JM. Factors associated with pregnant women's anticipations and experiences of HIV-related stigma in rural Kenya. AIDS Care. 2012 Sep 1;24(9):1173–80.

68. Kingori C, Reece M, Obeng S, Murray M, Shacham E, Dodge B, et al. Psychometric evaluation of a cross-culturally adapted felt stigma questionnaire among people living with HIV in Kenya. AIDS Patient Care STDS. 2013 Aug;27(8):481–8.

69. Peltzer K, Pengpid S. Prevalence And Associated Factors Of Enacted, Internalized And Anticipated Stigma Among People Living With HIV In South Africa: Results Of The First National Survey. HIV AIDS (Auckl). 2019 Nov 7;11:275–85.

70. Carrasco MA, Arias R, Figueroa ME. The multidimensional nature of HIV stigma: evidence from Mozambique. African Journal of AIDS Research (AJAR). 2017 Mar;16(1):11–8.

71. Bhana A, Mellins CA, Petersen I, Alicea S, Myeza N, Holst H, et al. The VUKA family program: Piloting a family-based psychosocial intervention to promote health and mental health among HIV infected early adolescents in South Africa. AIDS Care. 2014 Jan 2;26(1):1–11.

72. Chidrawi HC, Greeff M, Temane QM, Doak CM. HIV stigma experiences and stigmatisation before and after an intervention. Health SA Gesondheid. 2016 Oct 11;21(0):196–205.

73. Jürgensen M, Sandøy IF, Michelo C, Fylkesnes K. Effects of home-based Voluntary Counselling and Testing on HIV-related stigma: Findings from a cluster-randomized trial in Zambia. Social Science & Medicine. 2013 Mar 1;81:18–25.

74. Odimegwu CO, Akinyemi JO, Alabi OO. HIV-Stigma in Nigeria: Review of Research Studies, Policies, and Programmes. AIDS Research and Treatment. 2017 Dec 27;2017:e5812650.

75. Yang LH, Ho-Foster AR, Becker TD, Misra S, Rampa S, Poku OB, et al. Psychometric Validation of a Scale to Assess Culturally-Salient Aspects of HIV Stigma Among Women Living with HIV in Botswana: Engaging "What Matters Most" to Resist Stigma. AIDS Behav [Internet]. 2020 Aug 24 [cited 2021 Jan 27]; Available from: https://doi.org/10.1007/s10461-020-03012-y

76. Kunihira N, Nuwaha F, Mayanja R, Peterson S. Barriers to use of antiretroviral drugs in Rakai district of Uganda. Afr Health Sci. 2010 Jun;10(2):120–9.

77. Wyrod R. Masculinity and the persistence of AIDS stigma. Cult Health Sex. 2011 Apr;13(4):443–56.

78. Chan BT, Weiser SD, Boum Y, Siedner MJ, Mocello AR, Haberer JE, et al. Persistent HIV-related stigma in rural Uganda during a period of increasing HIV incidence despite treatment expansion. AIDS. 2015 Jan 2;29(1):83–90.

79. Mburu G, Ram M, Siu G, Bitira D, Skovdal M, Holland P. Intersectionality of HIV stigma and masculinity in eastern Uganda: implications for involving men in HIV programmes. BMC Public Health. 2014 Oct 11;14(1):1061.

80. Ashaba S, Kaida A, Coleman JN, Burns BF, Dunkley E, O'Neil K, et al. Psychosocial challenges facing women living with HIV during the perinatal period in rural Uganda. PLOS ONE. 2017 May 1;12(5):e0176256.

81. Mburu G, Ram M, Skovdal M, Bitira D, Hodgson I, Mwai GW, et al. Resisting and challenging stigma in Uganda: the role of support groups of people living with HIV. Journal of the International AIDS Society. 2013;16(3S2):18636.

82. Rakgoasi S, Odimegwu C. "Women get Infected but Men Die ...!" Narratives on Men , Masculinities and HIV/AIDS in Bostwana. International Journal of Men's Health. 2013 Aug 15;12:166–82.

83. Farahani M, Roumis D, Mahal A, Holmes M, Moalosi G, Molomo C, et al. Effects of AIDS-related disability on workforce participation and earned income in Botswana: A quasi-experimental evaluation. Health. 2013 Mar 5;5(3):409–16.

84. Pence BW, Gaynes BN, Atashili J, O'Donnell JK, Kats D, Whetten K, et al. Feasibility, Safety, Acceptability, and Preliminary Efficacy of Measurement-Based Care Depression Treatment for HIV Patients in Bamenda, Cameroon. AIDS Behav. 2014 Jun;18(6):1142–51.

85. Els C, Boshoff W, Scott C, Strydom W, Joubert G, Ryst E van der. Psychiatric co-morbidity in South African HIV/AIDS patients. South African Medical Journal [Internet].

1999 Jan 1 [cited 2019 Apr 29];89(9). Available from: https://www.ajol.info/index.php/samj/article/view/157740

86. Breuer E, Myer L, Struthers H, Joska JA. HIV/AIDS and mental health research in sub-Saharan Africa: a systematic review. Afr J AIDS Res. 2011 Jun;10(2):101–22.

87. Bernard C, Dabis F, de Rekeneire N. Prevalence and factors associated with depression in people living with HIV in sub-Saharan Africa: A systematic review and meta-analysis. PLoS ONE. 2017;12(8):e0181960.

88. Remien RH, Stirratt MJ, Nguyen N, Robbins RN, Pala AN, Mellins CA. Mental health and HIV/AIDS: the need for an integrated response. AIDS. 2019 Jul 15;33(9):1411–20.

89. Gupta R, Dandu M, Packel L, Rutherford G, Leiter K, Phaladze N, et al. Depression and HIV in Botswana: A Population-Based Study on Gender-Specific Socioeconomic and Behavioral Correlates. PLoS One [Internet]. 2010 Dec 8 [cited 2019 Apr 22];5(12). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2999532/

90. Olatayo Adeoti A, Dada MU, Fadare JO. Prevalence of Depression and Anxiety Disorders in People Living with HIV/AIDS in a Tertiary Hospital in South Western Nigeria. Med Rep Case Stud [Internet]. 2018 [cited 2021 May 3];03(01). Available from: https://www.omicsonline.org/open-access/prevalence-of-depression-and-anxiety-disorders-in-people-living-with-hivaids-in-a-tertiary-hospital-in-south-western-nigeria-2572-5130-1000150-99266.html

91. Maphisa JM. Mental health legislation in Botswana. BJPsych International. undefined/ed;1–3.

92. Parcesepe AM, Bernard C, Agler R, Ross J, Yotebieng M, Bass J, et al. Mental health and HIV: research priorities related to the implementation and scale up of 'treat all' in sub-Saharan Africa. J Virus Erad. 4(Suppl 2):16–25.

93. Badu E, O'Brien AP, Mitchell R. An integrative review of potential enablers and barriers to accessing mental health services in Ghana. Health Research Policy and Systems. 2018 Nov 16;16(1):110.

94. Zhou W, Yu Y, Yang M, Chen L, Xiao S. Policy development and challenges of global mental health: a systematic review of published studies of national-level mental health policies. BMC Psychiatry. 2018 May 18;18(1):138.

95. Sankoh O, Sevalie S, Weston M. Mental health in Africa. The Lancet Global Health. 2018 Sep 1;6(9):e954–5.

96. Sherr L, Clucas C, Harding R, Sibley E, Catalan J. HIV and depression--a systematic review of interventions. Psychol Health Med. 2011 Oct;16(5):493–527.

97. Rabkin JG. HIV and depression: 2008 review and update. Curr HIV/AIDS Rep. 2008 Nov;5(4):163–71.

98. Brandt R. The mental health of people living with HIV/AIDS in Africa: a systematic review. Afr J AIDS Res. 2009 Jun;8(2):123–33.

99. Bachmann S. Epidemiology of Suicide and the Psychiatric Perspective. Int J Environ Res Public Health [Internet]. 2018 Jul [cited 2020 Feb 18];15(7). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6068947/

100. World Health Organization. Adolescent mental health [Internet]. 2019 [cited 2020 Feb 18]. Available from: https://www.who.int/news-room/fact-sheets/detail/adolescent-mental-health

101. Betancourt T, Scorza P, Kanyanganzi F, Fawzi MCS, Sezibera V, Cyamatare F, et al. HIV and Child Mental Health: A Case-Control Study in Rwanda. Pediatrics. 2014 Aug;134(2):e464–72.

102. Kim MH, Mazenga AC, Yu X, Devandra A, Nguyen C, Ahmed S, et al. Factors associated with depression among adolescents living with HIV in Malawi. BMC Psychiatry. 2015 Oct 26;15(1):264.

103. Kemigisha E, Zanoni B, Bruce K, Menjivar R, Kadengye D, Atwine D, et al. Prevalence of depressive symptoms and associated factors among adolescents living with HIV/AIDS in South Western Uganda. AIDS Care. 2019 Oct;31(10):1297–303.

104. Kamau JW, Kuria W, Mathai M, Atwoli L, Kangethe R. Psychiatric morbidity among HIV-infected children and adolescents in a resource-poor Kenyan urban community. AIDS Care. 2012 Jul 1;24(7):836–42.

105. Vreeman RC, McCoy BM, Lee S. Mental health challenges among adolescents living with HIV. J Int AIDS Soc [Internet]. 2017 May 16 [cited 2020 Feb 18];20(Suppl 3). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5577712/

106. Owen JP, Baig B, Abbo C, Baheretibeb Y. Child and adolescent mental health in sub-Saharan Africa: a perspective from clinicians and researchers. BJPsych Int. 2016 May 1;13(2):45–7.

107. Akena D, Musisi S, Joska J, Stein DJ. The association between aids related stigma and major depressive disorder among HIV-positive individuals in Uganda. PLoS One. 2012;7(11):e48671.

108. Ngo VK, Wagner GJ, Huynh A, Ryan G, Musisi S. A qualitative analysis of the effects of depression and antidepressants on physical and work functioning among antiretroviral therapy clients in Uganda. J Int Assoc Provid AIDS Care. 2013 Dec;12(6):414–22.

109. Poku OB, Ho-Foster AR, Entaile P, Misra S, Mehta H, Rampa S, et al. 'Mothers moving towards empowerment' intervention to reduce stigma and improve treatment adherence in pregnant women living with HIV in Botswana: study protocol for a pragmatic clinical trial. Trials. 2020 Oct 7;21(1):832.

110. Westergaard RP, Hess T, Astemborski J, Mehta SH, Kirk GD. Longitudinal changes in engagement in care and viral suppression for HIV-infected injection drug users. AIDS. 2013 Oct 23;27(16):2559–66.

111. Meyer JP, Althoff AL, Altice FL. Optimizing care for HIV-infected people who use drugs: evidence-based approaches to overcoming healthcare disparities. Clin Infect Dis. 2013 Nov;57(9):1309–17.

Chapter 3: Relationships between Mental Health and the HIV Care Continuum for Adolescents Living with HIV: A Scoping Review of the Literature

3.1 Abstract

Introduction: Reviews have examined mental disorders experienced by Adolescents Living with HIV (ALWH), yet there is little understanding about mental disorders and the HIV care continuum. The aim of this was scoping review was to examine research on mental health and engagement in all steps along the HIV care continuum for ALWH in sub-Saharan Africa.

Methods: PubMed, CINAHL, EMBASE, and PsycINFO were searched through December 31, 2020. To be included in this review an article had to: present primary data, be from sub-Saharan Africa; have a study population of adolescents (age 10-19) living with HIV; be peer-reviewed; and assess symptoms or diagnoses of mental disorders in relation to one or more steps of the continuum. Title and abstract review were conducted by two authors, and a third author then confirmed articles that were selected for full text screening. Full text review involved a similar process in which both the first and second author extracted data from each article. Abstract and full text review involved double screening utilizing the software Covidence.

Results: 34 studies were included in this review. Most studies came from Eastern and Southern Africa and the majority assessed mental disorders at the HIV treatment step among both older and younger adolescents. There was a predominance of cross-sectional studies and use of Western conceptualized mental disorder measures. Depression and anxiety were the most common disorders examined, followed by general psychological distress, while suicide and post-traumatic stress disorder (PTSD) were examined in only a handful of studies. ALWH were primarily assessed at the “Engaged or Retained in Care” step of the continuum, with the majority of studies taking place prior to initiation of Universal Test and Treat policies.

Conclusions: The results from this scoping review suggest a predominance of the research among ALWH focuses on those engaged in care. The prevalent use of cross-sectional studies continues to generate a gap in our longitudinally understanding HIV and psychosocial outcomes among ALWH. More attention is also needed for other stages of the continuum, particularly the HIV testing and viral suppression steps, in order to comprehensively understand adolescent mental health needs and priority timepoints for intervention.

3.2 Background

Common mental disorders, such as depressive and anxiety disorders, are known to be prevalent comorbidities experienced by people living with HIV (PLHIV)(1). PLHIV are more likely to be diagnosed with mental disorders compared to individuals who are not living with the virus (1–5). As sub-Saharan Africa (SSA) represents approximately 70% of the global burden of HIV (1), the mental health of PLHIV in sub-Saharan Africa (SSA) remains a critical aspect of HIV care that necessitates attention.

Adolescents living with HIV (ALWH) are a particularly vulnerable subset of individuals within the population of PLHIV in SSA. Various studies among ALWH suggest a high prevalence of both depression and suicidality (6–8). This is particularly pertinent as depression is one of the leading causes of illness and disability among adolescents globally and suicide is the third leading cause of death among 15-19 year olds (9,10). Furthermore, ALWH are especially susceptible to mental disorders from a developmental perspective, given the behavioral and social changes they are experiencing at this critical age leading into adulthood (11) .

The HIV care continuum encompasses a series of steps from diagnosis to viral suppression that inform HIV treatment on a global scale (12). ALWH face myriad challenges that adults living with HIV do not, and as such, utilizing the care continuum as a framework for improving their linkage and retention in care and viral suppression is essential. Critical to this point is understanding the steps of the continuum in which ALWH are most engaged (13)(Wood et al., 2015) and how psychosocial elements may hinder their successful and sustained transition to care in adulthood. While recent reviews have examined the mental health challenges experienced by ALWH, understanding mental disorders as they relate to the full HIV care continuum remains an extant gap (14,15). To date, no scoping reviews have been published to examine research on mental disorders and engagement in all steps along the HIV care continuum among ALWH in SSA.

Objective

This scoping review seeks to characterize the published literature on mental disorders and the HIV care continuum in SSA for ALWH. Specifically, this review will assess the relationship between mental disorders (i.e., Depressive Disorders, Anxiety Disorders, Trauma and Stressor Related Disorders, Schizophrenia Spectrum and Other Psychotic Disorders, and Disruptive, Impulse-Control, and Conduct Disorders) and engagement in each step along the HIV care continuum for ALWH ages 10-19 years in SSA.

3.3 Methods

Definition of Terms

Adolescents were defined using the World Health Organization (WHO) definition of individuals ages 10-19 years of age. Younger adolescents are ages 10-14 and older adolescents are ages 15-19 (24,25). We used the HIV care continuum as a framework for understanding the intersection of HIV treatment and mental health assessment and care for ALWH. The care continuum exists in two iterations: pre-introduction of Universal Test and Treat and post-introduction of Universal Test and Treat (UTT) policies. Various studies were suggestive that early treatment of individuals living with HIV could be fundamental in the reduction of transmission rates (16,17) . Given this, the standard approach to addressing HIV transformed from the treatment as prevention model into the concept of UTT in approximately 2016. UTT consists of providing both HIV testing and counselling to populations and then antiretroviral therapy (ART) to all individuals who are living with HIV (18).

Prior to UTT, the care continuum consisted of five steps on the pathway from diagnosis to viral suppression: 1) HIV diagnosis, 2) linkage to care, 3) engagement or retainment in care, 4) adherence to ART, and 5) viral suppression. Linkage to care in this case meant no more than 3 months between HIV diagnosis and initiation of treatment (12). Being engaged or retained in care was variously described but commonly defined as having at least 2 or more viral load measures at least 3 months apart within the last year. ART adherence was also defined in multiple ways, but often was measured through pill counts and patient self-reports. Viral suppression was commonly defined as having less then 200 copies per milliliter of HIV obtained from a viral load measure that took place within the last year (12).

Following the establishment of UTT, the care continuum was modified to reflect this new strategy and the steps became: 1) HIV diagnosis, 2) linkage to care, 3) receiving HIV Care, 4) retainment in HIV care, and 5) viral suppression (19,20)5/24/21 10:09:00 PM. Linkage to care post-UTT encompasses having baseline labs taken, enrolling in an ART program and initiating ART, and receiving early counselling and adherence support (21). Receiving HIV care is defined as the visits that take place after the first follow up that ends the linkage to care step. Retention in care is defined as completing at least 2 or more HIV treatment visits with at least 90 days in between and within one calendar year (22). For the purposes of this review, we included studies at any of these stages of the HIV care continuum and accepted a range of definitions and measures for each step (e.g., a range of ART adherence measures), as long as the intention was to measure a step along this continuum in some way.

For the purposes of this review, included mental disorders are defined as those that fit within the following DSM-V domains: Depressive Disorders, Anxiety Disorders, Trauma and Stressor Related Disorders, and Schizophrenia Spectrum and Other Psychotic Disorders (23) and Suicide. For studies in which general and/or broad measures were used, that could be informative of the aforementioned mental disorders, but not diagnostic, we defined these as measuring general psychological distress and as eligible for inclusion in this review. Publications that solely focused on neurocognitive disorders, (e.g., epilepsy) were not included. In addition, studies that focused on alcohol and substance use disorders without consideration of a mental disorder were also excluded. However, if a study was eligible because it examined one of the specified mental disorder domains in relation to the HIV care continuum but also collected data on alcohol and/or substance use disorders, we extracted data on these behavioral conditions to assess their interrelationship (i.e., their potential as moderators or mediators of the mental health and care continuum relationship).

Eligibility Criteria

To be included in this review an article also had to meet the following inclusion criteria: 1) it presented primary quantitative or qualitative data from SSA; 2) the study population was adolescents (age 10-19) living with HIV or data were stratified by age and included this population; 3) it was published in a peer-reviewed journal; 4) it assessed symptoms or diagnoses of the specified mental disorders in relation to one or more of the above defined steps of the HIV care continuum (i.e., a) HIV testing and diagnosis, b) accessing medical care for HIV, c) starting ART initiation, d) ongoing engagement or retention in care for HIV, e) adherence to ART, f) viral suppression); and, 5) it was written in English.

An article was excluded from this scoping review if it met one or more of the following criteria: 1) it was a review paper, conference poster, instrument validation paper, conference oral presentation, or dissertation; 2) it focused exclusively on alcohol or drug use; 3) the study population was people living with HIV with neurocognitive disorders without the assessment of a mental disorder; 4) it did not provide information that enabled ascertainment of what step of the continuum participants may be on; 5) the study population was only adults (19 years or older) or included adolescents but did not stratify by age; and, 6) it did not report HIV status of study participants or present information that enabled ascertainment of HIV status.

Search Strategy

The search strategy was centered around three overarching domains: the HIV care continuum, mental health, and SSA. Search strings for each of these domains were developed and linked using AND to identify studies that potentially meet the inclusion criteria. Four electronic databases (PubMed, CINAHL, EMBASE, and PsycINFO) were searched through December 31st, 2020.

Data Extraction and Management

All data extraction for this review involved the first (OBP) and second author (NW) using the software Covidence. First, title and abstract review were conducted by both authors separately with any discrepancies jointly discussed. A third reviewer then confirmed articles that were selected via this initial process to undergo full text screening. Full text review involved a similar process in which both the first and second author confirmed article eligibility, and for those eligible, extracted data from each article. Regular meetings among the two authors allowed for discrepancies to be addressed. All data from the articles were put into a spreadsheet that included indicators for the following: study identification, which included citation, author(s), year of publication; study description, including study objectives, location and setting, recruitment method, population characteristics, type of mental disorders assessed, mental health measurements used, steps in the HIV care continuum (pre and post-UTT), study design, sample size, perinatal or behavioral transmission, and whether older and/or younger adolescents were included; outcomes, which included analytic approach, outcome measures, comparison groups, key findings, conclusions, and limitations. For any studies in which the dates of data collection were unclear, study authors were contacted directly and asked to verify whether it was conducted to assess the HIV care continuum pre- or post-UTT.

We also acknowledge that there are various potential ways in which to use the care continuum as a framework for understanding the diversity of studies that were reviewed. For this review, studies were assigned steps of the continuum based on either the point at which the actual analysis examining the relationship between HIV and mental health took place or based on the study question guiding the analysis (e.g. examining psychosocial factors related to retention in care for ALWH). This review was conducted in consideration of the PRISMA Extension for Scoping Reviews (26) and registered with Prospero on August 8th, 2020.

3.4 Results

In total, 6,433 studies were identified through the search, of which 34 were included in this review. Figure 3.1 presents a PRISMA flowchart of the results of the article screening. Out of the 6,433 studies, 3,720 studies had their titles and abstracts reviewed and 178 went through full text review. Of those excluded, the majority were due to either being conducted solely among adults or not presenting data stratified by age for adolescents. Tables 3.1 and 3.2 provide an overview separately of basic details of all studies conducted pre- and post-UTT, respectively: the country in which each study took place, description of the population, type of HIV transmission, study design, and mental disorders and care continuum steps assessed. Most studies (n=30) took place prior to the passage of UTT policy. Many studies included both older and younger adolescents, with 3 focusing on only older and 2 focusing on only younger adolescents. Most studies came from South Africa (n=12), followed by Uganda (n=6), Rwanda (n=4), Zambia (n=4), and Kenya (n=3). Nigeria, Ghana, Namibia, Zimbabwe, and Malawi each had 1 study. There was a predominance of cross-sectional studies (n=25), followed by qualitative (n=5), mixed methods (n=3), case-control (n=2) and one randomized controlled trial (RCT) (n=1).

The majority of studies these were among ALWH at the "Engaged or Retained in Care" (n=26) step of the continuum. There were also studies that assessed ALWH at both the "Engaged or Retained in Care" and "Adherence" (n=4) steps. For the 4 studies that took place post-UTT policy implementation, two were with ALWH at the "Received Care" step, one with adolescents at both the "Received HIV Care" and "Retained in Care" steps, and one at both the "Received Care" and "Viral Suppression" steps.

Table 3.3 presents the mental health measures used in each study and is organized by type of mental health measure used, and whether it was used with ALWH and/or their caregivers. Depression (n=24) and anxiety (n=8) were the most common disorders examined, with only a handful of studies assessing post-traumatic stress disorder (PTSD) (n=6), suicide (n=4), and conduct problems (n=2); some studies examined combinations of these (n=13). General psychological distress measures were used in 13 studies, with 5 of these utilized alongside of the mental disorder measures.

Below, we present selected and summarized results from all studies, first separated by pre-UTT and post-UTT, and then by stage of the HIV care continuum; complete findings are presented in Appendix A and B.

Figure 3.1. Search Summary

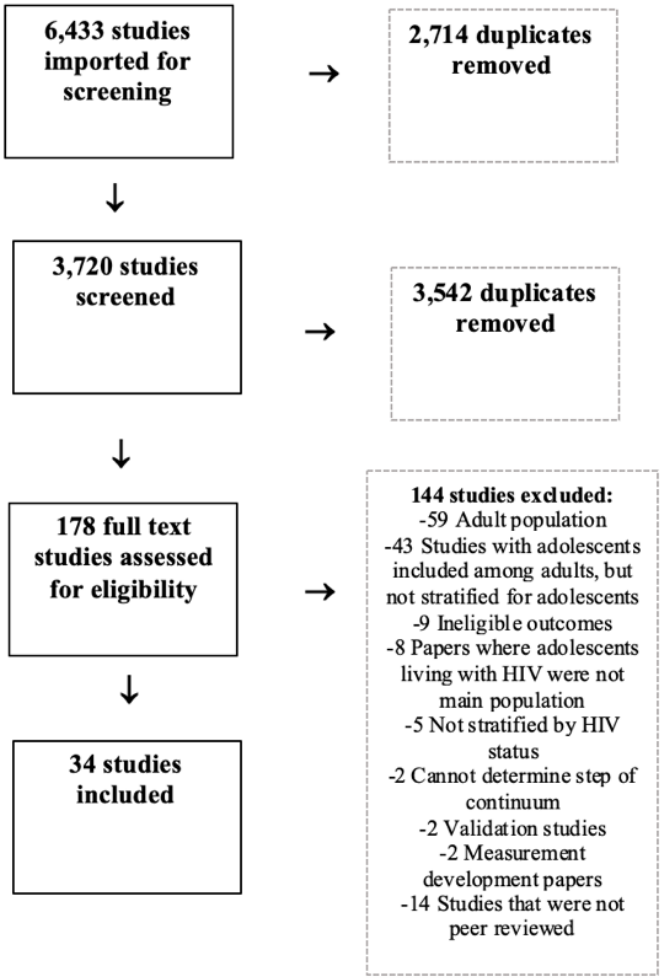


Table 3.1. Study Descriptions Pre-UTT

Citation	Country	Population	Older/Younger Adolescents*	Type of HIV Transmission	Study Design	Mental Disorders Assessed	HIV Care Continuum Steps
Abubakar et al., 2017	Kenya	44 ALWH 53 HIV-affected adolescents 33-unaffected adolescents	Both	Perinatal	Cross-sectional	Depression[a]	Engaged or retained in care
Adeyemo et al., 2019	Nigeria	201 ALWH	Both	Not reported	Cross-sectional	Suicide ideation	Engaged or retained in Care
Ashaba et al., 2018	Uganda	224 ALWH	Both	Not reported	Cross-sectional	Depression Suicide	Engaged or retained in care
Betancourt et al., 2014	Rwanda	218 ALWH 228 HIV-affected adolescents 237 HIV-unaffected adolescents	Both	Not reported	Case control	Depression[a] Anxiety[a] General psychological distress	Engaged or retained in care
Bhana et al., 2014	South Africa	74 families of ALWH	Younger	Perinatal	RCT	Depression General psychological distress	Engaged or retained in care
Boyes et al., 2019	South Africa	1,060 ALWH	Both	Perinatal and behavioral	Cross-sectional	Depression Anxiety PTSD General psychological distress	Engaged or retained in care
Casale et al., 2019	South Africa	1,053 ALWH	Both	Perinatal and behavioral	Cross-sectional	Suicidal ideation	Engaged or retained in care
Enimil et al., 2016	Ghana	40 ALWH	Both	Perinatal	Qualitative and cross-sectional questionnaire (Mixed	Depression	Engaged or retained in care

					Methods)		
Gentz et al., 2017	Namibia	99 ALWH	Both	Perinatal and behavioral	Cross-sectional	General psychological Distress	Engaged or retained in care
Kim et al., 2017	Malawi	519 ALWH	Both	Perinatal	Cross-sectional	Depression	Engaged or retained in care Adherence to ART
Li et al., 2010	South Africa	26 ALWH	Both	Perinatal and behavioral	Qualitative		Engaged or retained in care
Louw et al., 2016	South Africa	78 ALWH (14 ART naïve, 46 on ART without HIV-related encephalopathy (HIVE), 18 on ART with HIVE 30 HIV-unaffected adolescents	Both	Perinatal	Cross-sectional	Depression[a] Anxiety General psychological distress	Engaged or retained in care
Lyambai & Mwape, 2018	Zambia	103 ALWH	Both	Not reported	Multi-method	General psychological distress	Engaged or retained in care
Mbalinda et al., 2015	Uganda	614 ALWH	Both	Perinatal	Cross-sectional	General psychological distress	Engaged or retained in care
Menon et al., 2007	Zambia	127 ALWH	Both	Not reported	Cross-sectional**	General psychological distress	Engaged or retained in care
Menon et al., 2009	Zambia	127 ALWH 419 Adolescents in School (HIV status unknown)	Both	Perinatal and behavioral	Cross-sectional	General psychological distress	Engaged or retained in care
Mutumba et al., 2016	Uganda	464 ALWH	Both	Not reported	Cross-sectional	General psychological distress	Engaged or retained in HIV care Adherence to ART
Mutumba et al., 2017	Uganda	464 ALWH	Both	Both	Cross-sectional	General psychological distress	Engaged or retained in care
Nalukenge	Uganda	19 ALWH	Both	Perinatal	Qualitative	Depression	Engaged or retained

et al., 2019		19 caregivers				General psychological distress	in care
Nduwimana et al., 2017	Rwanda	218 ALWH 228 HIV- affected adolescents 235 HIV-unaffected adolescents	Both	Not reported	Cross-sectional	Depression Anxiety	Engaged or retained in care
Ng et al., 2015	Rwanda	218 ALWH 228 HIV affected adolescents 237 HIV-unaffected adolescents	Both	Not reported	Case control	Depression[a] Anxiety[b]	Engaged or retained in care
Okawa et al., 2018	Zambia	190 ALWH	Older	Not reported	Mixed Methods	Depression	Engaged or retained in care Adherence to ART
Osok et al., 2018	Kenya	14 pregnant ALWH 163 pregnant adolescents who were not diagnosed with HIV at time of study	Older	Not reported	Cross-sectional	Depression	Engaged or retained in care
Pantelic et al., 2017	South Africa	1,060 ALWH	Both	Not reported	Cross-sectional	Depression	Engaged or retained in care
Petersen et al., 2011	South Africa	25 ALWH 15 caregivers	Both	Not reported	Qualitative	N/A	Engaged or retained in care
Sherr et al., 2018	South Africa	1,024 ALWH	Both	Perinatal and Behavioral	Cross-sectional	Depression Anxiety PTSD Suicide ideation	Engaged or retained in care
Smith Fawzi et al., 2016	Rwanda	193 ALWH	Both	Not reported	Cross-sectional	Depression Combined Depression and Anxiety measure	Engaged or retained in care Adherence to ART

West et al., 2019	South Africa	278 ALWH	Both	Perinatal and behavioral	Cross-sectional	Depression Anxiety PTSD Suicide ideation	Engaged or Retained in Care
Willis et al., 2018	Zimbabwe	21 ALWH	Older	Perinatal and behavioral	Qualitative	N/A	Engaged or retained in care
Woollett et al., 2017	South Africa	343 ALWH	Both	Perinatal and behavioral	Cross-sectional	Depression Anxiety PTSD Suicide ideation	Engaged or retained in care

a Both adolescents and caregivers
b Caregivers
*Older/Younger indicates whether ALWH are older as defined by WHO (15-19) or younger (10-14)
**A multi-method study, only quantitative data pertained to study question

Table 3.2. Study Descriptions Post-UTT

Citation	Country	Population	Older/Younger Adolescents*	Type of HIV Transmission	Study Design	Mental Disorders Assessed	HIV Care Continuum Steps
Coetzee et al., 2019	South Africa	134 ALWH	Both	Not reported	Cross-sectional	Depression Anxiety	Received HIV Care
Enane et al., 2019	Kenya	6 hospitalized ALWH, 16 caregivers of hospitalized ALWH, 11 non-disclosed engaged ALWH, 55 disclosed engaged ALWH, 28 caregivers of engaged ALWH	Both	Perinatal	Qualitative	**N/A**	Received HIV care Retained in care
Kagee et al., 2019	South Africa	134 ALWH	Both	Not reported	Cross-sectional	Depression Anxiety General psychological distress	Received HIV Care
Kemigisha et al., 2019	Uganda	336 ALWH	Both	Not reported	Cross-sectional	Depression	Received HIV Care Viral suppression

*Older/younger indicates whether ALWH are older as defined by WHO (15-19) or younger (10-14)

Table 3.3. Mental Health Measures

Quantitative Measures	
Beck Depression Inventory (BDI-11)	ALWH 2 studies: (Abubakar et al., 2017; Kim et al., 2017) Caregivers: 1 study (Abubakar et al., 2017)
Child Behaviour Checklist (CBCL)	ALWH 1 study: (Louw et al., 2016)
Child Depression Inventory (CDI)	ALWH 7 studies: (Bhana et al., 2014; Boyes et al., 2019; Casale et al., 2019; Pantelic et al., 2017; Sherr et al., 2018; West et al., 2019; Woollett et al., 2017)
Children's Depression Rating Scale-Revised (CDRS-R)	ALWH: 1 study (Kim et al., 2017)
Center for Epidemiologic Studies Depression Scale (CES-D)	ALWH 1 study: (Okawa et al., 2018)
Center for Epidemiological Studies-Depression Scale for Children (CES-DC)	ALWH 5 studies: (Betancourt et al., 2014; Kemigisha et al., 2019**; Nduwimana et al., 2017; Ng et al., 2015; Smith Fawzi et al., 2016)
Child PTSD Checklist	ALWH 4 studies: (Boyes et al., 2019; Sherr et al., 2018; West et al., 2019; Woollett et al., 2017)
Edinburgh Postnatal Depression Screen (EPDS)	ALWH 1 study: (Osok et al., 2018)
Hopkins Symptoms Checklist-25 (HSCL-25)	Caregivers 2 studies: (Betancourt et al., 2014; Ng et al., 2015)
ICD-10 Major Depression Inventory (MDI)	ALWH 1 study: (Enimil et al., 2016)
Mini International Neuropsychiatric Interview for Children and Adolescents (MINI-KID)	ALWH 5 studies: (Adeyemo et al., 2019; Ashaba et al., 2018; Casale et al., 2019; Sherr et al., 2018; Woollett et al., 2017)
Medical Outcomes Study HIV Health Survey instrument (MOS-HIV)	ALWH 1 study: (Mbalinda et al., 2015)
Patient Health Questionnaire (PHQ-9)	ALWH 1 study: (Osok et al., 2018)
Pediatric Quality of Life Inventory (PedsQL)	ALWH 1 study (Kagee et al., 2019**)
Revised Children's Anxiety and Depression Scale (RCADS)	ALWH 2 studies: (Coetzee et al., 2019**; Kagee et al., 2019**)
Revised Children's Manifest Anxiety Scale (RCMAS)	ALWH 4 studies: (Boyes et al., 2019; Sherr et al., 2018; West et al., 2019; Woollett et al., 2017)
Strengths and Difficulties Questionnaire (SDQ)	ALWH 6 studies: (Bhana et al., 2014; Boyes et al., 2019; Gentz et al., 2017; Lyambai & Mwape,

	2018; Menon et al., 2009; Menon et al., 2007)
Study Designed Conduct Problems Measure	ALWH 1 study: (Betancourt et al., 2014)
Study Designed Psychological Distress Measure	ALWH 2 studies: (Mutumba et al., 2016; Mutumba et al., 2017)
World Health Organization Disability Assessment Schedule for Children (WHODAS-Child)	ALWH 1 study: (Betancourt et al., 2014)
World Health Organization Self-Report Questionnaire (SRQ-25)	ALWH 1 study: (Musisi & Kinyanda, 2009)
World Health Organization – Five Well-Being Index (WHO-5)	ALWH 1 study: (Enimil et al., 2016)
Youth Conduct Problems Scale–Rwanda (YCPS-R)	ALWH 1 study: (Ng et al., 2015)
Youth Self-Report (YSR) Internalizing Subscale	ALWH 3 studies: (Betancourt et al., 2014; Nduwimana et al., 2017; Ng et al., 2015)
Qualitative Measures	
Body Mapping	ALWH 1 study: (Willis et al., 2018)
Focus Groups	ALWH 3 studies: (Bhana et al., 2014; Enane et al., 2019**; Li et al., 2010)
In Depth Interviews	ALWH 4 studies: (Bhana et al., 2014; Enane et al., 2019**; Nalukenge et al., 2019; Petersen et al., 2011)

*Refers to the instrument used, whether the entire instrument or a section
**Study conducted Post-UTT

HIV Care Continuum and Mental Health Pre-UTT

"Engaged or Retained in Care"

Twenty-six studies prior to UTT took place at the "Engaged or Retained in Care" step of the continuum. South Africa had the highest number of studies (n=10), then Uganda (n=4), Rwanda (n=3), Zambia (n=3), Kenya (n=2), Nigeria (n=1), Ghana (n=1), Namibia (n=1), and Zimbabwe (n=1). Most used cross-sectional study designs (n=17), followed by qualitative (n=4), case control (n=2), mixed methods (n=1), multi-methods (n=1), and RCT (n=1). Most of the studies were among both older and younger adolescents, with 1 study among just younger and 2 with only older adolescents. Perinatal (n=6) and both perinatal and behavioral infection of adolescent participants (n=9) were commonly reported; however, almost half of the studies did not report mode of transmission (n=10). Across studies, sample sizes of adolescents ranged from

14-1,060 ALWH. Depression, anxiety, general psychological distress, PTSD, and suicidal ideation were the mental disorders that were measured within these studies.

Internalizing and Externalizing Symptoms

Measures for general psychological distress, depression, and anxiety were used to assess internalizing (i.e., anxiety, sadness, self-isolation) and externalizing (i.e., aggression, lack of impulse control, overactivity) symptoms in 6 cross-sectional studies (27,28). There were 2 studies that took place in Zambia, and 1 each in South Africa, Namibia, Rwanda, and Uganda. The studies included ALWH who were either perinatally or behaviorally infected, with 1 study not reporting on transmission type.

Two studies examined predictors of internalizing and externalizing symptoms. A Namibian study found that poverty (β =-0.231, p=0.023) and stigma (β =0.268, p=0.009) were key predictors for overall mental health difficulties for ALWH and stigma was also predictive of emotional symptoms alone (β =0.314, p=0.002) (29). In South Africa, only caregiver depression was found to be a statistically significant predictor of Total Problem Scores given the Child Behavior Checklist (CBCL) (F = 8.57, df = 5.102, $p < .01$) (30). A Ugandan study demonstrated that ALWH had 5 times the odds of having better mental health if they were in secondary school compared to those without any education (adjusted odds ratio (AOR) 5.3, 95% CI [1.86–15.41]), and those on ART had 4 times the odds of having better mental health compared to ALWH not on ART (AOR 3.9, 95 % CI [2.22–6.9]). Not having caregivers to discuss sexuality and those not satisfied with sexual and reproductive health services were also less likely to have good mental health (AOR 0.34, 95% CI [0.18–0.62]; AOR 0.6, 95% CI [0.40–0.89] respectively) (33).

The two studies from Zambia compared ALWH to uninfected adolescents. The first found that ALWH in Zambia had 2 times the odds of greater total difficulties scores (odds ratio

(OR) = 2.1, 95% CI [1.4 to 3.1]), 3 times the odds of having high scores for emotional symptoms (OR = 3.6, 95% CI [2.5 to 5.4]) and 7 times the odds to score abnormally for peer problems (OR = 7.1, 95% CI [4.9 to 10.2]) compared to a UK sample (31). The second study compared a Zambian school sample and UK normative sample to ALWH and results showed ALWH had higher total difficulty scores (School sample (a): 27.8% (116); UK(b):16.5% (698); HIV+(c): 29.1% (37) a vs c OR=0.9 (0.6-1.4) c vs b OR=2.1 (1.4-3.1) and emotional symptoms (School sample(a): 30.1% (126), UK(b) 11.2% (474), HIV+(c) 31.5% (40), a vs c OR=0.9 (0.6-1.4) c vs b OR=3.6 (2.5-5.4). Conversely, a study from Rwanda found that being HIV positive did not predict psychological aggression (Beta= −0.03 (−.09, 0.10) or daily hardships (Beta=0.05 95% CI [−0.54, 0.65], *p*=0.86) (32).

Overall, studies that focused on internalizing and externalizing symptoms showed that caregivers were critical in regard to psychopathology. In addition, while school was an important factor in mitigating mental health challenges, among ALWH, it did not ameliorate the heightened presentation of said challenges when compared with uninfected individuals also in school.

Depression

While depression had the most different number of measures used in its assessment across studies, depression was looked at as an outcome in 4 studies. Out of the 4 studies, 2 were conducted in Kenya, 1 in South Africa, and 1 in Zimbabwe. Two were conducted only among older adolescents and 2 with both older and younger adolescents. One had adolescents who were both perinatally and behaviorally infected, 1 only perinatally infected adolescents, and 2 did not report on transmission.

The cross-sectional study from Kenya was suggestive of a main effect that living with HIV was associated with having higher mean depression scores (18.4 [SD = 8.3) compared to HIV affected adolescents (16.8 [SD = 7.3]) and community controls (12.0 [SD = 7.9]) (34). The other study from Kenya was also cross-sectional. This study was among pregnant adolescents and found myriad factors that contributed to high depression scores including younger age (i.e. 15-16 years old compared to 17-18 years) ($F(2, 173) = 18.63$; $p < 0.001$), lack of social support ($t\ (174) = 8.0$; $p < 0.001$), stressful life events ($t\ (174) = -8.2$; $p < 0.001$), and a positive HIV diagnosis ($t\ (174) = -4.0$; $P < 0.001$) (35).

The study from South Africa was also cross-sectional and examined correlates of internalized HIV stigma, with consideration for enacted stigma as well. Internalized HIV stigma was attributed to depressive symptoms ($\beta = 0.445$, $p < .001$) and living in an urban household. Enacted HIV stigma ($\beta = 0.294$, $p < .001$) and abuse victimization ($\beta = 0.396$, $p < .001$) were found to be associated with more depressive symptoms for adolescents (36).

In the qualitative study from Zambia, ALWH described thinking of their depression as related to relationships in their lives, especially with wanting to feel valued by family and friends. They also felt they were different from others due to their HIV status and commonly felt isolated or rejected. Critical to coping were supportive family members and friends, and psychosocial support programs (37).

Overall, depression was associated with HIV status and lack of social support as critical factors for its onset.

Distress

There were 3 studies that examined distress as their main outcome, one each in Ghana, Uganda, and in Zambia. Cross-sectional, mixed methods, and multi-methods were the study designs, the studies included both older and younger adolescents. Only 1 study had adolescents who were perinatally and behaviorally infected, 1 included ALWH who were only perinatally infected, and 1 did not report transmission. General psychological distress and depression measures were used.

The study from Ghana found that ALWH had lower psychological health scores (mean difference= −3.26, 95% CI [−4.19 to −2.33]) compared to international age-based sample and a regional sample of mixed ages. This study also obtained qualitative data and found that poor treatment by family and peers and loss of relatives were among key challenges for ALWH, while religion, self-isolation, and social support were identified as coping mechanisms (38). With the Ugandan study, daily hassles ($\beta = 0.179$, $p < .001$), negative life events ($\beta = 0.221$, $p < .001$), HIV-related concerns ($\beta = 0.323$, $p < .001$), and stigma ($\beta = 0.155$, $p < .001$) were significantly associated with psychological distress (39). From Zambia, ALWH reported multiple mental disorders (57.3%) such as emotional and peer related challenges. It was also observed that where the adolescents received care in this study, that there was little understanding among nursing staff on adolescent mental health which contributed to the scarce measurement of disorders (40).

Overall, the studies from Ghana and Uganda are suggestive of the role of stigma impacting the distress levels of ALWH, while all 3 studies indicated the role of social connections as both a protective factor from and facilitator of distress.

Qualitative Explorations of Mental Health

Three studies were qualitative explorations of mental health among ALWH. All 3 included both older and younger adolescents: 1 included ALWH who were perinatally and behaviorally infected, 1 included ALWH who were only perinatally infected, and the other did not report on transmission. Mental health measures were not used in any of these studies.

Two studies took place in South Africa. The first study found that the ALWH felt poorly about their HIV status and had mixed emotions about the future ranging from being both happy and depressed to both confident and nervous (41). The second study from South Africa assessed both risk and protective factors for psychosocial challenges among ALWH. Common themes among adolescents were found to be feeling alone in the world due to their HIV status, not being able to express distress from HIV given HIV stigma in their families, and having suicidal ideation and aggressive behavior due to poor social support (42).The third qualitative study was done in Uganda and it found that HIV-related illness and the effects of ART led to mental health challenges as well as challenges with family illnesses, abuse and discrimination (43).

The qualitive studies elucidated challenges with the knowledge of one's HIV status as well as the effects of being on treatment.

Sociodemographic Characteristics in Association with Multiple Mental Disorders

There were 3 studies that included multiple mental disorders as their outcomes of interest. One was a case control study from Rwanda among both older and younger adolescents for whom HIV transmission model was not reported. This study used measures for depression, anxiety, and general psychological distress. This case-control study compared HIV-infected and uninfected youth; the former had higher odds of depression (OR = 1.32, 95% CI [0.90 to 1.95]), anxiety (OR=1.13, 95% CI [0.71 to 1.81]), and conduct problems (OR = 1.34, 95% CI [0.86 to 2.10]) (44). Two studies from South Africa included older and younger ALWH who were perinatally and behaviorally infected. One study measured depression, anxiety, PTSD, and general psychological distress and focused on correlates of mental health problems. They found relevant predictors included ART side effects, internalized and enacted stigma, negative clinic interactions, emotional abuse and bullying (45). The second examined the association between psychosocial factors and mental health outcomes. This latter study found that better social support was attributed with fewer depression symptoms (adjusted prevalence ratio (aPR) 0.25, 95% CI [0.10–0.59]) and fewer anxiety symptoms (aPR 0.30, 95% CI [0.13–0.71]), but not fewer PTSD symptoms (aPR 0.47, 95% CI [0.06–3.49]) (46).

Suicide

Only 1 study specifically assessed predictors of suicide among ALWH and it was conducted in Rwanda. The study sample included ALWH who were both older and younger in terms age. It did not present the mode of HIV infection and was a case control study.The study indicated that living with HIV was not a significant predictor of suicide ideation (AOR 1.04, 95% CI [0.52–2.08], p=0.91) or suicidal behavior (AOR: 1.80, 95% CI [0.87–3.69], p=0.11). However, living with HIV was a significant predictor of suicidal behavior when compared to adolescents unaffected by HIV (OR: 1.85 95% CI [1.12-3.05]) (47).

There were 2 cross-sectional studies that looked at associations of psychosocial factors with suicide and for which only suicide was measured. A study took place in Nigeria with 201 with both older and younger adolescents, for whom HIV transmission was not reported. The other study was conducted in South Africa with ALWH that were also both older and younger and both perinatally and behaviorally infected. The study with ALWH in Nigeria found that the loss of a family member was the only factor associated with current suicide ideation (B=1.570, SE: 0.536, WALD: 8.568, p=0.003, OR =4.807) (48). The study from South Africa showed HIV stigma being associated with higher depressive symptoms (B= 0.295, $p < .001$) and higher suicidal ideation and behavior (B = 0.185, $p < .001$), with depression also attributed to higher suicidal ideation and behavior (B = 0.164, $p < .001$) (49).

Mode of Infection

A cross-sectional study from South Africa focused on mode of infection as the outcome. ALWH were both older and younger and both perinatally and behaviorally infected. The study utilized depression, anxiety, PTSD, and suicide measures. It found that ALWH who were behaviorally infected presented with more depression ($B = 0.456$, $p = 0.018$), anxiety ($B = 1.192$, $p < 0.001$), and substance use ($OR = 2.99$ $p = 0.001$), with older adolescents specifically being more likely to report depression as well ($B = 0.09$, $p < 0.001$) (50).

Risk Factors for Mental Disorders

But there was only one study that assessed risk factors for mental disorders. The study was done in South Africa and included 343 ALWH who were both older and younger and perinatally and behaviorally infected. This cross-sectional study used depression, anxiety, PTSD, and suicide measures. Regarding key risk factors, ALWH who had been inappropriately touched had higher risk for depression (risk ratio (RR) = 2.22, $p= 0.01$) PTSD (RR = 3.08, $p = 0.02$), and anxiety (RR = 1.77, $p =0.00$). In addition, forced sex was significantly associated with higher risk of depression (RR = 3.55, $p = 0.02$), anxiety (RR = 3.01, $p = 0.01$), and PTSD (RR = 2.38, $p =0.04$). This study also elucidated that feeling unsafe at home was associated with a higher likelihood of depression (RR = 5.17, $p=0.00$), anxiety (RR = 2.92, $p =0.00$), and PTSD (RR = 3.94, $p =0.02$). Absence of a safe community space for adolescents also increased risk for depression (RR = 2.31, $p =0.00$), anxiety (RR = 2.02, $p = 0.00$), and PTSD (RR = 3.66, $p =0.01$) (8).

Bullying

Bullying was the focus of only 1 study and was examined in association with depression and suicidality. ALWH were both older and younger, and their mode of infection was not reported participated. Major Depressive Disorder, specifically, was significantly associated with bullying

(AOR = 1.09; 95% CI [1.00–1.20], *p* = 0.04), while suicidality was significantly associated with both bullying (AOR = 1.09; 95% CI [1.01–1.17], *p* = 0.02) and stigma (AOR = 1.30; 95% CI [1.03–1.30], *p* = 0.02) (6).

Intervention

There was a single study that evaluated a psychosocial intervention for ALWH and it was done in South Africa. ALWH participated in an RCT to assess a program that sought to mitigate mental health outcomes for younger adolescents who were perinatally infected. The RCT used measures for depression and general psychological distress. With the family based psychosocial program, depression scores notably improved (mean scores (higher worse): Comparison group: baseline: 3.19, follow up: 2.64; intervention: baseline: 3.31, follow Up: 2.03, Beta= -0.736, *p*=0.417). In addition, internalizing and externalizing behaviors also had positive changes (mean scores (higher worse): Comparison group: baseline: 18.80, follow up: 18.38; intervention: baseline: 18.79, follow up: 16.96, Beta=-1.412, *p*=0.371) (51).

"Engaged or Retained in Care" and "Adherence"

The remaining 4 studies that took place prior to UTT each engaged with ALWH at both the "Engaged or Retained in Care" and "Adherence" steps. All looked at psychosocial factors in association with adherence. A study took place in Malawi, Rwanda, Uganda, and Zambia and had 1,366 adolescents across all 4 studies. There were 3 studies that included older and younger adolescents, while 1 just had older. There were 3 studies that did not report on transmission and 1 had perinatally infected ALWH. In addition, there were 3 cross-sectional studies conducted and 1 mixed method with measures for depression, anxiety, and general psychological distress applied.

With the Malawian study, depression (AOR 1.7, 95% CI [1.08–2.70], *p* = 0.02) was associated with nonadherent behaviors (52). In Rwanda, it was found that nonadherence was associated with various mental health symptoms including irritability (self-report OR = 1.79, 95% CI [1.06– 3.04]; caregiver report OR = 1.97, 95% CI [1.22–3.18]) and conduct problems (self-report OR = 1.79, 95% CI [1.10– 2.90]; caregiver report OR = 3.35, 95% CI [2.00–5.61]). Conduct problems remained associated with nonadherence in multivariate analyses (caregiver report, OR = 2.90, 95% CI [1.55–5.43]) as well as depression (caregiver report, OR = 1.02, 95% CI [1.01–1.04]), with depression found to also be minimally significant given self-report from ALWH. In addition, while self-report of depression and anxiety symptoms were not found to be associated with adherence (OR = 1.68, 95% CI [0.92–3.07]), caregiver reports indicated a positive association with adherence (OR = 3.57, 95% CI 1.86–6.86) (53).

The Ugandan study showed that psychological distress was associated with nonadherence (OR = 1.75, 95% CI [1.04–2.95]), with social support being the only psychosocial resource that was significantly associated (OR = 0.42, 95% CI [0.22–0.79]) with nonadherence (54). However, the Zambian assessment found that scoring high for depression was not associated with nonadherence (AOR: 0.37, 95% CI [0.13–1.01], *p*=0.16), yet psychological distress was related to challenges with treatment for ALWH (55).

Overall, studies that were done at both the “Engaged or Retained in Care” and “Adherence” steps mostly found that depression was associated with nonadherence, with 1 conflicting study. Distress was also commonly assessed in regards to adherence and found to impede treatment.

HIV Care Continuum and Mental Health Post-UTT

Only 4 studies were conducted following UTT. Of these studies, 2 were conducted in South Africa, 1 in Kenya and in Uganda. All studies included both older and younger adolescents. Three did not report transmission, and 1 reported perinatal transmission. Depression and anxiety were assessed in 2 studies, with 1 of these also measuring general psychological distress. There was also 1 study that did not include a mental health measure and used qualitative methods. Half of the studies were with ALWH at the “Received HIV Care” step. Across all studies, the number of participants ranged from 6-336. There was a study that also assessed ALWH at both the “Received HIV Care” and “Retained in Care” steps, and the other at the “Received HIV Care” and “Viral Suppression” steps.

“Received Care” and “Retained in HIV Care”

Regarding the one qualitative study that took place post-UTT in Kenya, salient themes around mental health were explored. Depression and alcohol use, for example, were found to be salient among adolescents who were disengaged from care. Various forms of stigma and interpersonal conflict also lead to poor mental health. However, participants also stressed the importance of being motivated to stay health and received HIV education for them to remain adherent to HIV treatment (7).

“Received Care”

Post-UTT, understanding the association between quality of life and HIV was the focus of 2 studies, both of which were the only ones to take place at the “Received Care” step. Both were cross-sectional studies from South Africa. Adolescents were younger and older and the mode of infection was not reported in either study. Measures used in the studies were for depression, anxiety, and general psychological distress.

Both found significant associations indicating that common mental disorders were associated with poorer quality of life. One study specifically found both depression (β=0.32, t 2.03, *p*=0.00) and anxiety (β=0.15, t 1.87, *p*=0.04) to be significant predictors of quality of life for ALWH (56). The second also found depression to be a predictor of fatigue (Beta=10.904, SE= 2.675, Beta 0.311, t=4.076, *p*=.000), thus impacting quality of life for adolescents (57).

"Received Care" and "Viral Suppression"

Only 1 study in this review was among ALWH at both the "Received Care" and "Viral Suppression" steps. This is also the only study that is in consideration of viral suppression (i.e. had any analysis that examined this) as a continuum step in the overall review. The cross-sectional study from Uganda measured depression among 134 older and younger ALWH for whom their transmission type was not reported. It found that the odds of having depressive symptoms were 1.7 times higher for ALWH who had to travel more than half an hour to get to a clinic compared to those who did not have to travel as far (AOR= 1.66 95% CI [1.02-2.70], *p* = 0.041) (58).

Measurement of Mental Health

Throughout the studies presented in this scoping review there was a predominance of Western Conceptualized measures used for mental health as presented in Table 3.3. The Child Depression Inventory (CDI) (n=7), Center for Epidemiological Studies-Depression Scale for Children (CES-DC) (n=5), and the Mini International Neuropsychiatric Interview for Children and Adolescents (MINI-KID) (n=5) were the measures found to be most prevalent among all studies. In addition, most measures were used in studies pre-UTT, with the CES-DC, Pediatric Quality of Life Inventory (PedsQL), and Revised Children's Anxiety and Depression Scale (RCADS) used in research post-UTT. Furthermore, only 3 studies overall assessed mental disorders among both ALWH and caregivers, using the Beck Depression Inventory (BDI-11) (n=1) and the Hopkins Symptoms Checklist-25 (HSCL-25) (n=2). Finally, there were a few studies that applied qualitative methods (n=7) with in depth interviews (n=3), focus groups (n=2), both focus groups and in-depth interviews (n=1), and body mapping (n=1) used. Of those that had qualitative techniques, only 1 study was done post-UTT.

3.5 Discussion

The purpose of this scoping review was to explore the current literature on the relationship between mental health and the HIV care continuum for ALWH in SSA. 34 studies of both older and younger ALWH were included in this review, with most studies stemming from Eastern and Southern Africa. There was a predominance of cross-sectional studies and the use of mental health measures conceptualized in high income countries. Depression and anxiety were the most common disorders examined, followed by general psychological distress; suicide and post-traumatic stress disorder (PTSD) were examined in only a handful of studies. ALWH were primarily assessed at the “Engaged or Retained in Care” step of the continuum, with the majority of studies taking place prior to UTT.

There were clear gaps in knowledge along different steps of the HIV care continuum and at which ALWH may not be receiving mental health screening or treatment for mental health conditions. Only one study in the entire review considered mental health and HIV treatment in association with viral suppression (58) and no studies took place at either the “HIV diagnosis” or “Linked to Care” steps, either pre or post-UTT. Currently 80% of ALWH live in SSA, with many remaining unaware of their HIV status (62). While perinatal transmission has dramatically reduced across SSA, behavioral infection among adolescents is a key driver in the increasing incidence of HIV for youth (63) and this has been raised as a monumental challenge in meeting the 95-95-95 goals (60). In some ways, the findings on linkage to care are representative of the current landscape in terms of engaging ALWH in healthcare in SSA. In the era of UTT, despite advances in providing more accessible HIV care for adults, there remains limited youth friendly HIV programs across SSA (59–61).

Key populations have also been recognized as requiring attention in terms of HIV research and initiatives (64). Despite the importance of key populations driving the HIV epidemic in SSA, we only found one study that had a sub-population of ALWH, although not considered one of the key populations by UNAIDS (64): pregnant women (35). We know that sexual minorities, sex workers, persons who use substances, and adolescents are included in the UNAIDS definition of key populations in need (64). However, these categories of individuals are not mutually exclusive and as such not having any studies that consider mental health and HIV care among these populations who are youth is cause for concern (65,66). Adolescents who are sexual minorities, young individuals who inject drugs, and sex workers are known to be some of the most vulnerable to HIV and HIV-related complications (66). For example, one review found that a third of youth who were sexual minorities exhibited mental health conditions as 17% were found to have conduct disorder, 15% depression, and 9% PTSD (67). Mental health conditions are a known risk factor for HIV and high rates of mental health conditions amongst these populations will continue to drive the epidemic (68). Mental health conditions are also associated with higher prevalence of substance use and high-risk sexual behaviors among ALWH (14). However, in terms of the broad literature on ALWH, few studies focus on young individuals who are engaged in sex work, use substances, and who sexual minorities, that can speak to the challenges of risk factors for HIV as well as retention in HIV care for these specific groups (69);

which therefore has implications for understanding the impact of mental health in association with HIV for these youth.

Regardless of whether a key population of youth or not, the implications for the lack of mental health assessment in conjunction with HIV care, especially during testing and treatment initiation, also warrants attention as demonstrated by this review. The onset of mental health disorders commonly takes place during adolescence (70) and as adolescence is a critical developmental life stage, there are numerous risk factors that may perpetuate an adolescent developing a mental health condition. Factors such as peer pressure, sexual debut, and developing a sense of self are all well-known correlates of stress during adolescence (71). ALWH contend with these factors just as any other youth, yet have nearly double the risk for developing both depression and anxiety compared to adolescents who are not living with HIV (14). It is also important to acknowledge that despite depression and anxiety being highly prevalent disorders for ALWH (14), consideration needs to be taken given to under-researched psychosocial correlates of HIV such as suicide and PTSD. In SSA, rates of suicide among ALWH range from an estimated 4%-35% in SSA (6,72,73), however was only measured in 2 studies in this review (6,72). PTSD was only found among 4 studies in this review, yet PTSD can be common among ALWH, especially those who have lost parents to AIDS (8).

The overreliance on mental health measures conceptualized in high income countries is something to be emphasized as these measures can only be so informative of the extent of poor mental health if adaptation and validation are not rigorously conducted (74). Many researchers in global mental health will utilize qualitative methods to inform the adaptation of psychosocial measures or conduct qualitative studies on mental health factors exclusively (75,76). However, this review found very few studies that either utilized measures conceptualized with SSA or qualitative methods to understand the context of mental health for ALWH in SSA.

A final key challenge is that while many of the included studies assessed mental health among ALWH at a certain point in the care continuum, most did not actually assess the relationship between mental disorders and engagement in the care continuum; e.g., there were limited studies that compared mental health among those engaged and not engaged in treatment. This is particularly true for longitudinal studies that might assess how living with a mental disorder may or may not predict engagement in care after identified as living with HIV. Not having knowledge of the causal relationship between HIV and mental health limits our ability to conceptualize both preventative and treatment approaches for ALWH who are also living with mental health conditions.

The results of this scoping review should be interpreted in light of several limitations. The exclusion of non-English title, abstract, and papers may have limited our ability to capture relevant work on the intersection of HIV and mental health in a SSA context, particularly from areas of West Africa that may have been published in French journals. Our results may therefore only be generalizable to English speaking countries, but our search criteria have provided breadth of knowledge within this context consistent with the goals of a scoping review. We also did not evaluate quality of the included studies, though by extracting study design we have identified the common limitations of existing studies.

Conclusion

The studies presented in this review are unable to inform understanding of a comprehensive set of psychosocial factors that are associated with ALWH's HIV treatment. Given what this review has found, the literature as it stands on ALWH is not capturing the full extent of the process of going from HIV testing to viral suppression in conjunction with mental health and assessment of mental health at all points of HIV treatment is needed.

3.6 References

1. Parcesepe AM, Bernard C, Agler R, Ross J, Yotebieng M, Bass J, et al. Mental health and HIV: research priorities related to the implementation and scale up of 'treat all' in sub-Saharan Africa. J Virus Erad. 4(Suppl 2):16–25.

2. Brandt R. The mental health of people living with HIV/AIDS in Africa: a systematic review. Afr J AIDS Res. 2009 Jun;8(2):123–33.

3. Chibanda D, Benjamin L, Weiss HA, Abas M. Mental, neurological, and substance use disorders in people living with HIV/AIDS in low- and middle-income countries. J Acquir Immune Defic Syndr. 2014 Sep 1;67 Suppl 1:S54-67.

4. Narayan KMV, Miotti PG, Anand NP, Kline LM, Harmston C, Gulakowski R, et al. HIV and noncommunicable disease comorbidities in the era of antiretroviral therapy: a vital agenda for research in low- and middle-income country settings. J Acquir Immune Defic Syndr. 2014 Sep 1;67 Suppl 1:S2-7.

5. Sherr L, Clucas C, Harding R, Sibley E, Catalan J. HIV and depression--a systematic review of interventions. Psychol Health Med. 2011 Oct;16(5):493–527.

6. Ashaba S, Cooper-Vince C, Maling S, Rukundo GZ, Akena D, Tsai AC. Internalized HIV stigma, bullying, major depressive disorder, and high-risk suicidality among HIV-positive adolescents in rural Uganda. Global Mental Health [Internet]. 2018 ed [cited 2020 Apr 8];5. Available from: http://www.cambridge.org/core/journals/global-mental-health/article/internalized-hiv-stigma-bullying-major-depressive-disorder-and-highrisk-

suicidality-among-hivpositive-adolescents-in-rural-uganda/4E4E4E4935432BE2683760938226D0B9/core-reader#ref31

7. Enane LA, Apondi E, Toromo J, Bosma C, Ngeresa A, Nyandiko W, et al. “A problem shared is half solved” – a qualitative assessment of barriers and facilitators to adolescent retention in HIV care in western Kenya. AIDS Care. 2019 Sep 26;0(0):1–9.

8. Woollett N, Cluver L, Bandeira M, Brahmbhatt H. Identifying risks for mental health problems in HIV positive adolescents accessing HIV treatment in Johannesburg. Journal of Child & Adolescent Mental Health. 2017 May 31;29(1):11–26.

9. Bachmann S. Epidemiology of Suicide and the Psychiatric Perspective. Int J Environ Res Public Health [Internet]. 2018 Jul [cited 2020 Feb 18];15(7). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6068947/

10. WHO Adolescent mental health [Internet]. [cited 2021 May 10]. Available from: https://www.who.int/news-room/fact-sheets/detail/adolescent-mental-health

11. Kim MH, Mazenga AC, Yu X, Devandra A, Nguyen C, Ahmed S, et al. Factors associated with depression among adolescents living with HIV in Malawi. BMC Psychiatry. 2015 Oct 26;15(1):264.

12. Kay ES, Batey DS, Mugavero MJ. The HIV treatment cascade and care continuum: updates, goals, and recommendations for the future. AIDS Res Ther. 2016;13:35.

13. Wood SM, Dowshen N, Lowenthal E. Time to Improve the Global Human Immunodeficiency Virus/AIDS Care Continuum for Adolescents. JAMA Pediatr. 2015 Jul 1;169(7):619–20.

14. Vreeman RC, McCoy BM, Lee S. Mental health challenges among adolescents living with HIV. J Int AIDS Soc [Internet]. 2017 May 16 [cited 2020 Feb 18];20(Suppl 3). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5577712/

15. Mellins CA, Malee KM. Understanding the mental health of youth living with perinatal HIV infection: lessons learned and current challenges. J Int AIDS Soc. 2013 Jun 18;16:18593.

16. UNAIDS. Ending AIDS: progress towards the 90–90–90 targets [Internet]. 2017 [cited 2020 Mar 7]. Available from: https://www.unaids.org/en/resources/documents/2017/20170720_Global_AIDS_update_2017

17. Garnett GP, Baggaley RF. Treating our way out of the HIV pandemic: could we, would we, should we? The Lancet. 2009 Jan 3;373(9657):9–11.

18. Baggaley RF, Hollingsworth TD. How universal does universal test and treat have to be? The Lancet HIV. 2020 May 1;7(5):e306–8.

19. Understanding the HIV Care Continuum. [Internet] 2019;4. Centers for Disease Control and Prevention. 2019 [cited 2021 May 10]. Available from: https://www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-care-continuum.pdf

20. February 04 CSH govDate last updated:, 2021. HIV Care Continuum [Internet]. HIV.gov. 2021 [cited 2021 May 10]. Available from: https://www.hiv.gov/federal-response/policies-issues/hiv-aids-care-continuum

21. Herce ME, Chi BH, Liao RC, Hoffmann CJ. Re-thinking Linkage to Care in the Era of Universal Test and Treat: Insights from Implementation and Behavioral Science for Achieving the Second 90. AIDS Behav. 2019 Sep;23(Suppl 2):120–8.

22. Yehia BR, Stephens-Shields AJ, Fleishman JA, Berry SA, Agwu AL, Metlay JP, et al. The HIV Care Continuum: Changes over Time in Retention in Care and Viral Suppression. PLoS One [Internet]. 2015 Jun 18 [cited 2021 May 7];10(6). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4473034/

23. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders [Internet]. Fifth Edition. American Psychiatric Association; 2013 [cited 2020 Jan 2]. Available from: https://psychiatryonline.org/doi/book/10.1176/appi.books.9780890425596

24. WHO Adolescent health [Internet]. [cited 2021 May 10]. Available from: https://www.who.int/southeastasia/health-topics/adolescent-health

25. WHO | Very young adolescents [Internet]. WHO. World Health Organization; [cited 2021 Apr 27]. Available from: https://www.who.int/reproductivehealth/topics/adolescence/very_young_ados/en/

26. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med. 2018 Oct 2;169(7):467–73.

27. Achenbach TM, Edelbrock CS. Behavioral problems and competencies reported by parents of normal and disturbed children aged four through sixteen. Monogr Soc Res Child Dev. 1981;46(1):1–82.

28. Werry JS, Quay HC. The prevalence of behavior symptoms in younger elementary school children. Am J Orthopsychiatry. 1971 Jan;41(1):136–43.

29. Gentz SG, Romano IC, Martínez-Arias R, Ruiz-Casares M. Predictors of mental health problems in adolescents living with HIV in Namibia. Child and Adolescent Mental Health. 2017;22(4):179–85.

30. Louw K-A, Ipser J, Phillips N, Hoare J. Correlates of emotional and behavioural problems in children with perinatally acquired HIV in Cape Town, South Africa. AIDS Care. 2016 Jul 2;28(7):842–50.

31. Menon A, Glazebrook C, Campain N, Ngoma M. Mental Health and Disclosure of HIV Status in Zambian Adolescents With HIV Infection: Implications for Peer-Support Programs. JAIDS Journal of Acquired Immune Deficiency Syndromes. 2007 Nov 1;46(3):349–54.

32. Nduwimana E, Mukunzi S, Ng LC, Kirk CM, Bizimana JI, Betancourt TS. Mental Health of Children Living in Foster Families in Rural Rwanda: The Role of HIV and the Family Environment. AIDS and behavior. 2017;21(6):1518–29.

33. Mbalinda SN, Kiwanuka N, Kaye DK, Eriksson LE. Reproductive health and lifestyle factors associated with health-related quality of life among perinatally HIV-infected adolescents in Uganda. Health Qual Life Outcomes. 2015 Dec;13(1):170.

34. Abubakar A, Van de Vijver FJR, Hassan AS, Fischer R, Nyongesa MK, Kabunda B, et al. Cumulative Psychosocial Risk is a Salient Predictor of Depressive Symptoms among Vertically HIV-Infected and HIV-Affected Adolescents at the Kenyan Coast. Annals of Global Health. 2017 Dec 13;83(5–6):743.

35. Osok J, Kigamwa P, Stoep AV, Huang K-Y, Kumar M. Depression and its psychosocial risk factors in pregnant Kenyan adolescents: a cross-sectional study in a community health Centre of Nairobi. BMC Psychiatry. 2018 May 18;18(1):136.

36. Pantelic M, Boyes M, Cluver L, Meinck F. HIV, violence, blame and shame: pathways of risk to internalized HIV stigma among South African adolescents living with HIV. Journal of the International AIDS Society. 2017 Aug 21;20.

37. Willis N, Mavhu W, Wogrin C, Mutsinze A, Kagee A. Understanding the experience and manifestation of depression in adolescents living with HIV in Harare, Zimbabwe. PLOS ONE. 2018 Jan 3;13(1):e0190423.

38. Enimil A, Nugent N, Amoah C, Norman B, Antwi S, Ocran J, et al. Quality of life among Ghanaian adolescents living with perinatally acquired HIV: a mixed methods study. AIDS Care. 2016 Apr 2;28(4):460–4.

39. Mutumba M, Bauermeister JA, Harper GW, Musiime V, Lepkowski J, Resnicow K, et al. Psychological distress among Ugandan adolescents living with HIV: Examining stressors and the buffering role of general and religious coping strategies. Glob Public Health. 2017 Dec;12(12):1479–91.

40. Lyambai K, Mwape L. Mental Health Problems Experienced by HIV Positive Adolescents; A Case of Choma District, Zambia. OJPsych. 2018;08(02):97–114.

41. Li RJ, Jaspan HB, O'Brien V, Rabie H, Cotton MF, Nattrass N. Positive futures: a qualitative study on the needs of adolescents on antiretroviral therapy in South Africa. AIDS Care. 2010 Jun;22(6):751–8.

42. Petersen I, Bhana A, Myeza N, Alicea S, John S, Holst H, et al. Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: a qualitative investigation. AIDS Care. 2010 Aug;22(8):970–8.

43. Nalukenge W, Martin F, Seeley J, Kinyanda E. Knowledge and causal attributions for mental disorders in HIV-positive children and adolescents: results from rural and urban Uganda. Psychology, health & medicine. 2019;24(1):21–6.

44. Betancourt T, Scorza P, Kanyanganzi F, Fawzi MCS, Sezibera V, Cyamatare F, et al. HIV and Child Mental Health: A Case-Control Study in Rwanda. Pediatrics. 2014 Aug;134(2):e464–72.

45. Boyes ME, Cluver LD, Meinck F, Casale M, Newnham E. Mental health in South African adolescents living with HIV: correlates of internalising and externalising symptoms. AIDS Care. 2019 Jan 2;31(1):95–104.

46. West N, Schwartz S, Mudavanhu M, Hanrahan C, France H, Nel J, et al. Mental health in South African adolescents living with HIV. AIDS Care. 2019 Jan 2;31(1):117–24.

47. Ng LC, Kirk CM, Kanyanganzi F, Fawzi MC, Sezibera V, Shema E, et al. Risk and protective factors for suicidal ideation and behaviour in Rwandan children. The British journal of psychiatry : the journal of mental science. 2015;207(3):262–8.

48. Adeyemo S, Olorunkoya OG, Chinelo OL, Babalola G, Abojei CO. Prevalence and psychosocial correlates of suicidal ideation among adolescents living with HIV in Southwestern Nigeria, West Africa. HIV and AIDS Review. 2019;18(4):273–8.

49. Casale M, Boyes M, Pantelic M, Toska E, Cluver L. Suicidal thoughts and behaviour among South African adolescents living with HIV: Can social support buffer the impact of stigma? J Affect Disord. 2019 15;245:82–90.

50. Sherr L, Cluver LD, Toska E, He E. Differing psychological vulnerabilities among behaviourally and perinatally HIV infected adolescents in South Africa – implications for targeted health service provision. AIDS Care. 2018 Jun 20;30(sup2):92–101.

51. Bhana A, Mellins CA, Petersen I, Alicea S, Myeza N, Holst H, et al. The VUKA family program: Piloting a family-based psychosocial intervention to promote health and mental health among HIV infected early adolescents in South Africa. AIDS Care. 2014 Jan 2;26(1):1–11.

52. Kim MH, Mazenga AC, Yu X, Ahmed S, Paul ME, Kazembe PN, et al. High self-reported non-adherence to antiretroviral therapy amongst adolescents living with HIV in Malawi: barriers and associated factors. Journal of the International AIDS Society. 2017;20(1):21437.

53. Smith Fawzi MC, Ng L, Kanyanganzi F, Kirk C, Bizimana J, Cyamatare F, et al. Mental Health and Antiretroviral Adherence Among Youth Living With HIV in Rwanda. PEDIATRICS. 2016 Oct 1;138(4):e20153235–e20153235.

54. Mutumba M, Musiime V, Lepkwoski JM, Harper GW, Snow RC, Resnicow K, et al. Examining the relationship between psychological distress and adherence to anti-retroviral therapy among Ugandan adolescents living with HIV. AIDS Care. 2016 Jul 2;28(7):807–15.

55. Okawa S, Kabaghe SM, Mwiya M, Kikuchi K, Jimba M, Kankasa C, et al. Psychological well-being and adherence to antiretroviral therapy among adolescents living with HIV in Zambia. AIDS Care. 2018 May 4;30(5):634–42.

56. Kagee A, Coetzee B, Toit SD, Loades ME. Psychosocial predictors of quality of life among South Africa adolescents receiving antiretroviral therapy. Qual Life Res. 2019 Jan;28(1):57–65.

57. Coetzee BJ, Loades ME, Du Toit S, Kagee A. Correlates of Fatigue Among South African Adolescents Living with HIV and Receiving Antiretroviral Therapy. AIDS and behavior. 2019;23(3):602–8.

58. Kemigisha E, Zanoni B, Bruce K, Menjivar R, Kadengye D, Atwine D, et al. Prevalence of depressive symptoms and associated factors among adolescents living with HIV/AIDS in South Western Uganda. AIDS Care. 2019 Oct;31(10):1297–303.

59. Young people, HIV and AIDS [Internet]. Avert. 2015 [cited 2021 May 10]. Available from: https://www.avert.org/professionals/hiv-social-issues/key-affected-populations/young-people

60. Mark D, Hrapcak S, Ameyan W, Lovich R, Ronan A, Schmitz K, et al. Peer Support for Adolescents and Young People Living with HIV in sub-Saharan Africa: Emerging Insights and a Methodological Agenda. Curr HIV/AIDS Rep. 2019 Dec;16(6):467–74.

61. Michielsen K. Limited effectiveness of HIV prevention for young people in sub-Saharan Africa: studying the role of intervention and evaluation. Facts Views Vis Obgyn. 2013;5(3):196–208.

62. Slogrove AL, Sohn AH. The global epidemiology of adolescents living with HIV: Time for more granular data to improve adolescent health outcomes. Curr Opin HIV AIDS. 2018 May;13(3):170–8.

63. Idele P, Gillespie A, Porth T, Suzuki C, Mahy M, Kasedde S, et al. Epidemiology of HIV and AIDS among adolescents: current status, inequities, and data gaps. J Acquir Immune Defic Syndr. 2014 Jul 1;66 Suppl 2:S144-153.

64. 90-90-90: An ambitious treatment target to help end the AIDS epidemic. :40. [Internet] 2014 [cited 2021 9 May]. Available from: https://www.unaids.org/sites/default/files/media_asset/90-90-90_en.pdf

65. Tchankoni MK, Gbeasor-Komlanvi FA, Bitty-Anderson AM, Sewu EK, Zida-Compaore WIC, Alioum A, et al. Prevalence and factors associated with psychological distress among key populations in Togo, 2017. PLOS ONE. 2020 Apr 16;15(4):e0231726.

66. Bekker L-G, Hosek S. HIV and adolescents: focus on young key populations. J Int AIDS Soc [Internet]. 2015 Feb 26 [cited 2021 May 10];18(2Suppl 1). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4581085/

67. Mustanski BS, Garofalo R, Emerson EM. Mental health disorders, psychological distress, and suicidality in a diverse sample of lesbian, gay, bisexual, and transgender youths. Am J Public Health. 2010 Dec;100(12):2426–32.

68. Mutumba M, Harper GW. Mental health and support among young key populations: an ecological approach to understanding and intervention. J Int AIDS Soc [Internet]. 2015 Feb 26 [cited 2021 May 10];18(2Suppl 1). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4344542/

69. Lall P, Lim SH, Khairuddin N, Kamarulzaman A. Review: an urgent need for research on factors impacting adherence to and retention in care among HIV-positive youth and adolescents from key populations. J Int AIDS Soc. 2015;18(2 Suppl 1):19393.

70. Kessler RC, Amminger GP, Aguilar-Gaxiola S, Alonso J, Lee S, Ustun TB. Age of onset of mental disorders: A review of recent literature. Curr Opin Psychiatry. 2007 Jul;20(4):359–64.

71. Madiba S, Mokgatle M. Perceptions and Experiences about Self-Disclosure of HIV Status among Adolescents with Perinatal Acquired HIV in Poor-Resourced Communities in South Africa [Internet]. Vol. 2016, AIDS Research and Treatment. Hindawi; 2016 [cited 2020 Aug 17]. p. e2607249. Available from: https://www.hindawi.com/journals/art/2016/2607249/

72. Adeyemo S, Adeosun II, Ogun OC, Adewuya A, David AN, Adegbohun AA, et al. Depression and suicidality among adolescents living with human immunodeficiency virus in Lagos, Nigeria. Child Adolesc Psychiatry Ment Health. 2020 Aug 14;14(1):31.

73. Zietz S, Iritani BJ, Otieno FA, Ongili BO, Odongo FS, Rennie S, et al. Suicide behaviour among adolescents in a high HIV prevalence region of western Kenya: A mixed-methods study. Global Public Health. 2021 Jan 2;16(1):88–102.

74. Betancourt TS, Yang F, Bolton P, Normand S. Developing an African youth psychosocial assessment: an application of item response theory. Int J Methods Psychiatr Res. 2014 Jan 30;23(2):142–60.

75. Betancourt TS, Meyers-Ohki SE, Stevenson A, Ingabire C, Kanyanganzi F, Munyana M, et al. Using Mixed-Methods Research to Adapt and Evaluate a Family Strengthening Intervention in Rwanda. Afr J Trauma Stress. 2011 Jun;2(1):32–45.

76. Betancourt TS, Rubin-Smith JE, Beardslee WR, Stulac SN, Fayida I, Safren S. Understanding locally, culturally, and contextually relevant mental health problems among Rwandan children and adolescents affected by HIV/AIDS. AIDS Care. 2011 Apr;23(4):401–12.

77. Kurth AE, Lally MA, Choko AT, Inwani IW, Fortenberry JD. HIV testing and linkage to services for youth. J Int AIDS Soc [Internet]. 2015 Feb 26 [cited 2021 May 10];18(2Suppl 1). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4344538/

78. Ashaba S, Cooper-Vince CE, Vořechovská D, Rukundo GZ, Maling S, Akena D, et al. Community beliefs, HIV stigma, and depression among adolescents living with HIV in rural Uganda. African Journal of AIDS Research. 2019 Sep 27;18(3):169–80.

79. Kimera E, Vindevogel S, Reynaert D, Justice KM, Rubaihayo J, Maeyer JD, et al. Experiences and effects of HIV-related stigma among youth living with HIV/AIDS in Western Uganda: A photovoice study. PLOS ONE. 2020 Apr 24;15(4):e0232359.

80. Folayan MO, Odetoyinbo M, Brown B, Harrison A. Addressing the Socio-Development Needs of Adolescents Living with HIV/AIDS in Nigeria: A Call for Action. African Journal of Reproductive Health. 2014;18(3):93–101.

81. Remien RH, Stirratt MJ, Nguyen N, Robbins RN, Pala AN, Mellins CA. Mental health and HIV/AIDS: the need for an integrated response. AIDS. 2019 Jul 15;33(9):1411–20.

Chapter 4: Self-Disclosure of HIV Status and the Relationship to Mental Health among ALWH in Uganda

4.1 Abstract

Introduction: The current literature on ALWH and HIV status disclosure is scarce. HIV status disclosure is recognized as an important process in receiving social support when living with HIV. However, self-disclosure can also lead to poor psychosocial outcomes and diminished HIV treatment adherence. The limited evidence as to the mental health implications in regards to adolescent choice of disclosure requires attention.

Methods: Secondary analysis was conducted using data from the Pediatric HIV/AIDS Research Project (PHARP) in Uganda. Basic frequencies were calculated to assess how often ALWH chose to self-disclose to different types of individuals. One-way ANOVA was used to assess associations between sociodemographic factors and self-disclosure choice, and multiple linear regression was then used to explore the associations between disclosure variables and z-scores for depression and anxiety for the top four types of individuals adolescents reported most frequently self-disclosing to, number of types of individuals an adolescent self-disclosed to, and whether the adolescent reported self-disclosure to anyone.

Results: The majority of ALWH in this study had disclosed to at least one person with status disclosure to one's mother, father, sister(s), or brother(s) as the most common individuals adolescents chose to disclose to. Disclosure to any of these specific nuclear family members was not significantly associated with depression or anxiety symptoms. ALWH who had disclosed to any person reported lower depression and anxiety symptoms; however, a significant association was only observed with depression.

Conclusions: Our findings indicate an association between HIV status self-disclosure by adolescents and depression symptoms. The relative frequency with which adolescents disclose to their nuclear family members highlights the importance of targeting these family members in interventions aimed at improving the psychosocial health of ALWH. Further research to confirm these associations, explore directionality, and to understand the reasons why ALWH favored disclosure to nuclear family members over others is a critical next step in guiding supportive care tailored to adolescents.

4.2 Background

Almost half a million young individuals between the ages of 10-24 were newly infected with HIV in 2019 (1), and of the 2 million adolescents living with HIV (ALWH) globally, an estimated 70% were perinatally infected (2). The majority of these young individuals living with HIV, approximately 80%, reside in sub-Saharan Africa (SSA)(3). While more infants who were peri- or postnatally infected with HIV are surviving childhood, they remain vulnerable to advanced HIV-infection as they age. Further, ALWH have to contend with co-morbidities and disabilities, such as mental illness and neurodevelopmental conditions, while navigating a healthy transition to adulthood (3–6). ALWH are therefore an essential group to engage in the creation of developmentally tailored HIV/AIDS treatment and prevention interventions.

A focus on the psychosocial needs of ALWH is a critical part of the imperative to develop tailored treatment strategies, given that the first onset of many mental disorders commonly occurs during this developmental stage (7). ALWH are at increased risk of both depression and anxiety given the various psychosocial challenges they may experience living with a chronic illness, including feeling pressure to conceal their status and the limited social support they may have available to them on account of stigma (8–10). Poor mental health and lack of social support have been observed to be significant impediments of health seeking behaviors and adherence to antiretroviral therapy (ART)(11). Irregular adherence to ART and high-risk behaviors lead to suboptimal treatment effects for ALWH, increasing their own morbidity, mortality and risk for transmitting HIV (12) . Alternatively, promoting positive social support for ALWH is one strategy that has demonstrated promise for supporting a successful transition to healthy adulthood (13–15).

Disclosing HIV status can refer to both “self-disclosure”, when an individual decides whether, when, and how to reveal one’s status to others, and also to whether someone else discloses an individual's status with or without their consent (16,17). The World Health Organization (WHO) has advocated for more support of “beneficial disclosure,” defined as voluntarily self-disclosing one’s status while simultaneously respecting their autonomy and self-efficacy to do so (18). WHO has posited that the strengthening of health systems to safeguard HIV testing and treatment as well as increasing the protection of PLHIV from HIV stigma is a structural approach that would encourage increased beneficial disclosure (18).

HIV status disclosure, as a core element of initiating social support with implications for psychosocial outcomes, can represent a critical juncture in the lives of ALWH. However, the existing disclosure literature primarily focuses on parents decisions to inform a child or adolescent of their status that may have been previously unknown (19–23). As such, self-disclosure for ALWH continues to be a gap in research especially in consideration of the multiple complexities that may arise for ALWH considering disclosure (24,25). Adolescence is a time of fundamental developmental change and a desire to maintain friendships, establish a confident sense of self, and avoid stigma, can all shape ALWH’s choice of whether or not to disclose their status. The desire and expectation for autonomy among ALWH coupled with the transition to adulthood and to adult HIV care creates an amalgamation of stressors that can severely impact their health outcomes and make the adult literature on disclosure not generalizable to ALWH (26). Since adolescence is also a time of sexual debut and social expectations to engage in romantic and sexual relationships, hesitation to self-disclose due to fear of diminished social cohesion and exclusion from peers can also play a major role in the spread of HIV (13). Nonetheless, a few limited studies have shown that self-disclosure of an HIV status can, in some instances, lead to positive social support for ALWH (13–15,27). Selective disclosure of one's HIV status to individuals such as friends, partners, and teachers has been found to aid ALWH in gaining psychosocial support and adhering to ART, mitigating possible poor health outcomes for ALWH (28).

Given the majority of ALWH residing in low-resourced settings, particularly in SSA (3), research to understand how adolescents self-disclose and what factors are related to this disclosure is an essential first step to helping communities support ALWH and to promote positive HIV treatment and psychosocial outcomes for them. Uganda serves as a model setting for exploring the relationship between HIV status disclosure and psychosocial factors for ALWH. Adolescents comprise a third of the overall population and almost half of HIV/AIDS cases in Uganda. While Uganda has made significant progress with the prevention of mother to child transmission, a high prevalence of gender-based violence and loss of breastfeeding mothers living with HIV from care continue to facilitate vertical HIV transmission. Despite Uganda's gains in reducing HIV/AIDS transmission and mortality rates, a high proportion of new infections are occurring among adolescents (29,30) who remain highly vulnerable due to engagement in high-risk sexual behavior and substance use (31). Uganda has had great success in widescale provision of ART, but adherence among ALWH remains a challenge due to poverty and stigma (32,33) .

Few studies from Uganda have explored the associations between mental health and self-disclosure of HIV status among ALWH (11,14,34). Of those that do, disclosure of HIV status was found to be both positively and negatively associated with mental health. Whereas self-disclosure in this setting resulted in both internalized and enacted stigma leading to poor mental health, it also has led to familial support that enabled resisting stigma and adverse psychosocial outcomes (11,14). The importance of being able to talk with a caregiver about HIV has also been found to be associated with comfort in disclosing one’s status and coping with an HIV diagnosis in Uganda (34) . Furthermore, a study with ALWH, their caregivers, and health workers in Uganda emphasized the need for better support in preparing ALWH to self-disclose as it was a salient challenge related to their sustained healthcare given subsequent psychosocial challenges that could emerge post-disclosure (34).

Given the limited evidence as to the implications of HIV status disclosure on psychosocial outcomes for ALWH in Uganda, this study examines the relationship between self-disclosure and mental health outcomes for adolescents in this setting. We sought to characterize to whom ALWH chose to disclose, what sociodemographic factors were associated with this disclosure choice, and how the individual disclosed to was associated with depression and anxiety. Findings from this study can be used to inform future initiatives that support and prepare ALWH to self-disclose their HIV status.

4.3 Methods

Study Population and Data Collection

This study is a secondary data analysis of the Pediatric HIV/AIDS Research Project (PHARP). PHARP recruited adolescents (aged 11-18 years) from Uganda to understand differences in functional outcomes between three cohorts of participants: ALWH who were perinatally infected, adolescents who were exposed to HIV in utero but who were uninfected, and HIV-negative adolescents unexposed to HIV in utero. Participants were recruited from the database of patients currently receiving ART through the Kawaala Health Center in Kawempe, a division of Kampala. Eligibility for the parent study was limited to adolescents who were born in a hospital setting in order to verify HIV status and post birth clinical history, (i.e., those who were perinatally infected). Participants without an official birth record and/or antenatal register and delivery records were excluded. Between October 2018 and January 2020, caregivers of ALWH were contacted via telephone or approached when in the waiting area of the clinic to learn about the study. If caregivers were interested, they were asked to provide written informed consent and adolescents must also have provided assent to be included in the study. All participants enrolled in the study were followed for a period of 12 months starting October 23rd, 2019 through January 20th, 2020 with study surveys administered in Luganda by trained research assistants to adolescents (and caregivers) every 4 months. For the purposes of this analysis, we restricted to only ALWH who were perinatally infected (n=157). We further excluded adolescents who reported not taking a daily medication, followed by those who did not know the reason why they were taking a daily medication (e.g., ART for HIV), and finally adolescents who did not report HIV/AIDS as the reason for medication use as we did not want to inadvertently disclose their HIV status to them. Given this, only the subsample of perinatally infected ALWH who were aware of their HIV status and on ART at baseline were included (N=87).

Measures

This secondary data analysis draws from only the baseline data collection conducted in PHARP. The baseline survey included collection of the following demographic variables relevant to this study: age (11-18 years), sex (female or male), and education status (years of education). Adolescent age and sex were confirmed via birth records.

HIV Disclosure. The specific survey questions regarding disclosure in the parent study asked with whom an ALWH had chosen to share their HIV status. HIV disclosure was assessed by first asking ALWH whether they had self-disclosed their HIV status to anyone, and for those who had disclosed, to which of the following ten categories of individuals they disclosed their HIV status: spouse or steady sexual partner; mother; father; sister(s); brother(s); child; other female relative(s); other male relative(s); friend(s); or, other. Adolescents indicated a binary response of yes/no for each category. Other female or male relatives were individuals not included in one's nuclear familial unit, e.g., an aunt, uncle, cousin, niece or nephew. The "spouse or steady sexual partner", "child", and "other" variables were excluded from this analysis since each was uncommonly endorsed by study participants (<8%). For the purpose of this analysis, we examined HIV status disclosure in three ways: 1) any disclosure; 2) number of disclosure categories (by summing across the 7 disclosure options used in this study); and 3) specific disclosure choice among the four most common parties disclosed to in this sample.

Mental health. Mental health outcomes were measured using the Behavior Assessment System for Children (BASC-3). The BASC-3 was chosen for this study given its neurological and cognitive measurement properties and inclusion of externalizing problems, internalizing problems, and adaptive skill measures (35). This measure was adapted for cultural context by the PHARP study team and forward and backward translated between English and Luganda. For the purpose of this study, we focused on internalizing symptoms. The BASC-3 generates separate scores for anxiety (13 items) and depression (12 items), which for this study were standardized by age and sex using the HIV unexposed and uninfected adolescent cohort in Uganda as a reference population and are presented as continuous z-scores. The Cronbach's alpha for internal consistency for the depression and anxiety scales were both 0.74.

Statistical Analysis

Descriptive statistics were calculated to assess the prevalence of self-disclosure to different individuals. Chi-square test of independence for categorical variables and one-way ANOVA were conducted to compare differences in sociodemographic characteristics by status of self-disclosure to mother, father, sister(s), brother(s), other female relative(s), and other male relative(s), or friend(s). Multiple linear regression was then used to explore the associations between disclosure variables and z-scores for depression and anxiety. The top four disclosure choice variables with the highest responses among ALWH, number of disclosure categories, and any disclosure were modeled as the independent variables with depression and anxiety as the dependent outcomes in six separate, unadjusted models (Model 1 for each disclosure outcome). These models were then adjusted for the number of disclosure categories (Model 2). Age (continuous in years), sex (female, male) and education (not in school, in school) were added to the final models (Model 3).

All analyses were performed using Stata Version 15.1 (36). All statistical tests were performed at an alpha of 0.05. The study was approved by the research ethics review committees of Michigan State University (IRB Protocol#: 16-828), Makerere University College of Health Sciences, School of Medicine (Protocol REC REF# 2017-017) and the Uganda National Council for Science and Technology (Protocol #: SS 4378). This secondary analysis of deidentified data was exempted by the Johns Hopkins University Bloomberg School of Public Health Institutional Review Board.

4.4 Results

87 ALWH were included in analyses (Table 4.1). The overall mean age of participants was 14.70 years with approximately 60% being female and a third not currently in school. The average depression z-score was 0.32, and for anxiety was 0.16, i.e., they were 0.32 and 0.16 points over the mean age/sex standardized score of adolescents unexposed and uninfected with HIV on average. Over 70% of the adolescents had disclosed their HIV status to at least one individual.

Table 4.1. Sociodemographic Characteristics of ALWH (n=87)

	Total (n=87)
Age in Years, mean (sd)	14.70 (2.29)
Female, n(%)	51 (58.62)
Not in School, n(%)	29 (33.33)
Depression Z-Score, mean (sd)	0.32 (1.34)
Anxiety Z-Score, mean (sd)	0.16 (1.03)
Disclosed HIV status to one or more individuals, n (%)	61 (70.11)

Self-Disclosure Patterns

Figure 4.1 provides an overview of the different types of people to whom ALWH reported disclosing their HIV status. Almost two-thirds of ALWH (63%) had disclosed their status to their mother. The next individuals ALWH most frequently disclosed to was their father, sister(s), or brother(s), with over 50% indicating that they had disclosed to each. Other female or male relative(s) were less often disclosed to, with only 32% of participants reporting having disclosed to other female relative(s) and 29% to other male relative(s). Those least disclosed to were ALWH's friends, with only one-fifth of participants having told at least one friend about their HIV status. Similar patterns were observed for disclosure by participant sex. Both females and males had the same top four categories of individuals they disclosed to: their mother, father, sister(s), or brother(s). Females adolescents disclosed to anyone more frequently and to all categories of people as compared to male adolescents, including to their brother(s) and male relative(s) (Figure 4.2).

Figure 4.1. Frequency of Disclosure among ALWH (n=87)

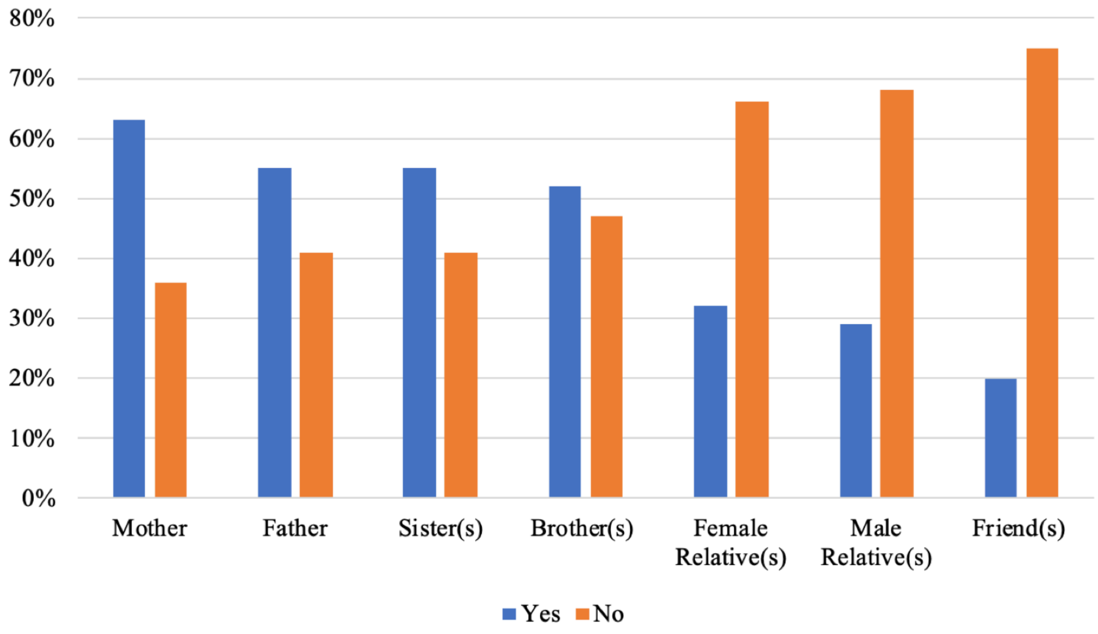
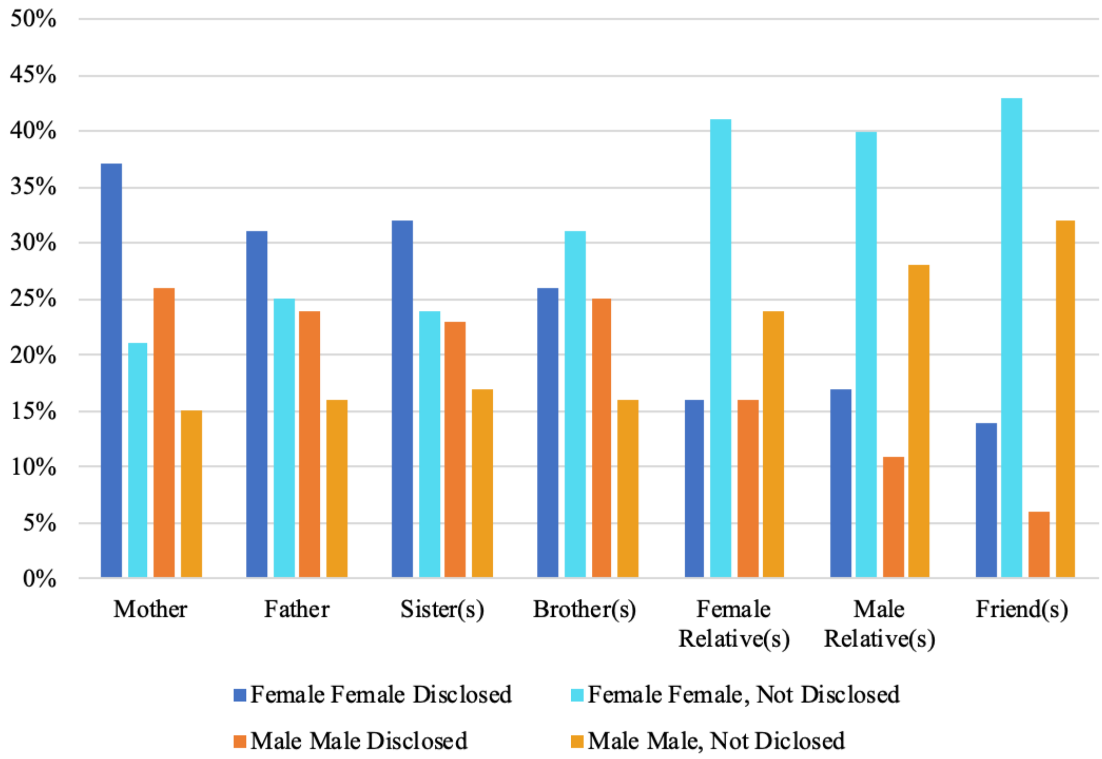


Figure 4.2. Frequency of Disclosure by Sex (n=87)



Sociodemographic Characteristics and Self-Disclosure Patterns

Table 4.2 presents sociodemographic characteristics and mental health outcomes by disclosure choice. The only statistically significant difference observed when examining an adolescent's age and who they disclosed to was for other male relative(s) (mean age among those who disclosed=15.5 vs. mean age among those who did not disclose=14.3, p=0.03). In addition, ALWH who were in school had greater prevalence of disclosing to both a female and male relative than those who were not in school.

Table 4.2. Differences in Sociodemographic Characteristics and Common Mental Disorder Symptoms by Disclosure of Status among ALWH (N=87)

	Mother		**Father**		**Sister(s)**		**Brother(s)**		**Other Female Relative(s)**		**Other Male Relative(s)**		**Friend(s)**	
	Yes (n=55)	**No (n=31)**	**Yes (n=48)**	**No (n=36)**	**Yes (n=48)**	**No (n=36)**	**Yes (n=45)**	**No (n=41)**	**Yes (n=28)**	**No (n=57)**	**Yes (n=25)**	**No (n=59)**	**Yes (n=17)**	**No (n=65)**
Age, mean (sd)	14.65 (2.35)	14.90 (2.15)	14.67 (2.35)	14.83 (2.21)	14.90 (2.27)	14.64 (2.27)	14.78 (2.37)	14.56 (2.23)	15.29 (2.27)	14.40 (2.27)	15.52 (2.26)	14.34 (2.26)	15.65 (2.32)	14.49 (2.26)
P-value[a]	0.63		0.74		0.61		0.66		0.10		0.03*		0.07	
Female, n(%)	32 (58.18)	18 (58.06)	27 (56.25)	22(61.11)	28 (58.33)	21 (58.33)	23 (51.11)	27 (65.85)	14 (50.00)	36 (63.16)	15 (60.00)	35 (59.32)	12 (70.59)	37 (56.92)
Male, n(%)	23(41.82)	13 (41.94)	21 (43.75)	14 (38.89)	20 (41.67)	15 (41.67)	22 (48.89)	14 (34.15)	14 (50.00)	21 (36.84)	10 (40.00)	24 (40.68)	5 (29.41)	28 (43.08)
P-value[a]	1.00		0.82		1.00		0.19		0.35		1.00		0.41	
In School, n(%)	36 (64.45)	21 (67.74)	30 (62.50)	25 (69.44)	29 (60.42)	27 (75.00)	26 (57.78)	30 (73.17)	13 (46.43)	42 (73.68)	11 (44.00)	44 (74.58)	8 (47.06)	46 (70.77)
Not in school, n (%)	18 (32.73)	10 (32.26)	17 (35.42)	11 (30.56)	19 (39.58)	8 (22.22)	18 (40.00)	11 (26.83)	14 (50.00)	15 (26.32)	14 (56.00)	14 (23.73)	9 (52.94)	18 (27.69)
P-value[a]	1.00		0.65		0.16		0.25		0.03*		0.01*		0.08	
Depression, mean (sd)	0.21 (1.23)	0.52 (1.55)	0.15 (1.30)	0.55 (1.44)	0.15 (1.27)	0.56 (1.48)	0.10 (1.16)	0.57 (1.51)	0.41 (1.13)	0.27 (1.46)	0.37 (1.16)	0.29 (1.45)	0.62 (1.27)	0.24 (1.41)
P-value[a]	0.32		0.18		0.18		0.11		0.66		0.81		0.32	
Anxiety, mean (sd)	0.16 (1.12)	0.14 (0.86)	0.09 (1.17)	0.23 (0.85)	0.11 (1.08)	0.21 (0.94)	0.09 (1.18)	0.24 (0.86)	0.25 (1.05)	0.11 (1.04)	0.18 (1.01)	0.11 (1.05)	0.30 (1.02)	0.09 (1.05)
P-value[a]	0.91		0.56		0.68		0.50		0.56		0.79		0.47	

[a] *P-value of the F statistic from the one way Anova*
*p<0.05

Self-Disclosure Patterns and Mental Health Outcomes

Results of linear regressions testing associations between any disclosure, number of types of individuals to whom an ALWH self-disclosed, and self-disclosure to each of the top 4 most frequently self-disclosed to type of individuals are presented in Table 4.3. In the fully adjusted model, any disclosure was significantly associated with lower depression z-scores (β= -0.51, CI=-1.12, 0.11). Any disclosure was also associated with lower anxiety z-scores in the fully adjusted model, but this was not significant (β=-0.09, CI=-0.59, 0.41). The number of types of individuals an adolescent reported self-disclosing to was non-significantly associated with lower depression (β= -0.08, CI=-0.19, 0.04) and anxiety z-scores (β= -0.02, CI=-0.11, 0.07) in the fully adjusted models. Self-disclosure to one's brother(s) versus non-self-disclosure to this type of individual was significantly associated with lower depression z-scores (β= -1.02, CI=-2.00, -0.05) in the fully adjusted models. Self-disclosure to one's father (β= -0.46, CI=-1.54, 0.62), sister(s) (β= -0.66, CI=-1.68, 0.36), and mother (β= -0.05, CI=-0.97, 0.87) were similarly negatively associated with depression z-scores in the fully adjusted models, but none of these associations reached statistical significance. Similar non-significant negative associations were found for anxiety, except that disclosure to mothers exhibited a non-significant positive association with anxiety z-scores.

Table 4.3. Linear Regression of Mental Health Outcomes on Disclosure of HIV Status among ALWH (N=87)

	Depression			**Anxiety**		
	Model 1[a]	**Model 2**[b]	**Model 3**[c]	**Model 1**[a]	**Model 2**[b]	**Model 3**[c]
	Beta (95% CI)	Beta (95% CI)	Beta (95% CI)	Beta (95% CI)	Beta (95% CI)	Beta (95% CI)
Disclosed to anyone	-0.43 (-1.06, 0.20)	--	-0.51 (-1.12, 0.11)*	-0.07 (-0.57, 0.43)	--	-0.09 (-0.59, 0.41)
Number of disclosure categories	-0.04 (-0.15, 0.08)	--	-0.08 (-0.19, 0.04)	-0.01 (-0.09, 0.08)	--	-0.02 (-0.11, 0.07)
Disclosed to mother	-0.31 (-0.92, 0.30)	-0.35 (-1.27, 0.57)	-0.05 (-0.97, 0.87)	0.03 (-0.45, 0.50)	0.10 (-0.61, 0.81)	0.27 (-0.45, 1.00)
Disclosed to father	-0.41 (-1.01, 0.20)	-0.73 (-1.81, 0.34)	-0.46 (-1.54, 0.62)	-0.14 (-0.61, 0.33)	-0.37 (-1.20, 0.46)	-0.20 (-1.06, 0.66)
Disclosed to sister(s)	-0.41 (-1.02, 0.20)	-0.70 (-1.73, 0.34)	-0.66 (-1.68, 0.36)	-0.10 (-0.56, 0.37)	-0.18 (-0.96, 0.61)	-0.08 (-0.88, 0.72)
Disclosed to brother(s)	-0.47 (-1.06, 0.11)	-0.90 (-1.90, 0.10)	-1.02 (-2.00, -0.05)*	-0.16 (-0.61, 0.30)	-0.39 (-1.17, 0.39)	-0.43 (-1.22, 0.36)

[a] Unadjusted model

[b] Adjusted for number of categories of people an adolescent indicated disclosing to

[c] Adjusted for number of categories of people an adolescent indicated disclosing to, age, sex, and education

*$p<0.05$

4.5 Discussion

This exploratory study sought to understand to whom ALWH in Uganda self-disclose their HIV status, any potential differences among ALWH in who they chose to disclose to, and the association of disclosure choices with anxiety and depression. Most adolescents had self-disclosed their HIV status to at least one person, and those adolescents reported lower depression and anxiety z-scores, with a significant association observed only with depression. Despite mothers being the most frequently mentioned person an adolescent had self-disclosed their HIV status to across participant demographic categories, the association between disclosure to mothers and both depression and anxiety symptoms was non-significant.

Few studies have examined associations between HIV status self-disclosure and mental health among ALWH in SS A(37). Disclosure among one's family being generally non-significantly associated with these symptoms (with the exception of disclosure to brothers and depression symptoms) in our study contradicts a recent study from Kenya in which disclosing to family members versus non-family members resulted in marginally higher depressive symptoms. However, this study did not differentiate between nuclear family and extended family members (37). Regarding our findings, it is worth considering that the potential beneficial outcomes associated with disclosing to one's nuclear family compared to their extended family or friends may be a reflection of the close-knit environment within which ALWH live their daily lives. Studies that have found family cohesion being associated with HIV disclosure among adults, perhaps reflect greater trust and connectedness within the family (38). In close-knit families or families living in close proximity, it is also possible that nuclear family members are more likely to be or become aware of an adolescent's HIV status, as it can be harder or almost unavoidable in these conditions to maintain the secret of one's status (39). This may make self-disclosure inevitable or less impactful as studies have demonstrated that ALWH may feel a lack of control when families know their status and exert control over when and to whom they are allowed to disclose to (40).

While it might be assumed that mothers already know the HIV status of their perinatally infected children, adolescents in this study were asked who they had told about their status, with further clarification of who specifically had they chosen to share their HIV status with provided by the research assistant and as detailed in the study survey. Therefore, our findings may reflect and adolescent’s choice to voluntarily engage with relatives including their mothers about their HIV status, even if assumed they may already know. Our finding that mothers were the most disclosed to type of person coincides with the literature on HIV status disclosure (37,41). However, more research is needed to understand the implications of this broadly for ALWH. Our findings indicate the possibility of poorer psychosocial outcomes associated with disclosing to one’s mother in the case of anxiety, though results are non-significant and can only be interpreted as suggestive and exploratory. This could stem from the fact that should an ALWH disclose to others about their status, it can indicate a mother’s HIV status as well, placing unwanted burden on them. This can create familial stress that compounds poor mental health for ALWH (13). It has also been found that while ALWH may want to self-disclose, negative parental attitudes about this prevent them from doing so which can lead to stressors such as isolation and feeling lonely (42), which correlate with depression and anxiety (43).

Our results showed disclosure to peers was uncommon among both youth in and out of school and among both females and males. The fear of being rejected by friends or having friends share one’s HIV status without their consent is a commonly cited reason for ALWH not disclosing their status to peers (13,14,44). Our findings also did not show that ALWH who had disclosed to peers experienced any significant association with mental health symptoms. Of note, prior studies that have found diminished social support from peers upon disclosure (45) and increased mental health difficulties. Conversely, one study found that disclosure to close friends was not associated with distress, while disclosing to acquaintances was (46). Participants in our study may have collapsed friends and acquaintances in responding and there may be subgroups of ALWH who experience positive versus negative reactions from friends. This suggests the need for qualitative studies specifically focused on disclosure to peers that can provide more nuanced insight as to how decisions to disclose to different types of peers may be made and how these different types of disclosure may be differentially understood to be related to overall psychosocial wellness, positively or negatively. Even less is known about the negative effects of disclosure to a non-nuclear family member, even though our study found disclosure to these individuals to be more common than peer disclosure. Relatives such as aunts have also been found to provide support to ALWH (28), yet there is a scarcity of research in which to contextualize our findings on relatives and possible worse mental health scores.

While patterns in who was most commonly disclosed to were similar by adolescent sex, female ALWH disclosed more frequently across all categories of individuals than male ALWH, including to male family members. Evidence is currently limited as to what differences may exist among female versus male ALWH in self-disclosure of HIV (10). An existing study from Uganda found lower levels of disclosure from female adolescents as compared to males (10), unlike in our study. Reasons for having observed lower disclosure among females in other studies from SSA have been hypothesized as their experience of greater social and economic vulnerability and greater fear of being rejected by others (47,48). However, previous literature on ALWH in Uganda specifically found female adolescents communicate more and in turn receive more social support then their male counterparts (49), which coincides with our finding and may suggest something unique about the Ugandan context deserving of further in-depth exploration.

Our exploratory findings point to the need for a multi-method study as to the reasons ALWH choose to disclose to particular individuals in a larger population in order to confirm patterns seen in this assessment. Reliance on only quantitative findings does not allow for understanding the decisions behind choice of disclosure for ALWH and understanding across a variety of sociodemographic is integral to having a more comprehensive view of adolescents in Uganda. Research as to the poorer mental health outcomes for those who disclosed to relatives outside of the immediate family is especially needed given that ALWH may be cared for by these individuals at some point in their lives (50). In addition, extant literature calls for better support for ALWH to self-disclose and to be equipped with better capacity to assess who to disclose to and ways to cope with negative outcomes of disclosure (18). Our findings point to these efforts being targeted among the immediate nuclear family with whom ALWH are most likely to live. Future research should ask ALWH who they would want to disclose to, why they seek to disclose to those individuals specifically (with a focus on perception of existing knowledge of their status included), and what characteristics are important in assessing to whom to disclose.

Furthermore, it is important to consider the general difficulty in assessing self-disclosure of HIV status to mothers in perinatally infected populations. ALWH may not be aware that their mother knows their HIV status and upon self-disclosing to them, are initiating a discussion about HIV for the first time. Future studies should consider asking an ALWH who disclosed their HIV status to them, with whom they have specifically engaged about their HIV status through self-disclosure, and if an individual lists their mother as knowing their status prior to their self-disclosure or despite having not disclosed. It may also be important to assess if when an adolescent self-discloses to anyone their status, whether or not they assumed that individual already had knowledge of their status or not. In addition, given the potential associations seen in this exploratory analysis between self-disclosure choices and mental health, these choices require further examination in conjunction with adherence. Disclosure choice may be predictive of adherence patterns, given the evidence as to positive social support leading to better sustainment of HIV treatment (51).

Limitations

This study and its findings should be considered in light of several limitations. We consider this study exploratory as this was secondary analysis and this analysis was not powered to look conclusively at relationships explored. In addition, we acknowledge that there is significant heterogeneity in experiences within the adolescent developmental period that this study is unable to parse out due to its small sample size. We looked for differences between age groups defined as younger (10-14) and older (15-18) (52,53) and did not observe meaningful differences which could also be due to said sample size. We therefore chose to consolidate age groups for this study to preserve sample size. In addition, we acknowledge that studying a group of adolescents in Uganda means we are understanding disclosure and mental health within a specific cultural setting(s). Future studies should explore the culturally specific nuances of disclosure and mental health for this population. Adding to this point about culture and, also given that we have a clinic sample, both factors limit generalizability to participants recruited from the community and from varying cultural backgrounds. Of additional importance, ALWH exhibiting higher levels of depression and anxiety may have been less likely to be engaged in care and thus to have enrolled in our study. Furthermore, the mental health measure used in this study, the BASC-3, has not been validated in Uganda and thus it is possible that important aspects of mental health are not captured in its use. However, careful attention was paid to the adaptation and translation of this measure for use in this population. It is possible that one's mental health influences one's choices to disclose rather than disclosure leading to different mental health outcomes. ALWH who are also exhibiting poor mental health may be less likely to disclose to anyone compared to those who are less impacted psychosocially and longitudinal study to confirm this is required. We were also unable to assess the exposure of self-disclosing one's HIV status and the time to develop mental health symptoms, which is deserving of future study as there may be critical windows of exposure as it relates to psychosocial impacts.

4.6 Conclusion

Our study adds knowledge to the literature from SSA on individual choice by an ALWH on to whom to self-disclose their status and possible associations of these different choices with mental health. Specifically, we explored nuances about choice in HIV status self-disclosure not typically captured in studies by including a wider range of disclosure choices than what has been studied in SSA among adolescents. Our findings of lower depression symptoms associated with self-disclosing HIV status to anyone versus no one and disclosing to a brother(s) versus no one highlight possible psychosocial implications of selective self-disclosure to specific individuals by ALWH. As both rejection and support can stem from self-disclosure, it is essential to first understand who ALWH are disclosing to and how it is related to mental health to begin to parse helpful and harmful reactions to disclosure and begin to target future research and intervention efforts aimed at increasing social support for ALWH. As ALWH are developing increasing independence during this major developmental time, a sole focus on understanding disclosure of an ALWH’s HIV status to them from someone else in lieu of attention to self-disclosure, undermines ALWH’s autonomy and ultimately understanding of how to best support their psychosocial wellbeing and ability to thrive.

4.7 References

1. Adolescent HIV prevention [Internet]. UNICEF DATA. 2020 [cited 2021 May 5]. Available from: https://data.unicef.org/topic/hivaids/adolescents-young-people/

2. Ritchwood TD, Malo V, Jones C, Metzger IW, Atujuna M, Marcus R, et al. Healthcare retention and clinical outcomes among adolescents living with HIV after transition from pediatric to adult care: a systematic review. BMC Public Health. 2020 Aug 3;20(1):1195.

3. Slogrove AL, Sohn AH. The global epidemiology of adolescents living with HIV: Time for more granular data to improve adolescent health outcomes. Curr Opin HIV AIDS. 2018 May;13(3):170–8.

4. Sohn AH, Hazra R. Old Problems for New Providers: Managing the Postpediatric HIV Generation. Clin Infect Dis. 2017 Apr 15;64(8):1113–4.

5. Garvie PA, Brummel SS, Allison SM, Malee KM, Mellins CA, Wilkins ML, et al. Roles of Medication Responsibility, Executive and Adaptive Functioning in Adherence for Children and Adolescents With Perinatally Acquired HIV. Pediatr Infect Dis J. 2017 Aug;36(8):751–7.

6. Mutumba M, Bauermeister JA, Elkington KS, Bucek A, Dolezal C, Leu C-S, et al. A Prospective Longitudinal Study of Mental Health Symptoms Among Perinatally HIV-Infected and HIV-Exposed but Uninfected Urban Youths. J Adolesc Health. 2016 Apr;58(4):460–6.

7. Kessler RC, Amminger GP, Aguilar-Gaxiola S, Alonso J, Lee S, Ustun TB. Age of onset of mental disorders: A review of recent literature. Curr Opin Psychiatry. 2007 Jul;20(4):359–64.

8. Bhana A, Abas MA, Kelly J, van Pinxteren M, Mudekunye LA, Pantelic M. Mental health interventions for adolescents living with HIV or affected by HIV in low- and middle-income countries: systematic review. BJPsych Open. 2020;6(5):e104.

9. Vreeman RC, McCoy BM, Lee S. Mental health challenges among adolescents living with HIV: Vreeman RC et al. J Int AIDS Soc. 2017;20(0):21497.

10. Kim MH, Mazenga AC, Yu X, Devandra A, Nguyen C, Ahmed S, et al. Factors associated with depression among adolescents living with HIV in Malawi. BMC Psychiatry. 2015 Oct 26;15(1):264.

11. Ashaba S, Cooper-Vince CE, Vořechovská D, Rukundo GZ, Maling S, Akena D, et al. Community beliefs, HIV stigma, and depression among adolescents living with HIV in rural Uganda. African Journal of AIDS Research. 2019 Sep 27;18(3):169–80.

12. Thurston IB, Bogart LM, Wachman M, Closson EF, Skeer MR, Mimiaga MJ. Adaptation of an HIV Medication Adherence Intervention for Adolescents and Young Adults. Cogn Behav Pract. 2014 May;21(2):191–205.

13. Madiba S, Mokgatle M. Perceptions and experiences about self-disclosure of HIV status among adolescents with perinatal acquired HIV in poor-resourced communities in South Africa. AIDS Res Treat. 2016;2016:2607249.

14. Nöstlinger C, Bakeera-Kitaka S, Buyze J, Loos J, Buvé A. Factors influencing social self-disclosure among adolescents living with HIV in Eastern Africa. AIDS Care. 2015 Nov 2;27(sup1):36–46.

15. Hodgson I, Ross J, Haamujompa C, Gitau-Mburu D. Living as an adolescent with HIV in Zambia – lived experiences, sexual health and reproductive needs. AIDS Care. 2012 Oct 1;24(10):1204–10.

16. Obermeyer CM, Baijal P, Pegurri E. Facilitating HIV Disclosure Across Diverse Settings: A Review. Am J Public Health. 2011 Jun 1;101(6):1011–23.

17. Stutterheim SE, Bos AER, Pryor JB, Brands R, Liebregts M, Schaalma HP. Psychological and social correlates of HIV status disclosure: the significance of stigma visibility. AIDS Educ Prev. 2011 Aug;23(4):382–92.

18. World Health Organization. [Internet]. Essential prevention and care interventions for adults and adolescents living with HIV in resource-limited settings. Geneva: World Health Organization; 2008. [cited 2021 May 5]. Available from: https://www.who.int/hiv/pub/guidelines/EP/en/

19. Lester P, Chesney M, Cooke M, Whalley P, Perez B, Petru A, et al. Diagnostic Disclosure to HIV-Infected Children: How Parents Decide when and what to Tell. Clin Child Psychol Psychiatry. 2002 Jan 1;7(1):85–99.

20. Gyamfi E, Okyere P, Enoch A, Appiah-Brempong E. Prevalence of, and barriers to the disclosure of HIV status to infected children and adolescents in a district of Ghana. BMC International Health and Human Rights. 2017 Apr 8;17(1):8.

21. Aderomilehin O, Hanciles-Amu A, Ozoya OO. Perspectives and practice of HIV disclosure to children and adolescents by health-care providers and caregivers in sub-Saharan Africa: A systematic review. Front Public Health. 2016;4:166.

22. John-Stewart GC, Wariua G, Beima-Sofie KM, Richardson BA, Farquhar C, Maleche-Obimbo E, et al. Prevalence, perceptions, and correlates of pediatric HIV disclosure in an HIV treatment program in Kenya. AIDS Care. 2013 Sep 1;25(9):1067–76.

23. Ngeno B, Waruru A, Inwani I, Nganga L, Wangari EN, Katana A, et al. Disclosure and Clinical Outcomes Among Young Adolescents Living With HIV in Kenya. Journal of Adolescent Health. 2019 Feb 1;64(2):242–9.

24. Evangeli M. The Adolescent HIV Disclosure Cognition and Affect Scale: Preliminary Reliability and Validity. J Pediatr Psychol. 2017 Jul 1;42(6):711–20.

25. Weintraub A, Mellins CA, Warne P, Dolezal C, Elkington K, Bucek A, et al. Patterns and Correlates of Serostatus Disclosure to Sexual Partners by Perinatally-Infected Adolescents and Young Adults. AIDS Behav. 2017 Jan;21(1):129–40.

26. Hoare J, Phillips N, Brittain K, Myer L, Zar HJ, Stein DJ. Mental Health and Functional Competence in the Cape Town Adolescent Antiretroviral Cohort: JAIDS Journal of Acquired Immune Deficiency Syndromes. 2019 Aug;81(4):e109–16.

27. Sherman BF, Bonanno GA, Wiener LS, Battles HB. When children tell their friends they have AIDS: possible consequences for psychological well-being and disease progression. Psychosom Med. 2000 Apr;62(2):238–47.

28. Mutumba M, Bauermeister JA, Musiime V, Byaruhanga J, Francis K, Snow RC, et al. Psychosocial Challenges and Strategies for Coping with HIV Among Adolescents in Uganda: A Qualitative Study. AIDS Patient Care and STDs. 2015 Feb;29(2):86–94.

29. HIV and AIDS in Uganda [Internet]. Avert. 2019 [cited 2021 May 5]. Available from: https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/uganda

30. Kibombo R, Neema S, Ahmed FH. Perceptions of risk to HIV Infection among Adolescents in Uganda: Are they Related to Sexual Behaviour? Afr J Reprod Health. 2007;11(3):168–81.

31. Kasirye R. Sexual risks, Substance abuse and Protective factors among, Kampala Street and slum children. J Mental Health & Clin Psychology. 2018 Mar 1;2(1):14–8.

32. Bikaako-Kajura W, Luyirika E, Purcell DW, Downing J, Kaharuza F, Mermin J, et al. Disclosure of HIV Status and Adherence to Daily Drug Regimens Among HIV-infected Children in Uganda. AIDS Behav. 2006 Jun 22;10(1):85.

33. Linnemayr S, Huang H, Luoto J, Kambugu A, Thirumurthy H, Haberer JE, et al. Text Messaging for Improving Antiretroviral Therapy Adherence: No Effects After 1 Year in a Randomized Controlled Trial Among Adolescents and Young Adults. Am J Public Health. 2017 Dec;107(12):1944–50.

34. Mutumba M, Mugerwa H, Musiime V, Gautam A, Nakyambadde H, Matama C, et al. Perceptions of strategies and intervention approaches for HIV self-management among Ugandan adolescents: A qualitative study. J Int Assoc Provid AIDS Care. 2019;18:2325958218823246.

35. Altmann RA, Reynolds CR, Kamphaus RW, Vannest KJ. BASC-3. In: Kreutzer J, DeLuca J, Caplan B, editors. Encyclopedia of Clinical Neuropsychology [Internet]. Cham: Springer International Publishing; 2017 [cited 2021 May 5]. p. 1–7. Available from: https://doi.org/10.1007/978-3-319-56782-2_1524-2

36. StataCorp. 2017. *Stata Statistical Software: Release 15*. College Station, TX: StataCorp LLC

37. Mugo C, Seeh D, Guthrie B, Moreno M, Kumar M, John-Stewart G, et al. Association of experienced and internalized stigma with self-disclosure of HIV status by youth living with HIV. AIDS Behav [Internet]. 2021; Available from: http://dx.doi.org/10.1007/s10461-020-03137-0

38. Simoni JM, Demas P, Mason HRC, Drossman JA, Davis ML. HIV Disclosure Among Women of African Descent: Associations with Coping, Social Support, and Psychological Adaptation. AIDS Behav. 2000 Jun 1;4(2):147–58.

39. Damulira C, Mukasa MN, Byansi W, Nabunya P, Kivumbi A, Namatovu P, et al. Examining the relationship of social support and family cohesion on ART adherence among HIV-positive adolescents in southern Uganda: baseline findings. Vulnerable Children and Youth Studies. 2019 Apr 3;14(2):181–90.

40. Mburu G, Ram M, Oxenham D, Haamujompa C, Iorpenda K, Ferguson L. Responding to adolescents living with HIV in Zambia: A social–ecological approach. Children and Youth Services Review. 2014 Oct 1;45:9–17.

41. Olumide A, Owoaje E. Patterns and predictors of disclosure of HIV positive status among youth living with HIV in Ibadan, Nigeria. Int J Adolesc Med Health. 2018 Jan 15;32(1).

42. Hogwood J, Campbell T, Butler S. I wish I could tell you but I can’t: Adolescents with perinatally acquired HIV and their dilemmas around self-disclosure. Clin Child Psychol Psychiatry. 2013 Jan 1;18(1):44–60.

43. Johnson HD, Lavoie JC, Mahoney M. Interparental Conflict and Family Cohesion: Predictors of Loneliness, Social Anxiety, and Social Avoidance in Late Adolescence. Journal of Adolescent Research. 2001;16(3):304-318.

44. Mburu G, Hodgson I, Kalibala S, Haamujompa C, Cataldo F, Lowenthal ED, et al. Adolescent HIV disclosure in Zambia: barriers, facilitators and outcomes. Journal of the International AIDS Society. 2014;17(1):18866.

45. Lee S, Yamazaki M, Harris DR, Harper GW, Ellen J. Social Support and Human Immunodeficiency Virus-Status Disclosure to Friends and Family: Implications for Human Immunodeficiency Virus-Positive Youth. Journal of Adolescent Health. 2015 Jul 1;57(1):73–80.

46. Lam PK, Naar-King S, Wright K. Social Support and Disclosure as Predictors of Mental Health in HIV-Positive Youth. AIDS Patient Care and STDs. 2007 Jan 1;21(1):20–9.

47. Simbayi LC, Kalichman SC, Strebel A, Cloete A, Henda N, Mqeketo A. Disclosure of HIV status to sex partners and sexual risk behaviours among HIV-positive men and women, Cape Town, South Africa. Sex Transm Infect. 2007 Feb;83(1):29–34.

48. Mucheto P, Chadambuka A, Shambira G, Tshimanga M, Gombe N, Nyamayaro W. Determinants of nondisclosure of HIV status among women attending the prevention of mother to child transmission programme, Makonde district, Zimbabwe, 2009. Pan Afr Med J. 2011;8:51.

49. Nabunya P, Byansi W, Sensoy Bahar O, McKay M, Ssewamala FM, Damulira C. Factors associated with HIV disclosure and HIV-related stigma among adolescents living with HIV in southwestern Uganda. Front Psychiatry. 2020;11:772.

50. Kim MH, Mazenga AC, Yu X, Ahmed S, Paul ME, Kazembe PN, et al. High self-reported non-adherence to antiretroviral therapy amongst adolescents living with HIV in Malawi: barriers and associated factors. Journal of the International AIDS Society. 2017;20(1):21437.

51. Mengesha MM, Ajema D, Teshome A, Tura AK. The association between diagnosis disclosure and adherence to antiretroviral therapy among adolescents living with HIV in sub-Saharan Africa: a protocol for systematic review and meta-analysis. Systematic Reviews. 2020 Jul 14;9(1):160.

52. WHO | Very young adolescents [Internet]. WHO. World Health Organization; [cited 2021 Apr 27]. Available from: https://www.who.int/reproductivehealth/topics/adolescence/very_young_ados/en/

53. Sacks D, Canadian Paediatric Society, Adolescent Health Committee. Age limits and adolescents. Paediatr Child Health. 2003;8(9):577–87.

Chapter 5: "It's better if I die because even in the hospital, there is a stigma, people they still gossip": The Impact of Gossip as Stigma for Persons Living with HIV in Botswana

5.1 Abstract

Introduction: In 2002, Botswana became the first country in sub-Saharan Africa to offer universal access to antiretroviral therapy. Yet, Botswana continues to have a high prevalence of HIV. Despite universal access, uptake of HIV testing and treatment remain below global targets, suggesting a strong influence of social and cultural factors in impeding treatment. This study specifically advances this area by analyzing cultural aspects of stigma as gossip among PLHIV in Botswana.

Methods: A total of 5 focus groups and 46 in-depth semi-structured interviews were conducted in Gaborone, Botswana in 2017. Each focus group and interview comprised of either individuals living with HIV or general community members for whom we did not ask about their HIV status. Focus groups and interview transcripts were assessed using a two-step directed content analytical approach and subsequent inductive thematic analysis.

Results: Results indicated that gossip regarding one's HIV status can diminish one's community standing and lead to poor psychosocial outcomes and non-adherence to ART. Additionally, gendered vulnerabilities to stigma suggest women and men experience differential harmful outcomes. Of equal importance is the emergence of data revealing protective factors that mitigate if not reverse stigma such as appearing healthy, accepting one's HIV status, and having a mediator to help educate those who gossip.

Conclusions: This study advances the literature on HIV stigma by outlining how gossip operates among PLHIV in Botswana as both a mechanism for stigma and a type of stigma in of itself.

Results are informative of the ways in which research and practice should incorporate support for PLHIV to resist and cope with gossip.

5.2 Background

Decades of biomedical research and intervention related to the advent and widespread implementation of HIV antiretroviral therapy (ART) have curbed HIV transmission and prolonged the lives of people living with HIV (PLHIV). However, progress in addressing psychosocial factors that shape the HIV epidemic has been slower, and these factors continue to hinder HIV prevention and treatment efforts globally(1). HIV stigma is one such psychosocial factor that can severely limit health seeking behaviors and treatment adherence, in addition to perpetuating poor mental health outcomes for PLHIV(1,2) . HIV stigma refers to processes that devalue PLHIV through labelling and enacting subsequent discrimination or exclusion at the individual, societal, and structural levels (3). Importantly, stigma can also be experienced by PLHIV as the perception or anticipation of maltreatment and as the internalization of negative thoughts, attitudes, and behaviors(4).

In 2002, Botswana became the first sub-Saharan African country to provide universal access to HIV treatment, and it remains an exemplar of national response to the epidemic (5). Yet, Botswana continues to have the 4th highest prevalence of HIV in the world (6,7). Given the long history of universal access to care, Botswana provides a unique setting for contextualizing HIV stigma as a barrier to nonadherence, as resources are not a primary impediment to accessing treatment(5). Previous studies in Botswana have demonstrated how stigma is felt most acutely by PLHIV when it keeps individuals from being a respected and valued member of society, effectively preventing the achievement of full personhood (8,9). Since notions of personhood are gendered in Botswana(9,10), by association the nature and experience of HIV stigma is also gendered. For men, a positive HIV status threatens masculinity by fostering perceptions that they are incapable of fulfilling the role of provider for their families on account of discrimination they could face, particularly regarding both getting and keeping employment(8,9). Women were also found to bear a disproportionate burden of HIV stigma due to antenatal care policies requiring HIV testing during pregnancy. These policies often lead to women being the first identified in a relationship as living with HIV, which results in women being blamed for its transmission (9).

Extant literature from Botswana is suggestive of gossip operating as both a mechanism of labeling individuals as living with HIV and being a form of stigma in of itself (8,9). Among existing studies that touch on gossip and HIV, gossip has been shown to be a common form of enacted stigma for PLHIV. Studies also find that gossip is largely not focused on blaming PLHIV for the spread of HIV, but rather used to center the actions of PLHIV as to blame for their own HIV infection, such as labeling women living with HIV as promiscuous (9,11). While this prior research suggests that gossip about HIV in Botswana can lead to differential outcomes by gender and precipitates poor psychopathology (8,9,12), the mechanisms by which gossip about HIV engenders or acts as a form of HIV stigma have yet to be explored.

Broadly, gossip is considered a major public health challenge in its own right, given its impediment to prevention, diagnosis, and treatment of health conditions (13–15). Gossip has been described as a means of distinguishing between groups of people: those who fulfill societal expectations and those who do not (16). Gossip may therefore serve to label PLHIV, which then allows them to be subjected to stigma, when a PLHIV’s status is inferred or assumed based on the observation of specific behaviors or characteristics. Gossip has also been conceptualized as a means of social control, or an approach by which to maintain cultural and social norms when an individual or their behaviors are appraised as threatening to those norms (16). Fear of gossip has been found to be pervasive among PLHIV and to prevent them from seeking clinical care and to be a salient reason for choosing not to self-disclose (17,18).

Yet, few studies have focused exclusively on clarifying how gossip operates in public health, particularly as it relates to PLHIV. This study seeks to advance the understanding of gossip as a labelling process and vehicle for stigma among PLHIV in Botswana. Through application of the What Matters Most (WMM) theoretical framework that elicits core aspects of personhood among individuals within specific cultural settings as a means of understanding stigma, we examine gossip as HIV stigma within Setswana culture (19). In addition, we explore the ways in which gossip can undermine or interfere with biomedical prevention and treatment approaches designed to control the epidemic in the Botswanan context. We strive to elucidate the process and impact of gossip and use this to necessitate a biopsychosocial approach to addressing HIV stigma in Botswana.

5.3 Methods

Participants

In 2017, participants were purposively sampled for 5 focus groups (FGs) of 5-6 individuals each or 46 in-depth semi-structured interviews (IDIs) in Gaborone, the largest city and capital of Botswana. Our purposive sampling strategy aimed to recruit a balance of men and women, as well as both PLHIV and individuals for whom we did not ask their HIV status to facilitate understanding of HIV stigma from the perspectives of those with lived experience with HIV and the general community. Participation was limited to adults aged 18 or older living in Gaborone, with additional eligibility criteria for PLHIV being that they were currently receiving clinical care for HIV, and for individuals whose HIV status was unknown to researchers, being willing to discuss HIV stigma. Participants living with HIV were recruited from a large public hospital with specialty HIV clinical care services. Individuals from the general community (i.e., HIV status unknown) were recruited from Main Mall in Gaborone, a central plaza within the city. All participants were given a choice as to whether they wanted to participate in either a FG or IDI, as well as if they preferred the use of Setswana (i.e., the local language) or English.

Written informed consent was obtained for all participants, and they were compensated 50 pula (~$5 US) for their travel. Approval for this study came from the Institutional Review Boards of the Botswana Ministry of Health and Wellness, University of Botswana, Princess Marina Hospital, University of Pennsylvania, Columbia University, and New York University.

Data Collection and Procedures

Data collection and procedures have been previously described elsewhere (9,20). WMM was used as the framework for this study as its purpose is to make explicit the salient activities and cultural values integral to one's daily life that interact with how stigma is experienced in a specific cultural context. The framework further facilitates exploration of cultural capabilities that serve as risk and protective factors for HIV stigma(19,21,22). Semi-structured FG and IDI guides were designed based on this framework and its implementation in prior studies (19,23) examining the cultural underpinnings of stigma. The questions were modeled to cover the domains and topics represented in the Devaluation-Discrimination Scale (DDS) but retooled to be open ended (24). Both guides consisted of six original questions from the DDS and then four culturally and contextually specific interview items for the purposes of this specific study's aims (Appendix C). One item elicited factors that enabled HIV identification and subsequent stigma ("When does a woman/man typically find out that they are HIV positive?"), two items specifically asked about aspects integral to personhood ("What does it mean to be a proper man (or woman) in Botswana?"; "Does having HIV affect a proper man (or woman's) status?"), and the last of the four items asked about the role of gossip in Setswana culture ("Does gossip effect a person with HIV's ability to be a good Batswanan?"). In addition, participants could and did spontaneously express examples of WMM in Setswana culture across all items.

The use of FGs was intentional to elicit cultural norms associated with HIV stigma in this setting. IDIs were then used to obtain more nuanced understandings of these norms. Therefore, FGs were conducted first and separately among women and men living with HIV and separately among women and men from the general community. The FG guides were iteratively modified throughout data collection to refine questions in order to capture emergent themes expressed by participants. FGs were co-facilitated and IDIs were independently conducted by 4 bilingual Setswana research assistants from Gaborone and 1 Ghanaian American research assistant, who conducted the interviews solely in English. FGs were facilitated by the Principal investigator in partnership with a Setswana research assistant. Each FG group ranged from 60-120 minutes in duration. Subsequently, IDIs were conducted by the 5 research assistants. As with the FG guides, IDI guides were iteratively updated throughout the course of data collection to explore emerging themes in greater depth and to build upon the information elicited. IDIs were of 60-90 minutes in duration. Both FGs and IDIs were audio recorded and simultaneously transcribed and translated to English if a session was conducted in Setswana.

Data Analysis

The data analysis for this study was conducted in two phases. During the first phase, initial coding of transcripts involved a two-step directed content analytical approach using word processing software; codes were organized into categories using spreadsheets. The first step in the coding process was deductive and consisted of operationally defining coding categories informed by categories from prior qualitative work in other settings by the Principal Investigator that had also drawn on the WMM framework to understand stigma. The categories were the following: 1) cultural capacities necessary to fulfill womanhood or manhood, 2) how WMM shapes stigma, 3) the ability of fulfilling WMM to protect an individual from stigma, and 4) structural vulnerabilities to inform how the intersection of structural factors and “what mattered most” in Setswana culture led to marginalization of PLHIV. The first step was completed by having two sets of coding teams each apply codes to two FG transcripts and then present their findings to one another over six meetings to conceptualize operational definitions for each category that became the basis for the study codebook. The resultant codebook was then used by four pairs of coders to highlight participant descriptions of mechanisms of HIV stigma as it related to fulfilling obligations expected of an individual within the Setswana culture in all of the remaining FG and IDI transcripts. Each coding pair coded transcripts separately, but then would meet to address and resolve discrepancies. Each coding team then presented their findings to the entire study team during weekly 60-minute calls over the course of 18 months (~70 meetings). New codes were adapted and added to the codebook for use by all coding teams throughout these meetings based on emergent findings.

The second step of this initial coding scheme was the inductive elucidation of the relationships between categories to understand how the intersection of structural factors and “what mattered most” in Setswana culture led to marginalization of PLHIV. A sub-team met 13 times (~26 hours) to discuss the conceptualization of these relationships and presented their conclusions to the entire study team after having reached consensus, with further refinements made based on the full study team discussion.

The first phase of data analysis for this study had an intentional gendered focus, yet gossip emerged as a cross-gender theme stemming from the category WMM shapes stigma.

Based on our findings from this first phase and building off the aforementioned coding approach, we completed a second phase of coding for the purposes of this manuscript: to specifically examine the ways gossip generates and operates as stigma in this sample. A team of four coding pairs each individually re-coded the FG and IDI transcripts using an inductive thematic analysis approach. The entire coding team met 4 times (~8 hours), with each pair presenting their emergent themes. During these meetings, themes were modified to reach consensus among all team members as to how to contextualize the role of gossip in Setswana culture as it pertains to HIV.

It should also be noted that throughout the data analysis, consideration was taken as to the potential for different themes to emerge from FGs versus IDIs since they garner different forms of information. Throughout the coding process, coding teams compared emergent themes arising from data collected via both methods to assess for divergences. Through the iterative coding and re-coding of all transcripts, this study was able to thoroughly assess whether there were evident differences. Given these comparisons, it was concluded that themes did not substantially vary between FGs and IDIs and as such this study presents findings from both methods together in the results section.

5.4 Results

Participants

A total of 84 participants (n=43 women and n=41 men) completed either a FG (n=38: n=20 women; n=18 men) or IDI (n=46: n=23 women; n=23 men). Demographic characteristics of participants who contributed data to this analysis are presented in Table 5.1. More than half (n=45) of participants were individuals who reported living with HIV. For women, the mean age was 42.2 years, the majority had at least completed secondary school, and almost half were unemployed. For men, mean age was slightly younger than women (41.4 years), the majority had completed at least secondary school, and under one-third (30%) were unemployed. The majority of men (46.4%) and women (55.8%) reported being single, i.e., not in a relationship.

Gender Dynamics of Setswana Culture and their Intersection with HIV

Gossip was experienced across both genders in the sample. However, as the sociocultural roles of men and women are different, the content and drivers of gossip were different. For women, being a mother is expected, ascribes status, and is fundamental to being regarded as a respected woman in Setswana culture. Being a mother is also associated with an expectation that a woman will remain home and care for others. Female participants explained how not meeting these roles could lead to gossip about your ability to be a woman in the eyes of others.

> …a proper Motswana woman is also judged**, the way she is seen in the community, is reflected by the way she takes care of her own children**, especially bathing them, making sure they have food, and they go to school… she has to be very faithful, and take care of the children - **IDI, man, living with HIV**
>
> They [community] will gossip, ‘you are a barren woman**, you don’t bear children, you are like a bull in a kraal** [your purpose is to bear children], **but you are a woman - IDI, woman, living with HIV**
>
> **We take it that a woman belongs to the home, so we wonder if she has HIV** [if seen with others outside of the home], there is no woman in her. **She is a whore, there is no woman-IDI, man, living with HIV**

Men also described culturally specific expectations that must be met to be afforded respect within society, including being able to provide for their families. Failing in these roles led to questioning a person’s capabilities as a “real man” in Setswana culture.

> **A real man is the one who is employed,** ensures that his children are well fed, hygiene taken care of, clothed well, ensures that the wife is taken care of, even doing farming. [He] should be married**-IDI, woman, living with HIV**
>
> **A real man should be seen as also carrying out the home duties**. By rearing cattle, rearing goats, be a Motswana man. A Setswana man should be seen by the cattle he owns. **And his home, taking care of his home**…having cleared the yard and cutting the trees, making a good fireplace. Those are the things that a real man will be praised for. **If**

> **those things are missing, then you should know there is no real man in that home. - IDI, man, living with HIV**

The inability to fulfill one's male duty to be a provider could elicit stigma for any man. However, in order for a man living with HIV to be successful, it was also imperative that he conceal his HIV status to avoid gossip which could hinder his success by not receiving job offers or opportunities to further advance himself.

> It is [possible for an HIV+ man to be successful] but most of them keep their statuses to themselves to avoid rumors. **If other people know your status in the community, it is very hard to be successful as maybe employers will be reluctant to offer you jobs or tenders. So the best way is to keep it to yourself. - FG, man, unknown HIV status**

Gendered Engagement in Gossip

Participants also described gendered notions about who enacts gossip. For women, there was a clear line between who does and does not gossip, and that they are the ones who perpetrate gossip.

> **Even in the Bible, a woman gossips, but sometimes a woman can gossip about something that is geared towards the truth. Men don't gossip**. He will face you and burst at you, "you see, I don't like PLHIV", but women will say, "apparently that woman is living with HIV, she is not good**"- IDI, woman, living with HIV**

Women also had little power to combat gossip spread about them by men or other women, especially when it came to HIV.

> **As a woman if I'm sleeping around, I'd be called a slut but then it's different in that men, they can sleep around, but then the responsibility would be on the woman that she is the one who is at fault.** His family are the ones who are going to say that I am the one who gave him HIV **- IDI, woman, unknown HIV status**

Gossip among men, however, was not expected and even described as violating social support that men are expected to provide to one another. It was also pointed out that men consider gossip from women to be trivial, as women were generally thought to engage in talk about others (while men were not).

> **When a man is being gossiped by other men it is not good because as men we believe that men are supposed to be supportive to the other man** so if now the men are the ones who are gossiping about you, it's really not acceptable and it's not good at all. But if a woman gossips about other man, women are like that. **Even in the society we know that women are people who talks too much so we accept it.** Of course, it felt like losing status, if man gossips **- IDI, man, HIV status unknown**

Men's social standing was most threatened when other men gossiped about them, yet this was a rarity as gossip among men was seen as atypical, while women could face severe consequences stemming from both men and women discussing their behaviors.

Precipitators of Gossip

The majority of participants agreed that there were particular behaviors that could lead to gossip about one's HIV status. Being seen at the infectious disease clinic or taking medication were especially pertinent triggers of HIV-related gossip.

> **The individual [would] struggle with going to the clinic to get their medication because they would be seen by people, and then people would be talking about them. I think if it was possible [to take them], with no one knowing, then that would be better.** It is really bad here because it is not like in the suburbs where you get into your own yard and then there is a wall around. So here, most houses don't have fences or walls around them so people see you and then they talk about you - **IDI, woman, HIV status unknown**
>
> **It can affect a person, if I'm at the clinic and I'm getting medication and then people see me and then they then say, "I saw her at so and so place doing so and so",** then that might then make me stop taking my medication - **IDI, woman, HIV status unknown**

Labeling through Gossip

Gossip is one way that people in the community convey the HIV status of PLHIV, including the status of PLHIV who choose not to disclose their HIV status to others. This nonconsensual disclosure in turn can lead to others in the community demonstrating avoidant behavior toward the individual with HIV.

> **You hear people saying, "oh so and so has HIV, I don't want to sit next to them** or that their skin is getting worse", so usually it's not something that is done but rather it's

> what people are saying, lots of gossiping…**usually you can't tell that somebody has HIV, but then you can hear it from other people who tell you, when they are gossiping that this person has HIV - IDI, woman, unknown HIV status**

> I have experienced [gossip] by myself. I used to like sell fried chips and meat at night, at the pubs. So there is this other guy, came and wanted food. **[His friend] told him that he can't buy food from a dead body - FG, man, living with HIV**

Through referring to someone as dangerous, sick, and infectious, gossip can reveal one's HIV status without their consent while also spreading harmful notions about HIV.

> It was like the guy was interested [in] me. So he just took my number and said "I will call you, and I will see you. He didn't call. He just asked [others], "Do you know the girl by the name [X] who is staying next that side". **And they said, "Hey why do you want that girl, she is dangerous, she is sick, she will infect you."** [The guy] called me and said, " Hey, I am afraid, people say this and that" and I just said no if you want me, or you want to see me, you can come and talk about that issue…**the fact that you didn't tell that particular person about your status, and then somebody else will tell it's so demoralizing** and it's like if I am the one who is infected, **it's like to that person I am a liar, I am hiding something big to him/her, you know, I am a liar somehow. Because I didn't have that time to say my status - IDI, woman, living with HIV**

The element of choice is removed when others disclose one's status and label them as living with HIV through gossip. Gossip can also incorrectly imply that PLHIV are trying to hide their status, when in actuality a PLHIV is willing to share their status with others.

Permanence of Gossip

Gossip in this setting was viewed as an enduring part of social life. Many believed that the effects of being identified as living with HIV through gossip could have lasting effects for how a PLHIV views their community.

> [The community] will forget, but as a victim you will not forget, [the community] will definitely forget, that is why **there is a Setswana saying that, the perpetrator forgets, but the victim doesn't forget - IDI, woman, living with HIV**

> [The gossip] it will be permanent**, hence the Setswana saying, "a word that goes out of mouth never returns empty".** You must know that when somebody says something to you, it will be difficult for you to forget, of course the one who said it might forget - **IDI, man, living with HIV**

Though community members may forget the specific act(s) of gossip, it was clear from participants that gossip ascribed a stigmatized status to a PLHIV that was retained in the minds of community members, shaping interactions with that person and how they were talked about and thought about even after death.

> Yes, they will still isolate him/her [even after gossip stops]. Even assisting each other will not be the same as before. There are times when he/she would be embroiled in a fight, and if he/she gets hurt and bleeds, **nobody will come to the rescue because they will say, "should you get in contact with his/her blood, you will also get infected" - IDI, woman, HIV status unknown**

> [The community will] never forget. **Because you find out that when someone dies, they will be talk that that person had HIV, even after having taken treatment for a long time - IDI, man, living with HIV**

Negative External and Internal Consequences of Gossip

While gossip served as a mechanism of HIV stigma, it could also generate anticipation of future maltreatment and negative self-beliefs for PLHIV, and therefore foster anticipated and internalized stigma as well. Participants commonly discussed self/internalized stigma that resulted from gossip as related to stress and low self-esteem. Regardless of whether community members actively stigmatized PLHIV using gossip, for a PLHIV, the fear of gossip itself had impact as isolation was used as a strategy to avoid gossip from others.

> **He says now people feel restricted with HIV because of this whole gossip thing**. They end up isolating themselves from the community because they are afraid…they will ask themselves**, if I engage in social gatherings once I leave people will talk bad about you – IDI, man, living with HIV**

Losing control of managing others' knowledge of their HIV status was seen as a stressor in of itself associated with gossip. The social fact of gossip symbolized and could engender fear that many more individuals would learn or knew of a PLHIV's status.

> It's very difficult because a secret doesn't stay and most of us like secretive things, we don't like telling the truth. **Being gossiped that you have HIV is more painful than**

> **somebody just approaching you and telling you, because when they gossip, the news will spread more - IDI, woman, HIV status unknown**

Furthermore, and in consideration as to HIV treatment specifically, not adhering to HIV treatment as prescribed was a common problem that stemmed from gossip along with defaulting on one's medication or no longer attending clinic appointments.

> Some [PLHIV] they end up leaving their medication. **Some of them they don't even come for their appointments because they say what will people say if they, if I go there they will see me, they will talk about me?** Yes, they get sick. I've seen people developing…behind the ears and their legs, they swell. Some of them they change color. If you are white, you started becoming gray, your lips they change color because you don't take your medication properly**…It's the effects of gossip or just gossip itself - IDI, woman, living with HIV**

> My elder sister, **she was going to take ARVs [antiretrovirals] at the clinic and then she started seeing people she knew and they were there, at the village and just talking about her,** saying people were saying that they see that she takes medication, **so she actually stopped going**, she only started going back again when her health had become so bad that she had to go and she didn't care anymore because she was feeling so sick but also that she was getting counselling at the clinic. - **IDI, woman, HIV status unknown**

While individuals may have understood the dangers of not taking their medication, the social implications of gossip were viewed as more detrimental to wellbeing; it would be better to physically die rather than undergo what can be considered a social death.

> **Some people they just ignore [HIV] because they fear of the gossip,** people…they end just ignoring not going to the hospital. **They are just accepting that it's better if I die because even in the hospital, there is a stigma, people they still gossip**. So some people they prefer it that way, **that it is better if l die and not live again in this earth. - IDI, man, HIV status unknown**

> **Some [people] test themselves, but some they just leave it until they die…they don't want people to know their HIV status because they know that people start gossiping,** talking a lot of negative things about them, and again they will start looking back how they used to live their life…**people will be talking about their past life, how they used to live and that they are the one who brought the condition to themselves. - IDI, man, HIV status unknown**

PLHIV face myriad risks by choosing to seek clinical care to maintain their health, and this also meant the increased risk of others seeing them when getting medical care. Preservation of one's self could become a choice between maintaining one's social standing versus their life.

Strategies to Mitigate Gossip and Stigma

Participants identified various ways that gossip could be mitigated and addressed in order to prevent poor psychosocial outcomes and treatment non-adherence among PLHIV. Town/village elders, village leaders, and health care workers were all seen as key individuals who could educate others as to the harmful effects of gossip for PLHIV.

> **Social workers, they are the ones who can manage because it's their duty.** If they come to someone's yard then that person will be free to talk to them, it's not the same as when just a regular person does it. **They are the ones that can help to bring the person back to normal. - IDI, man, living with HIV**
>
> **Tribal leaders can try, social workers**, I don't know what they are called nowadays but yes social workers, they can try to stop gossip. Yes, even the nearest clinic, like where I stay we have a clinic there, **the nurses there can stop gossip, we even advise them that during the teachings they have at the clinics they can teach people about that. - IDI, man, living with HIV**

Other participants felt that instead of placing the burden of intervening solely on people in specific social or professional roles, it was the responsibility of everyone to prevent gossip. These participants felt that having key members of the community, such as elders and healthcare works, step in could exacerbate conflict.

> ...if you have the **responsibility as a parent or as a community member**, having the responsibility, when you find there is gossip, you could intervene. - **IDI, woman, living with HIV**
>
> At the kgotlas (public meetings)…**every single parent who has the responsibility in the community, must intervene.** Then the Dikgosi (tribal chiefs) could be notified, **but l encourage the community not to drag the issue before Dikgosi before they could discuss the issue amongst themselves. This could lead to a conflict, as people, you need to sit and talk and forgive each other. - IDI, woman, living with HIV**

It is important to note that gossip was also considered to be malleable in this setting. While there was a perceived permanence of labels applied via gossip as discussed previously, there were ways participants felt that the consequences of gossip could be circumvented even when the label of HIV had been applied to PLHIV through gossip. Aside from individuals stepping in on behalf of PLHIV, a main theme that emerged was the importance of PLHIV staying healthy and adhering to medication to personally combat gossip and its stigmatizing effects. The ability to maintain one's health and not have physical symptoms of HIV reduced the consequences of past gossip from others.

> It will be forgotten because **I will enroll in ARV treatment, and be a glowing gentleman** like you, you see? Then people will ultimately forget the impact that once happened to you. – **IDI, man, unknown HIV status**

Self-acceptance of one's status was also seen as a critical means of not being affected by gossip on a psychosocial level and of coping with HIV in general.

> I think what could be done is only when one accepts themselves. That is the only way, because once you have accepted yourself you wouldn't care about [gossipers]-**IDI, woman, living with HIV**

> [Gossip] should not deter you if you are determined to live however you want to live. Yes, as long as you have accepted your status [gossip will not affect you]. - **IDI, woman, living with HIV**

PLHIV could feel a sense of freedom in living with HIV given their knowledge of their own status. They also used this knowledge as a way to challenge those who gossiped about them.

> **You will only stop gossiping when you see me glowing, adhering to my treatment, by then it would be you who is sick or has changed.** That is when you would start questioning yourself on why you did that. Because I wouldn't know if I have HIV unless I go for testing. I would feel like, "I know you have HIV", while I don't know about myself! **Once I go to the hospital and get tested for HIV, and I am found to be positive, I will be ashamed, even if I don't tell you, l will be guilt stricken. - IDI, man, HIV status unknown**

> **If it was me, you gossip about my status, l will say to you, "I am better, because l know my status, what about you"?** "Do you know your status? You don't know. You'll

> go before me, because you don’t know your status”. **Me, I am a free person because I know my status - IDI, woman, living with HIV**

5.5 Discussion

Our study elucidates gossip as a mechanism for, as well as a form of stigma, for PLHIV in Botswana. Important precipitators of gossip about HIV included being seen at a health clinic or taking medication, which could lead to subsequent labeling of a person as living with HIV and threaten the person’s autonomy to decide to whom, how, and when to self-disclose their positive status. The harmful psychosocial effects of gossip were understood to hinder testing for HIV, clinical care, and adherence to treatment. Nevertheless, PLHIV in this study also expressed myriad protective factors or coping mechanisms that could empower PLHIV to resist gossip and/or maintain their health despite experiencing gossip.

In our study, the consequences of gossip were described as gendered, in line with previous research (8,9). Multiple studies in other sub-Saharan settings have found women to fear disclosing their HIV status to their partners out of fear of rejection (25). Participants in our study also discussed promiscuity as being attributed to women living with HIV via gossip, which is consistent with findings from studies that pointed to women experiencing more harmful effects of gossip on account of it serving to ascribe immoral behaviors to them (26). Men living with HIV, however, were not unaffected by gossip. Men living with HIV in various settings have expressed fear of gossip due to its threat to their masculinity and social standing, particularly the anticipated impact on their employment(8,27), which is consistent with our finding that gossip could limit men’s ability to fulfill their role of provider as expected in modern Setswana culture.

Our findings also support a common sentiment observed in other studies that women are more likely to discuss social standing and relationships, and thus to gossip(28–30). There is even evidence from South Africa that women will actively choose not to have female friends to avoid gossip, as it is considered to be what “women do”(31). In addition, as was this case in our study, prior research has found men to be adamant about not engaging in gossip (30).

Numerous studies have identified gossip as a barrier to self-disclosure(25,32,33) . Our findings align with these studies as participants living with HIV in our study expressed a desire to conceal their status due to the potential outcome of gossip. In addition, some participants wanted the freedom to share their HIV status on their own terms and not have it be revealed via gossip, thus leading to stigma. These first two points can be informed by the Disclosure Process Model, which posits that negative experiences with disclosure, such as rejection and stigma, may lead to more concealment of one’s status in the future (34). The exclusionary practices toward PLHIV in Botswana is evident of gossip being used as a signal to them that they now viewed as “other” within their communities (35). These negative experiences include the psychosocial implications of gossip as expressed in this study to include stress, low self-worth, and even preferring to die rather than seek treatment. As suggested in our findings as well, other studies have also conceptualized gossip as a form of a social death sentence for PLHIV given the resulting ostracization (36).

Notwithstanding, participants in this study were clear about the importance of self-acceptance and self-disclosure as a means of coping with their HIV status as well as combating gossip. The act of self-disclosing to mitigate gossip has been found to be a critical strategy to combat stigma for PLHIV in multiple sub-Saharan African countries(37). Self-disclosing as a means of disrupting gossip was only one of many ways participants felt that gossip could be addressed, as various actors in the community were seen as key individuals to address gossip. Therefore, not all participants living with HIV were powerless in the face of gossip, with self-disclosure and self-acceptance of one’s status being key forms of resilience. Positive social support that enables valuing oneself and the ability to cope with an HIV diagnosis has been demonstrated in various studies as a core mechanism in the resistance of stigma for PLHIV(38–40).

The findings of this work must be considered in light of several limitations. First, recruitment and data collection for this study took place in a singular location, Gaborone. Despite the majority of Botswana's population living within 100 kilometers of Gaborone, interpretations of our findings may not be reflective of the experiences of those in rural areas of the country. We also acknowledge that our participants tended to be older, thus this study was unable to equally capture the perspectives of young adults living with HIV, an age group that requires more attention in Botswana (6). Finally, known PLHIV who participated in our study were recruited from an HIV clinic. As these participants had to currently be receiving HIV care at the time of the study, and due to us not asking general community members about their status, we are missing the perspectives of PLHIV who are at different points of HIV testing and treatment and who are not seeking care due to factors such as stigma.

Conclusion

Our study adds to prior literature that has demonstrated stigma to be an important barrier to HIV care and a social determinant of mental and physical health by providing a nuanced examination of gossip as mechanism and form of stigma against PLHIV. Botswana has one of the highest rates of HIV in the world, and while the country has made critical gains in addressing the HIV epidemic from a biomedical perspective, HIV stigma remains common(8,9). While it is known that stigma is a barrier to HIV care in that it can lead to diminished quality of life, poor mental health, and higher mortality(2), our study emphasizes the role of gossip specifically. Our study is uniquely positioned to inform both the biomedical and psychosocial implications of gossip for PLHIV in Botswana by eliciting both risk and protective factors for gossip about HIV. Critical next steps for research and practice include incorporating support for PLHIV into existing HIV services to specifically resist gossip and advocating for the protections of PLHIV from gossip through community awareness and policy change.

Table 5.1. Sociodemographic Characteristics of Participants in Gaborone, Botswana

Demographic Characteristic	**Full sample (*N* = 84)**		**Women (*n* = 43)**		**Men (*n* = 41)**	
	n	**%**	***n***	**%**	***n***	**%**
HIV status						
Living with HIV	45	*53.6*	24	*55.8*	21	*51.2*
HIV status unknown	39	*46.4*	19	*44.2*	20	*48.8*
Age (Mean, SD)	(41.8, 13.1)		(42.2, 12.5)		(41.4, 14.1)	
Education						
Less than 7 years (< Form 1)	17	*20.2*	7	*16.3*	10	*24.4*
More than 7 years (≥ Form 1)	54	*64.3*	29	*67.4*	25	*61.0*
Unknown	13	*15.5*	7	*16.3*	6	*14.6*
Employment						
Unemployed	29	*34.5*	20	*46.5*	9	*22.0*
Employed or Self-Employed	43	*51.2*	14	*32.6*	29	*70.7*
Retired	1	*1.2*	0	-	1	*2.4*
Unknown	11	*13.1*	9	*20.9*	2	*4.9*
Relationship status						
Married or Cohabitating	21	*25.0*	8	*18.6*	13	*31.7*
Single	43	*51.2*	24	*55.8*	19	*46.4*
Partnered	12	*14.3*	6	*14.0*	6	*14.6*
Unknown	8	*9.5*	5	*11.6*	3	*7.3*
Children (Mean, SD)*	(2.2, 1.0)		(2.2, 1.1)		(2.2, 1.0)	

5.6 References

1. Mahajan AP, Sayles JN, Patel VA, Remien RH, Ortiz D, Szekeres G, et al. Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. AIDS. 2008 Aug;22(Suppl 2):S67–79.

2. Pescosolido BA, Martin JK, Lang A, Olafsdottir S. Rethinking theoretical approaches to stigma: a Framework Integrating Normative Influences on Stigma (FINIS). Soc Sci Med. 2008 Aug;67(3):431–40.

3. Stangl AL, Earnshaw VA, Logie CH, van Brakel W, C. Simbayi L, Barré I, et al. The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. BMC Medicine. 2019 Feb 15;17(1):31.

4. Thapa S, Hannes K, Cargo M, Buve A, Peters S, Dauphin S, et al. Stigma reduction in relation to HIV test uptake in low- and middle-income countries: a realist review. BMC Public Health. 2018 Nov 20;18(1):1277.

5. Ramogola-Masire D, Poku O, Mazhani L, Ndwapi N, Misra S, Arscott-Mills T, et al. Botswana’s HIV response: Policies, context, and future directions. Journal of Community Psychology. 2020;48(3):1066–70.

6. AVERT. HIV and AIDS in Botswana [Internet]. Avert. 2019 [cited 2020 Feb 18]. Available from: https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/botswana

7. Kandala N-B, Campbell EK, Rakgoasi SD, Madi-Segwagwe BC, Fako TT. The geography of HIV/AIDS prevalence rates in Botswana. HIV AIDS (Auckl). 2012 Jul 18;4:95–102.

8. Misra S, Mehta HT, Eschliman EL, Rampa S, Poku OB, Wang W-Q, et al. Identifying "What Matters Most" to Men in Botswana to Promote Resistance to HIV-Related Stigma. Qual Health Res. 2021 Mar 25;10497323211001360.

9. Yang L, Poku O, Misra S, Mehta H, Rampa S, Eisenberg MM, et al. Stigma, Structural Vulnerability, and "What Matters Most" Among Women Living with HIV in Botswana, 2017. American Journal of Public Health. 2021 (accepted)

10. Rakgoasi S, Odimegwu C. "Women get Infected but Men Die ...!" Narratives on Men , Masculinities and HIV/AIDS in Bostwana. International Journal of Men's Health. 2013 Aug 15;12:166–82.

11. Treves-Kagan S, Steward WT, Ntswane L, Haller R, Gilvydis JM, Gulati H, et al. Why increasing availability of ART is not enough: a rapid, community-based study on how HIV-related stigma impacts engagement to care in rural South Africa. BMC Public Health. 2016 Jan 28;16(1):87.

12. Becker TD, Ho-Foster AR, Poku OB, Marobela S, Mehta H, Cao DTX, et al. "it's when the trees blossom": Explanatory beliefs, stigma, and mental illness in the context of HIV in Botswana. Qual Health Res. 2019;29(11):1566–80.

13. Abdoli A. Gossip, Rumors, and the COVID-19 Crisis. Disaster Med Public Health Prep. 2020 Aug;14(4):e29–30.

14. Hall KS, Manu A, Morhe E, Dalton VK, Challa S, Loll D, et al. Bad girl and unmet family planning need among Sub-Saharan African adolescents: the role of sexual and reproductive health stigma. Qual Res Med Healthc. 2018 May 30;2(1):55–64.

15. Moses T. Being treated differently: Stigma experiences with family, peers, and school staff among adolescents with mental health disorders. Social Science & Medicine. 2010 Apr 1;70(7):985–93.

16. Smith LC, Lucas KJ, Latkin C. Rumor and gossip: Social discourse on HIV and AIDS. Anthropology & Medicine. 1999 Apr 1;6(1):121–31.

17. Maleke K, Daniels J, Lane T, Struthers H, McIntyre J, Coates T. How social stigma sustains the HIV treatment gap for MSM in Mpumalanga, South Africa. Glob Health Promot. 2019 Dec;26(4):6–13.

18. Rodriguez-Hart C, Bradley C, German D, Musci R, Orazulike I, Baral S, et al. The Synergistic Impact of Sexual Stigma and Psychosocial Well-Being on HIV Testing: A Mixed-Methods Study Among Nigerian Men who have Sex with Men. AIDS Behav. 2018 Dec;22(12):3905–15.

19. Yang LH, Kleinman A, Link BG, Phelan JC, Lee S, Good B. Culture and stigma: adding moral experience to stigma theory. Soc Sci Med. 2007 Apr;64(7):1524–35.

20. Poku O, Becker T, Ho-Foster A, Rampa S, Entaile P, Yang L, et al. Reflections on Qualitatively Investigating HIV and Mental Illness Stigma in Botswana With a Multicultural and Multinational Team [Internet]. 1 Oliver's Yard, 55 City Road, London EC1Y 1SP United Kingdom: SAGE Publications Ltd; 2020 [cited 2021 May

8]. Available from: https://methods.sagepub.com/case/reflections-qualitatively-investigating-hiv-mental-illness-stigma-botswana

21. Yang LH, Purdie-Vaughns V, Kotabe H, Link BG, Saw A, Wong G, et al. Culture, threat, and mental illness stigma: Identifying culture-specific threat among Chinese-American groups. Social Science & Medicine. 2013 Jul 1;88:56–67.

22. Yang LH, Chen F-P, Sia KJ, Lam J, Lam K, Ngo H, et al. “What matters most:” a cultural mechanism moderating structural vulnerability and moral experience of mental illness stigma. Soc Sci Med. 2014 Feb;103:84–93.

23. Yang LH, Thornicroft G, Alvarado R, Vega E, Link BG. Recent advances in cross-cultural measurement in psychiatric epidemiology: utilizing “what matters most” to identify culture-specific aspects of stigma. Int J Epidemiol. 2014 Apr;43(2):494–510.

24. Link BG, Cullen FT, Struening E, Shrout PE, Dohrenwend BP. A modified labeling theory approach to mental disorders: An empirical assessment. Am Sociol Rev. 1989;54(3):400

25. Knettel BA, Minja L, Chumba LN, Oshosen M, Cichowitz C, Mmbaga BT, et al. Serostatus disclosure among a cohort of HIV-infected pregnant women enrolled in HIV care in Moshi, Tanzania: A mixed-methods study. SSM Popul Health. 2019;7(100323):007–007.

26. Bond V, Chase E, Aggleton P. Stigma, HIV/AIDS and prevention of mother-to-child transmission in Zambia. Evaluation and program planning. 2002;25:347–56.

27. Siu GE, Wight D, Seeley J. ‘Dented’ and ‘Resuscitated’ masculinities: The impact of HIV diagnosis and/or enrolment on antiretroviral treatment on masculine identities in rural eastern Uganda. SAHARA J. 2014 Jan 2;11(1):211–21.

28. McAndrew FT. The “sword of a woman”: Gossip and female aggression. Aggression and Violent Behavior. 2014 May 1;19(3):196–9.

29. Davis AC, Dufort C, Desrochers J, Vaillancourt T, Arnocky S. Gossip as an Intrasexual Competition Strategy: Sex Differences in Gossip Frequency, Content, and Attitudes. Evolutionary Psychological Science. 2018 Jun 1;4(2):141–53.

30. Eckhaus E, Ben-Hador B. Gossip and gender differences: A content analysis approach. Journal of Gender Studies. 2019 Jan;28(1):97–108.

31. Jewkes R, Morrell R. Sexuality and the limits of agency among South African teenage women: theorising femininities and their connections to HIV risk practices. Soc Sci Med. 2012 Jun;74(11):1729–37.

32. Neville Miller A, Rubin DL. Factors Leading to Self-Disclosure of a Positive HIV Diagnosis in Nairobi, Kenya: People Living With HIV/AIDS in the Sub-Sahara. Qual Health Res. 2007 May;17(5):586–98.

33. Root R. Situating experiences of HIV-related stigma in Swaziland. Global Public Health. 2010 Sep;5(5):523–38.

34. Chaudoir SR, Fisher JD. The disclosure processes model: Understanding disclosure decision-making and post-disclosure outcomes among people living with a concealable stigmatized identity. Psychol Bull. 2010 Mar;136(2):236–56.

35. Kako PM, Dubrosky R. "You Comfort Yourself and Believe in Yourself": Exploring Lived Experiences of Stigma in HIV-Positive Kenyan Women. Issues in Mental Health Nursing. 2013 Mar 5;34(3):150–7.

36. Aarnio P, Olsson P, Chimbiri A, Kulmala T. Male involvement in antenatal HIV counseling and testing: exploring men's perceptions in rural Malawi. AIDS Care. 2009 Dec;21(12):1537–46.

37. Makoae LN, Greeff M, Phetlhu RD, Uys LR, Naidoo JR, Kohi TW, et al. Coping with HIV/AIDS Stigma in Five African Countries. J Assoc Nurses AIDS Care. 2008;19(2):137–46.

38. Goudge J, Ngoma B, Manderson L, Schneider H. Stigma, identity and resistance among people living with HIV in South Africa. SAHARA J. 2009 Nov;6(3):94–104.

39. Gilbert L, Walker L. "My biggest fear was that people would reject me once they knew my status...": stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg, South Africa. Health Soc Care Community. 2010 Mar;18(2):139–46.

40. Abrahams N, Jewkes R. Managing and resisting stigma: a qualitative study among people living with HIV in South Africa. J Int AIDS Soc. 2012;15(2):17330

Chapter 6: Discussion

The purpose of this dissertation was to consider the need for more psychosocially informed approaches to addressing the HIV/AIDS epidemic in SSA. There is a paucity of studies that examine the intersections of disclosure- whether intentional, inadvertent, or without consent- stigma, and mental health among both adult PLHIV and ALWH. With the majority of HIV and mental health research in SSA concentrated on adults, this dissertation also sought to provide an overview of gaps and opportunities for advancing understanding of the mental health needs of ALWH by taking disclosure of HIV status into greater consideration. Therefore, this dissertation:

1: *Conducted a scoping review that examines the relationships between mental health and the HIV Care Continuum for ALWH in SSA* (Chapter 3)

2: *Characterized patterns of disclosure and their relationship to mental health among ALWH in Uganda (Chapter 4)*

3: *Qualitatively assessed how gossip eliminates the choice to self-disclose one's HIV status in Botswana (Chapter 5)*

6.1 Summary and Implications of Findings

In Chapter 3, we examined the relationship between mental health and engagement in treatment across the HIV care continuum, and our main findings were that the mental health of ALWH was primarily assessed at the "Engaged or Retained in Care" step of the continuum in studies that took place prior to the implementation of Universal Test and Treat policies. More adolescents are acquiring HIV in SSA through horizontal transmission (1), which exacerbates the need for understanding the intersection of HIV and mental health during HIV testing, treatment initiation, and adherence phases of care. Given observed associations between depression and anxiety and sustained treatment for ALWH (2,3), there are clear gaps in when adolescents are having their mental health assessed, let alone addressed, in the continuum. The predominance of cross-sectional studies in particular limits our ability to draw strong inferences about how mental health shapes engagement in the care continuum and vice versa, which is needed to inform public health efforts. For instance, the emphasis on understanding the impact of mental health on treatment adherence is of great importance, given that older adolescents (i.e. ages 15-19) (4,5) will be transitioning into adult care which requires more autonomy and self-efficacy to navigate their HIV treatment (6,7). The prevalence of mental health measures conceptualized in high income countries with limited adaptation and validation within SSA speaks to a reliance on using existing tools with limited attention to rigor and evaluation. While many studies do assess mental health broadly for ALWH in SSA, this overreliance on tools from high income settings can lead to spurious results (3) that further impede addressing the limited access to mental health care for ALWH in SSA (8–10).

Our finding in Chapter 4 that ALWH were most frequently choosing to disclose to nuclear family members aligns with the few studies that do exist on disclosure choices made by adolescents (2,11). A majority of ALWH in SSA are known to have disclosed more to family members then to peers and partners (2). There are mixed results from the literature stemming from SSA as to whether disclosing to one’s family versus others is a better decision in terms of one’s psychosocial wellbeing (2,12). A study from Kenya posited that ALWH may perceive more stigma and discrimination from family then peers, and as such disclosure to one’s family was thought to have led to higher rates of depression (2). We found an association between depression for ALWH in Uganda (Chapter 4) who chose to self-disclose to anyone versus not self-disclose their HIV status and to a brother(s) versus not to a brother. Studies from South Africa, Tanzania, and Zambia have found that family is the most important source from which to draw social support for ALWH, as fear of gossip and other forms of stigma are commonplace (12–14)5/24/21 10:09:00 PM.

In Chapter 5, the exploration of gossip as stigma for adults living with HIV in Botswana was undertaken to better understand disclosure in all forms as a psychosocial factor important in the HIV epidemic response and how the concepts of disclosure and stigma may overlap in complex ways. Our findings make a meaningful contribution to the existing literature by highlighting gossip as both a marker of living with HIV and as a form of HIV stigma in of itself. By utilizing the What Matters Most theoretical framework to qualitatively explore the cultural nuances of HIV stigma, we found that participants expressed challenges related to stigma associated with multiple forms of disclosure: self-disclosure, inadvertent disclosure, and disclosure without their consent. Many described the subsequent gossip that derived from being seen at a clinic and how gossip about one's status was a driver for social isolation. The fear of gossip from others was evident in the decision to avoid seeking clinical care for HIV and resisting care to circumvent a "social death" that came with others knowing one's HIV status, a theme found in other studies on disclosure from SSA as well (15). Gossip is a widely attributed reason for PLHIV choosing not to self-disclose their HIV status and widely cited fear expressed by both ALWH and adults living with HIV, as gossip can threaten one's social status (16,17). In our study from Botswana, the fear of gossip as stigma led to various stressors that had clear perceived psychosocial and mortality-related outcomes. Experiences of gossip also highlighted the significance of social support and importance of self-acceptance to resist stigma for participants.

Together, Chapters 3-5 of this dissertation contribute to the literature by demonstrating a need for concerted attention as to the social dynamics of HIV, particularly with regards to joint efforts to address disclosure, stigma, and mental health, given their overlap. For ALWH, we found that there was little evidence that consideration for mental health was being integrated into HIV treatment across critical steps in care at present, which has implications for the already limited youth HIV and psychosocial support services available in SSA (8,9) . We were also able to examine how ALWH's choice of whom to self-disclose their HIV status to has the potential for differential association with mental health outcomes in our exploratory analysis. In this population in particular, there is a need to move beyond disclosure of parents to adolescents about their status and a focus on disclosure between partners to support adolescents as they gain autonomy in navigating their life with HIV (2). Furthermore, we were able to elucidate the operationalization of gossip in Botswana and how disclosure without one's consent can be especially harmful to the psychosocial wellbeing of PLWH. This points to continued gaps in addressing the relationship between stigma and its mental health consequences for adults living with HIV that as a next step should be examined among ALWH, as well.

Thus, from a life course approach, this research details psychosocial challenges that ALWH can experience, while making clear the need for enhanced support that remains limited for adults living with HIV in SSA. Overall, this work as a whole points to how the importance of psychosocial factors cannot be understated when it comes to living with a stigmatized health condition and resisting negative treatment from others across the life course.

6.2 Limitations

The findings of this dissertation should be considered in light of several limitations. First, the findings for Chapters 4 stem from a secondary analysis of existing data. Therefore, the findings from this chapter come from a study that was not designed to answer the central aims of this chapter. The use of secondary data resulted in a small sample size that limits our ability to draw definitive conclusions from the analyses, and thus we consider these findings exploratory. Given differences in culture and the context of HIV treatment, generalizability to ALWH who are not residing in Uganda is likely limited. It is also possible that by grouping adolescents together from ages 10-19 in Chapter 4 (as well as in Chapter 3), done based on lack of sufficient data or evidence within age group for stratified analysis, these two chapters may mask significant heterogeneity in experiences within the adolescent developmental period.

The qualitative study on gossip (Chapter 5) is not restricted to adolescents and mainly consists of individuals who are not adolescents or young adults. Therefore, the results of this aim are speculative as to how they can apply to a younger population. Yet, the unique emphasis on gossip through a theoretical assessment of stigma can inform subsequent work that considers gossip as a stigmatizing mechanism among AWLH. Chapter 5 also draws from a study in which participants were recruited from only one location and the results may not reflect PLHIV in rural areas of Botswana. Recruiting PLHIV who were currently engaged in care also means that the perspectives captured in Chapter 5 are not informative of individuals who are at different points in their HIV treatment.

6.3 Implications for Future Research

The results from this dissertation are suggestive of various ways in which future studies can advance the understanding of disclosure, stigma, and mental health in SSA. There is a scarcity of research looking at the relationship between mental health and HIV care for PLHIV at the testing, treatment initiation, adherence, and viral suppression stages of care (18,19). It is essential to contextualize whether mental disorders are more severe at different points along the

HIV Care Continuum, if mental disorders may be more or less disruptive to engaging in the care continuum at different points, and whether different disorders may be more prevalent at different continuum steps (20). It would be of further importance to couple mental health assessments with qualitative methods to understand specific life stressors associated with presentation of mental symptoms at different junctures of HIV treatment and how these stressors may be informed by developmental life stage.

Research that can better inform the psychosocial factors that shape mental health and quality of life for PLWH at these different points of HIV treatment are also needed, given what we have observed around the intersection of mental health with issues of disclosure and stigma among adolescents and adults living with HIV in this dissertation. The reasons as to why certain individuals are more likely to be disclosed to versus others can enable better programs for supporting disclosure through engagement with specified individuals of importance (2). Confirming the characteristics of said individuals and how disclosure to them informs associations with mental health should be done among large cohorts of PLHIV to also consider key sociodemographic factors. Having culturally and contextually appropriate measures for this purpose can improve resources that promote self-disclosure. Utilizing qualitative research to truly understand the mechanism of different types of HIV stigma in specific settings and across the life course would allow for the conceptualization of culturally valid measurements to inform HIV stigma reduction in SSA. Measurement development more broadly in SSA is also needed for mental health and stigma (21). Recent work for HIV stigma in Botswana can serve as a model for scale development and outlines a replicable process by which other countries and populations could have more accurate tools by which to measure the psychosocial aspects of HIV(22).

6.4 Implications for Practice

This dissertation exemplifies the need for the integration of psychosocial support that can address multiple, interrelated psychosocial factors into HIV treatment research, programing, and policy agendas in SSA. More provider training and task sharing models for dedicated mental health services for PLHIV would lead to multiple sources of support to mitigate poor psychopathology, in a setting in which there are limited existing resources (23). Additionally, increasing the cadre of mental health professionals focused on ALWH and their transition to adult care would provide ample opportunity to reduce their risk for mental disorders during this critical developmental period (23,24). Increasing access to HIV peer support programs could be especially useful for ALWH, as there is evidence that having established peer models specifically to establish groups of ALWH can be fundamental to having built in social support as they transition to adult HIV care (25).

Initiatives to advance the lives of PLHIV must also consider the multidimensional experiences of disclosure and stigma (26–28). As the 95-95-95 Goals call for the elimination of discrimination against PLHIV (29), there are many individual level factors that need to be advanced in terms of addressing the social challenges of living with HIV. Both clinic and community-based approaches could incorporate working with both adolescents and adults to identify trusted individual to whom to disclose (12,30). A built-in system within HIV treatment that encourages and engages with important individuals in the lives of PLHIV could lead to a sustained support system being put in place to help resist poor psychosocial outcomes that can stem from experiences of stigma (25,31). There is also a need for structural protections in place for PLHIV that would improve the landscape in which the legalization of punishing for non-disclosure would be eliminated (25,32). HIV testing and counseling could be contextually informed to provide newly diagnosed PLHIV with evidence-based supports to help thrive in their communities and remain adherent to care during a known period in which many PLHIV choose not to initiate care. Clinical counselling and community-based support programs, especially in the form of support groups for PLHIV, could be essential in instilling a sense of self-worth and connecting PLHIV to multiple resources for obtaining diverse forms of support (25,32)

The journey from HIV diagnosis to viral suppression can be arduous, and at multiple points along this treatment continuum, individuals may stop and re-initiate care (33). Adolescents who were perinatally infected may also struggle to navigate adult care once they are expected to independently manage their treatment (34). Disengagement in HIV treatment causes worse HIV prognosis and can result in multiple co-morbidities (35,36) . When PLHIV return to treatment, more complex and expensive clinical regimes may be required to reduce the impacts of the virus (37). More recognition of the utility of social support as a protective factor against treatment non-adherence is needed for PLHIV (36). The ways disclosure, stigma, and mental health are profoundly impactful in the relationship between support and treatment should be the next frontier of addressing the HIV epidemic.

In summary, both separately and compounded, disclsoure, stigma and mental health are known psychosocial factors that place PLHIV at a higher liklihood of reduced overall quality of life and non-adherence to HIV treatment across the life course (28,38). Therefore, access to treatment alone is only a core piece of addressing the epidemic in SSA, where concentrated attention is needed in order to make global progress towards ending the HIV/AIDS epidemic (39). As health disparities and access to treatment can be driven by stigma and discrimination, this goal is likely not achievable without attention being paid to the psychosocial mechanisms of HIV (40). Accordingly, the research presented in this dissertation is grounded in the argument that the end of the epidemic cannot and will not be achieved without utilization of a biopsychosocial theoretical framework.

6.5 References

1. Slogrove AL, Sohn AH. The global epidemiology of adolescents living with HIV: Time for more granular data to improve adolescent health outcomes. Curr Opin HIV AIDS. 2018 May;13(3):170–8.

2. Mugo C, Seeh D, Guthrie B, Moreno M, Kumar M, John-Stewart G, et al. Association of experienced and internalized stigma with self-disclosure of HIV status by youth living with HIV. AIDS Behav [Internet]. 2021 Jan 3 [cited 2021 Apr 27]; Available from: http://link.springer.com/10.1007/s10461-020-03137-0

3. Vreeman RC, McCoy BM, Lee S. Mental health challenges among adolescents living with HIV. J Int AIDS Soc [Internet]. 2017 May 16 [cited 2020 Feb 18];20(Suppl 3). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5577712/

4. WHO | Very young adolescents [Internet]. WHO. World Health Organization; [cited 2021 May 7]. Available from: https://www.who.int/reproductivehealth/topics/adolescence/very_young_ados/en/

5. WHO. Adolescent Health [Internet]. Available from: https://www.who.int/southeastasia/health-topics/adolescent-health

6. Lall P, Lim SH, Khairuddin N, Kamarulzaman A. Review: an urgent need for research on factors impacting adherence to and retention in care among HIV-positive youth and adolescents from key populations. J Int AIDS Soc. 2015;18(2 Suppl 1):19393.

7. Hussen SA, Andes K, Gilliard D, Chakraborty R, Del Rio C, Malebranche DJ. Transition to adulthood and antiretroviral adherence among HIV-positive young Black men who have sex with men. Am J Public Health. 2015 Apr;105(4):725–31.

8. Kutcher S, Perkins K, Gilberds H, Udedi M, Ubuguyu O, Njau T, et al. Creating Evidence-Based Youth Mental Health Policy in Sub-Saharan Africa: A Description of the Integrated Approach to Addressing the Issue of Youth Depression in Malawi and Tanzania. Front Psychiatry [Internet]. 2019 [cited 2021 May 11];10. Available from: https://www.frontiersin.org/articles/10.3389/fpsyt.2019.00542/full

9. Juma K, Wekesah FM, Kabiru CW, Izugbara CO. Burden, Drivers, and Impacts of Poor Mental Health in Young People of West and Central Africa: Implications for Research and Programming. In: McLean ML, editor. West African Youth Challenges and Opportunity Pathways [Internet]. Cham: Springer International Publishing; 2020 [cited 2021 May 11]. p. 233–65. (Gender and Cultural Studies in Africa and the Diaspora). Available from: https://doi.org/10.1007/978-3-030-21092-2_11

10. Parcesepe AM, Bernard C, Agler R, Ross J, Yotebieng M, Bass J, et al. Mental health and HIV: research priorities related to the implementation and scale up of ‘treat all’ in sub-Saharan Africa. J Virus Erad. 4(Suppl 2):16–25.

11. Gabbidon K, Chenneville T, Peless T, Sheared-Evans S. Self-Disclosure of HIV Status Among Youth Living with HIV: A Global Systematic Review. AIDS Behav. 2020 Jan;24(1):114–41.

12. Madiba S, Mokgatle M. Perceptions and Experiences about Self-Disclosure of HIV Status among Adolescents with Perinatal Acquired HIV in Poor-Resourced Communities in South Africa. AIDS Res Treat [Internet]. 2016 [cited 2021 May 11];2016. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5031873/

13. Mburu G, Hodgson I, Kalibala S, Haamujompa C, Cataldo F, Lowenthal ED, et al. Adolescent HIV disclosure in Zambia: barriers, facilitators and outcomes. Journal of the International AIDS Society. 2014;17(1):18866.

14. Daniel M. Keeping the secret: how HIV-positive children in Iringa, Tanzania, respond to the perceived need for silence and secrecy. Journal of Child & Adolescent Mental Health. 2015 Jan 2;27(1):11–23.

15. Aarnio P, Olsson P, Chimbiri A, Kulmala T. Male involvement in antenatal HIV counseling and testing: exploring men’s perceptions in rural Malawi. AIDS Care. 2009 Dec;21(12):1537–46.

16. Abrahams N, Jewkes R. Managing and resisting stigma: a qualitative study among people living with HIV in South Africa. J Int AIDS Soc [Internet]. 2012 Aug 13 [cited 2021 Apr 26];15(2). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3494166/

17. Kimera E, Vindevogel S, Reynaert D, Justice KM, Rubaihayo J, Maeyer JD, et al. Experiences and effects of HIV-related stigma among youth living with HIV/AIDS in Western Uganda: A photovoice study. PLOS ONE. 2020 Apr 24;15(4):e0232359.

18. Chartier M, Maier M. Engagement Along the HIV Care Continuum and the Potential Role f Mental Health and Substance Use Disorders. Fed Pract. 2015 Feb;32(Suppl 2):10S-14S.

19. Remien RH, Stirratt MJ, Nguyen N, Robbins RN, Pala AN, Mellins CA. Mental health and HIV/AIDS: the need for an integrated response. AIDS. 2019 Jul 15;33(9):1411–20.

20. Wood SM, Dowshen N, Lowenthal E. Time to Improve the Global Human Immunodeficiency Virus/AIDS Care Continuum for Adolescents. JAMA Pediatr. 2015 Jul 1;169(7):619–20.

21. Odimegwu CO, Akinyemi JO, Alabi OO. HIV-Stigma in Nigeria: Review of Research Studies, Policies, and Programmes. AIDS Research and Treatment. 2017 Dec 27;2017:e5812650.

22. Yang LH, Ho-Foster AR, Becker TD, Misra S, Rampa S, Poku OB, et al. Psychometric Validation of a Scale to Assess Culturally-Salient Aspects of HIV Stigma Among Women Living with HIV in Botswana: Engaging "What Matters Most" to Resist Stigma. AIDS Behav. 2021 Feb;25(2):459–74.

23. Bhana A, Abas MA, Kelly J, van Pinxteren M, Mudekunye LA, Pantelic M. Mental health interventions for adolescents living with HIV or affected by HIV in low- and middle-income countries: systematic review. BJPsych Open [Internet]. 2020 Sep 4 [cited 2021 Apr 27];6(5). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7488323/

24. Laurenzi CA, Skeen S, Gordon S, Akin-Olugbade O, Abrahams N, Bradshaw M, et al. Preventing mental health conditions in adolescents living with HIV: an urgent need for evidence. J Int AIDS Soc [Internet]. 2020 Aug 31 [cited 2021 May 10];23(Suppl 5). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7459172/

25. Mark D, Hrapcak S, Ameyan W, Lovich R, Ronan A, Schmitz K, et al. Peer Support for Adolescents and Young People Living with HIV in sub-Saharan Africa: Emerging Insights and a Methodological Agenda. Curr HIV/AIDS Rep. 2019 Dec;16(6):467–74.

26. Yang H, Li X, Stanton B, Fang X, Lin D, Naar-King S. HIV-related knowledge, stigma, and willingness to disclose: A mediation analysis. AIDS Care. 2006 Oct;18(7):717–24.

27. Obermeyer CM, Baijal P, Pegurri E. Facilitating HIV Disclosure Across Diverse Settings: A Review. Am J Public Health. 2011 Jun;101(6):1011–23.

28. Rueda S, Mitra S, Chen S, Gogolishvili D, Globerman J, Chambers L, et al. Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. BMJ Open. 2016 Jul 1;6(7):e011453.

29. Fast Track UNAIDS. [Internet]. 2014 [cited 2021 9 May]. Available from: https://www.unaids.org/sites/default/files/media_asset/90-90-90_en.pdf

30. Grainger C. Understanding disclosure behaviours in HIV-positive young people. J Infect Prev. 2017 Jan;18(1):35–9.

31. Willis N, Milanzi A, Mawodzeke M, Dziwa C, Armstrong A, Yekeye I, et al. Effectiveness of community adolescent treatment supporters (CATS) interventions in improving linkage and retention in care, adherence to ART and psychosocial well-being: a randomised trial among adolescents living with HIV in rural Zimbabwe. BMC Public Health. 2019 Jan 28;19(1):117.

32. Mburu G, Ram M, Skovdal M, Bitira D, Hodgson I, Mwai GW, et al. Resisting and challenging stigma in Uganda: the role of support groups of people living with HIV. Journal of the International AIDS Society. 2013;16(3S2):18636.

33. Kay ES, Batey DS, Mugavero MJ. The HIV treatment cascade and care continuum: updates, goals, and recommendations for the future. AIDS Research and Therapy. 2016 Nov 8;13(1):35.

34. Ritchwood TD, Malo V, Jones C, Metzger IW, Atujuna M, Marcus R, et al. Healthcare retention and clinical outcomes among adolescents living with HIV after transition from pediatric to adult care: a systematic review. BMC Public Health. 2020 Aug 3;20(1):1195.

35. Fielden SJ, Rusch MLA, Yip B, Wood E, Shannon K, Levy AR, et al. Nonadherence Increases the Risk of Hospitalization Among HIV-Infected Antiretroviral Naïve Patients Started on HAART. Journal of the International Association of Physicians in AIDS Care. 2008 Sep;7(5):238–44.

36. Iacob SA, Iacob DG, Jugulete G. Improving the Adherence to Antiretroviral Therapy, a Difficult but Essential Task for a Successful HIV Treatment—Clinical Points of View and Practical Considerations. Front Pharmacol [Internet]. 2017 Nov 23 [cited 2020 Mar 7];8. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5703840/

37. Burns R, Borges J, Blasco P, Vandenbulcke A, Mukui I, Magalasi D, et al. ‘I saw it as a second chance’: A qualitative exploration of experiences of treatment failure and regimen change among people living with HIV on second- and third-line antiretroviral therapy in Kenya, Malawi and Mozambique. Global Public Health. 2019 Aug 3;14(8):1112–24.

38. Nabunya P, Byansi W, Sensoy Bahar O, McKay M, Ssewamala FM, Damulira C. Factors Associated With HIV Disclosure and HIV-Related Stigma Among Adolescents Living With HIV in Southwestern Uganda. Front Psychiatry [Internet]. 2020 [cited 2021 Apr 21];11. Available from: https://www.frontiersin.org/articles/10.3389/fpsyt.2020.00772/full

39. Cohen MA. Biopsychosocial approach to the human immunodeficiency virus epidemic. A clinician's primer. Gen Hosp Psychiatry. 1990 Mar;12(2):98–123.

40. SDGs | UNAIDS [Internet]. [cited 2021 May 9]. Available from: https://www.unaids.org/en/SDGs

Supplementary Materials

Appendix A: Pre-UTT Study Findings

Study	**Key Results**
Abubakar et al., 2017	• Analysis indicated a main effect of HIV status on mean BDI scores in HIV-infected (18.4 [SD = 8.3) and HIV-affected (16.8 [SD = 7.3]) adolescents compared to the community controls (12.0 [SD = 7.9]), F (2, 127) = 6.704, P < .002, η2 = .095; Post hoc analysis showed that scores of HIV-infected adolescents were higher than those of community controls (P < .001) • HIV-affected adolescents had scores that were higher than those of the community controls (P = .007), but there was no difference between HIV-infected and HIV-affected adolescents (P = .304) • Results of path analytic model showed that the high scores for depression of the adolescents could largely be attributed to the level of cumulative psychosocial risk experienced; Path estimates in table 2: Maternal HIV status -> Psychosocial risk (Estimate:0.560; SE:0.055; Est./S.E:10.14; P: 0.000); Child HIV status -> nutritional status (Estimate: Estimate: 0.382; SE: 0.075; Est/SE: –5.06; P:0.000); Psychosocial risk -> BDI score (Estimate: 0.242; SE: 0.081; Est/SE: 2.98; P: 0.003) • The impact of maternal HIV status was fully mediated by psychosocial risk, while the impact of the adolescent's HIV status was partially mediated by psychosocial risk. Nutritional status did not have a significant role in predicting BDI scores
Adeyemo et al., 2019	• The lifetime prevalence of suicidal ideation was 33.3% (n = 67) while the prevalence rate of cur-rent suicidal ideation was 14.9% (n = 30) • In the regression model, having lost a family member was the only variable associated with current suicidal ideation (B: 1.570; SE: 0.536; WALD: 8.568; p=0.003, OR =4.807, 95% CI 1.680-13.757 • No statistically significant associations of lifetime suicidal ideation
Ashaba et al., 2018	• Thirty-seven participants (16%) had major depressive disorder, 30 (13%) had suicidality, and nine (4%) had high-risk suicidality • In multivariable logistic regression models, major depressive disorder had a statistically significant association with bullying (AOR = 1.09; 95% CI 1.00–1.20; p = 0.04); while suicidality (low, moderate, high risk) had statistically significant associations with both bullying (AOR = 1.09; 95% CI 1.01–1.17; p = 0.02) and stigma (AOR = 1.30; 95% CI 1.03–1.30; p = 0.02)
Betancourt et al., 2014	• Model 1 is the unadjusted model; HIV-positive: CESD-C: Model 1: 2.65 (1.72), not statistically significant • Model 2 adjusts for child age (measured continuously), gender, school attendance, whether the child's mother was the primary caregiver, and socioeconomic status (SES), measured by a family wealth index created using items from the 2010 Rwandan Demographic and Health Survey; Model 2: 1.59 (1.72), not statistically significant • Model 3 includes additional contextual variables that could account for differences in child mental health: caregiver mental health, daily hardships, death of a caregiver, social service access, harsh punishment, and stigma, not statistically significant • YSR Anxiety/internalizing (*= p<0.05): Model 1: 0.13* (0.04); Model 2: 0.14* (0.04); Model 3: 0.02 (0.04). Odds ratios for mental health problems in HIV-positive children and HIV-affected children were not different at the P < .05 level of significance
Bhana et al., 2014	• CDI - N, Mean SD range: VUKA 64 3.25 2.67 0-12; Control 58 2.34 2.35 0-11. SDQ - N, Mean SD range: VUKA 54 18.80 3.56 11-26; Control 47 17.68 4.34 11-32 • Multivariate analysis: Comparison group (mean scores) - Adherence BL: 4.79; FU: 4.36; VUKA (mean scores) BL: 3.71, FU: 4.81, Beta: 1.527, P=0.05 • CDI (higher worse): Comparison group: BL: 3.19, FU: 2.64; VUKA: BL: 3.31, FU: 2.03,

	Beta: -0.736, p=0.417 • SDQ (higher worse): Comparison group: BL: 18.80, FU: 18.38; VUKA: BL: 18.79, FU: 16.96, Beta: -1.412, p=.371 • SDQ (higher worse): Comparison group: BL: 18.80, FU: 18.38; VUKA: BL: 18.79, FU: 16.96, Beta=-1.412, *p*=0.371 •
Boyes et al., 2019	• Depression score (M, SD): Males 1.01 (1.58), Females 1.22 (1.92); Anxiety score (M, SD): Males 1.93 (2.34), Females 2.36 (2.82)**, p<0.01; Posttraumatic stress score (M, SD): Males 4.27 (5.83), Females 5.78 (7.39)*** p<0.001; Conduct problems score (M, SD), Males 1.43 (1.41), Females 1.45 (1.47) • Associations with mental disorders: Depression, factor, B (SE), β, ***p < 0.001, **p < 0.01., *p < 0.05.: Overall health, −0.18 (0.08), −0.06*; Internalized stigma, 0.29 (0.05), 0.17***; Negative clinic interactions, 0.06 (0.02), 0.07** • (Summary of final mental health regression models (B (SE), β, ***p < 0.001, **p < 0.01., *p < 0.05)): Depression scores: Overall health: −0.18 (0.08), −0.06*; Side-effects 0.49 (0.12). 0.12***; Internalised stigma 0.29 (0.05), 0.17***; negative clinic interactions 0.06 (0.02), 0.07**; Clinic support group −0.32 (0.10), −0.09**; Past year emotional abuse 0.56 (0.14), 0.12***; Lifetime sexual abuse 0.83 (0.25), 0.10**; Bullying victimisation 0.04 (0.02), 0.07*; Social support −0.11 (0.02), −0.13***; positive parenting −0.04 (0.01), −0.11***; self-efficacy −0.04 (0.02), −0.07*; age 0.07 (0.02), 0.11***; R-squared 0.28***; Anxiety scores: Overall health −0.44 (0.12), −0.10***; side-effects 0.51 (0.17), 0.08**; anticipated stigma 0.30 (0.08), 0.10***; internalised stigma 0.54 (0.07), 0.21***; clinic support group −0.43 (0.14), −0.08**; past year emotional abuse 1.17 (0.19), 0.18***; lifetime sexual abuse 1.08 (0.34), 0.08**; Bullying victimzation 0.15 (0.02), 0.20***; positive parenting −0.05 (0.01), −0.09**; poor parental monitoring 0.02 (.01), 0.06*; self-efficacy −0.06 (0.02), −0.07**; poverty 0.10 (0.04), 0.07**; R-squared 0.36***; PTSD scores: overall health −1.51 (0.31), −0.13***; mode of infection 0.93 (0.44), 0.06*; enacted stigma 1.16 (0.39), 0.08**; internalised stigma 1.36 (0.19), 0.20***; past year emotional abuse 1.04 (0.51), 0.06*; bullying victimisation 0.33 (0.06), 0.16***; positive parenting −0.28 (0.04), −0.21***; age −0.28 (0.04), −0.21***; rural/urban −1.91 (0.43), −0.12***; r-squared 0.32***; Conduct problem scores: internalised stigma: 0.17 (0.04), 0.12***; past year emotional abuse 0.44 (0.12), 0.12***; bullying victimisation 0.05 (0.01), 0.12***; positive parenting −.04 (0.01), −0.14***; self-efficacy −0.08 (0.01), −0.18***; poverty −0.05 (0.02), −0.06*; age 0.07 (0.02), 0.13***; rural/urban −0.30 (0.10), −0.08**; r-squared 0.17***
Casale et al., 2019	• Eight percent (84 adolescents) reported some level of suicidal thoughts over the previous month and approximately half (4%) of these participants indicated that they had tried to kill themselves during that period • Partial correlations between stigma, support resources, depression and suicidal thoughts and behaviour: ***p < 0.001, **p < 0.01., *p < 0.05: Stigma and depression (0.308***); stigma and suicidal thoughts or behavior (0.300***); depression and suicidal thoughts or behavior (0.348***); depression and social support group attendance (−0.036); suicidal thoughts or behavior and support group attendance (−0.020) • Higher HIV-related stigma is directly associated with higher depressive symptoms (B = 0.295; p < .001) and higher suicidal thoughts and behaviour (B = 0.185; p < .001) in this sample. Depression is also associated with higher suicidal thoughts and behaviour scores (B = 0.164; p < .001)
Enimil et al., 2016	• Quantitative: (N=40), Mean (95% CI) or % (n): WHO 5 WBI Total score (scale 0-100): 69.00 (60.02 to 77.98), 52% (21) screened positive; ICD10: Total score (0-50), 10.80 (8.31 to 13.74), 3% (1) screened positive, 10% (4) reported at least mild depressive symptoms. QOL: Psychological health scale: 11.54 (11.01 to 12.09) • Independent samples t-tests indicated that compared to an international age-based normative sample, the study sample reported lower QOL on all domains, Physical Health (mean difference = −2.18 [95% CI = −3.13 to −1.23); Psychological Health

	(−3.26 [−4.19 to −2.33]); Social Relationships (−1.96 [−3.04 to −0.88]); and Environment (−1.69 [−2.59 to−0.79]) • Compared to a regional sample of mixed ages, participants also reported lower QOL on the Physical Health (−1.98 [−3.07 to −0.89]); and the Psychological Health subscales (−2.36 [−3.43 to−1.29]), but not on the Social Relationships (−0.36 [−1.77 to1.05]) or Environment (−0.09 [−1.02 to 0.84]) subscales • Qualitative: Psychological Well-Being: Distress about life circumstances- Loss of family, food insecurity, access to education, poor treatment by family or friends • Distress about HIV- Worry about of the future, sadness when thinking about HIV, social comparisons, perceived stigma • Coping strategies for HIV- Avoidance of reminders, religious faith, distraction, empowerment, withdraw from others, cognitive reframing, hope for the future, support from family and friends, lack of opportunity to discuss HIV with others
Gentz et al., 2017	• Poverty was associated with more total mental health difficulties, t(96)=2.63,p=.010, and more emotional symptoms, t(96)=3.45,p=.001, whereas better social support was a protective factor, particularly caregiver support (r=.337,p=.001) • Adherence problems, HIV-related stigma and disclosing one's own HIV status to others were also associated with more total mental health difficulties • Poverty (b=.231,p=.023) and stigma (b=.268,p=.009) were the best predictors for total mental health difficulties, whereas stigma (b=.314,p=.002) predicted emotional symptoms • Social support had a protective effect on peer problems (p=.001,b=.349)
Kim et al., 2017	• After adjusting for age and gender (Table 2), variables associated with non-adherence included negative past life experiences in the past year (experiencing household deaths and witnessed household violence or experienced violence), being bullied for taking their medicines, hospital admissions in the past year, missed clinic appointment in the past 6 months, depression (as measured by the CDRS-R, AOR 1.7, 95% CI [1.08–2.70],p = 0.02), poor treatment self-efficacy and alcohol use in the past 30 days
Li et al., 2010	• Adolescents' daily lives were influenced by an array of factors. Unsurprisingly, they felt badly about being HIV positive • Conflict in the peer environment was a common theme, though it remains unknown whether this discord was related to HIV status, or represented a more general feature of young peoples' communities • Half of participants indicated that they felt a mix of positive and negative emotions about the future; for example, it was common for individuals to choose both ''happy'' and ''depressed'' or ''confident'' and ''nervous'' when describing the future
Louw et al., 2016	• Greater caregiver depression scores were significantly associated with lower perceived resources across all participants (R = −0.25, P < .01) • Caregiver depression was the only significant predictor of greater Total Problems scores in the full model, after controlling for age and gender (F = 8.57, df = 5.102, P < .01) • An interaction between HIV status and caregiver depression was observed (t = −2.20, P = .03), with follow-up within-group analyses confirming that caregiver depression predicted greater Total Problems scores both in HIV-negative youth (β = 0.61, P < .001), and to a lesser extent, in HIV-positive youth (β = 0.25, P < .001)
Lyambai & Mwape, 2018	• Quantitative: More than three quarters of the adolescents had mental health problems as revealed by both the Self rated SDQ (85.4%) and the Parent rated SDQ (62.5%). Of this number, 57.3 percent and 30.2 percent had multiple mental health problems as indicated by the self-rated and parent rated SDQ respectively • 14.6% of adolescents and 37.5% of parents reported no mental health problems; 28.1% of adolescents and 32.3% of parents reported a single mental problem; 57.3% of adolescents and 30.2% of parents reported multiple mental health problems • Majority of the respondents (70 %) had high level of internalized stigma; majority (53.7%) of the respondents who had high level of stigma had multiple mental health

	problems and only 10.5 percent who had moderate level of stigma had no mental health problems; there is a statistically significant relationship between level of stigma and presence of mental health problems (X2 = 1.123, P = 0.003) • Qualitative interviews with nurses: Clients who seemed to have significant mental health problems were referred to the psychiatric clinic for screening by the clinical officer psychiatry. However most of the adolescents preferred to avoid going to the psychiatric clinic for fear of stigma and discrimination • Majority of the nurses stated that there were no routine or protocols followed in the screening for mental health problems among adolescents • Almost all nurses reported that psychological care was being offered to all the clients during routine reviews. However, it was noted that counselling done by the psychosocial counsellors was the only psychotherapeutic service available for the adolescents living with HIV • The general observation was that most of the staff expressed lack of understanding of childhood mental health problems and hence had challenges screening and identifying mental health problems in the adolescents. If they suspected a child to have a mental health problem, they would refer such a child to the mental health unit for assessment and treatment
Mbalinda et al., 2015	• Adolescents in secondary school were five times more likely to present with better mental health than those who did not have any form of education (AOR 5.3, 95 % CI: 1.86–15.41) • Adolescents recruited from the Northern region were less likely (AOR 0.50, 95 % CI: 0.32–0.78) to present with better mental health than those recruited from other regions • Adolescents on ART were four time more likely to present with a better mental health (AOR 3.9, 95 % CI: 2.22–6.9) • Participants who desired to have a child in future were two times more likely (AOR 1.7, 95 % CI: 1.05–3.00) to present with a better mental health than those who never intended to have children in the future • Adolescents who never discussed with their guardians on sexuality issues were less likely (AOR 0.6, 95 % CI: 0.40–0.89), to present with a better mental health compared to those who discussed with their guardians • Adolescents who had friends who smoked were less likely (AOR 0.57, 95 % CI: 0.35–0.98) to present with a better mental health • Adolescents who were not satisfied with SRH services were less likely (AOR 0.34, 95 % CI: 0.18–0.62) to present with a better mental health
Menon et al., 2007	• Young people in the Zambian sample were more than twice as likely to score outside the normal range for the total difficulties score (odds ratio [OR] = 2.1, 95% confidence interval [CI]: 1.4 to 3.1) compared with the UK sample; they were also 3 times more likely to have extreme scores for emotional symptoms (OR = 3.6, 95% CI: 2.5 to 5.4) and 7 times more likely to score in the abnormal range for peer problems (OR = 7.1, 95% CI: 4.9 to 10.2; rates of conduct disorders were comparable between the groups, but the Zambian sample had less than half the rates of hyperactivity (OR = 0.4, 95% CI: 0.2 to 0.7 • Participants who reported that they had health problems (n = 54, 42.5%) had higher total SDQ-Y scores, indicating more emotional and behavioral difficulties (median = 12.0) compared with those who did not report health problems(median = 9.0). This was found to be significant (z =22.027;P,0.05) • There was, however, no relation between WHO clinical staging and mental health • Univariate analyses showed no differences in continuous SDQ-Y scores between children who had had their HIV status disclosed and those who were unaware of their status; there were fewer participants in the disclosed group with extreme scores in the borderline or abnormal range for emotional difficulties (18.8% vs. 38.8%,x2=

	4.1,df=1;P= 0.04),however. - To control for possible confounding factors, a logistic regression analysis was performed with emotional difficulties in the borderline or abnormal range (yes/no) as the dependent variable and age, gender, and disclosure status as the independent variables. Only disclosure status entered into the analysis, with children in the non-disclosure group being more than twice as likely to experience concerning levels of emotional difficulties as those in the disclosed group (OR = 2.63, 95% CI: 1.11 to 6.26)
Menon et al., 2009	- Majority of the sample reported that they had no health problems (57.5%, N=73). Those who reported health problems had higher total SDQ score (median = 12.0) compared to those who did not report health problems (median = 9.0), this was found to be significant (P <0.05, Z= - 2.027) - Odds ratios for SDQ-Y scores in the sample of Zambian school children (n=420) borderline or abnormal range for the sample compared to an HIV positive Zambian sample (n=127) and UK sample normative sample (n=4228) - Total difficulties: School sample(a): 27.8% (116); UK(b):16.5% (698); HIV+(c): 29.1% (37) a vs c OR=0.9 (0.6-1.4) c vs b OR=2.1 (1.4-3.1); Emotional Symptoms: school sample(a): 30.1% (126), UK(b) 11.2% (474), HIV+(c) 31.5% (40), a vs c OR=0.9 (0.6-1.4) c vs b OR=3.6 (2.5-5.4)
Mutumba et al., 2016	- In the multivariate model simultaneously adjusting for respondents' socio-demographic characteristics and psychosocial resources, psychological distress was associated with non-adherence (model 3: OR = 1.75 [95% CI: 1.04–2.95]). Among the psychosocial resources, only satisfaction with social support was significantly associated with non-adherence (OR = 0.42 [95% CI: 0.22–0.79]) - In the multivariate model simultaneously adjusting for respondents' socio-demographic characteristics and psychosocial resources, psychological distress was associated with non-adherence (model 3: OR = 1.63 [95% CI: 1.08–2.46]); among the psychosocial resources, frequency of praying privately (OR = 1.22 [95% CI: 1.08–1.39]) and frequency of attending religious services (OR = 1.38 [95% CI: 1.09–1.74]) were significantly associated with greater odds of non-adherence, while satisfaction with social support (OR = 0.42 [95% CI: 0.26–0.67]) was significantly associated with lower odds of non-adherence to the medical regimen - In the multivariate model simultaneously adjusting for respondents' socio-demographic characteristics and psychosocial resources, psychological distress was associated with non-adherence (model 3: OR = 1.79 [95% CI: 1.19–2.69]); among the psychosocial resources, only frequency of praying privately (OR = 1.14 [95% CI: 1.01–1.29]) was significantly associated with greater odds for non-adherence. In this model, frequency of attending religious services, satisfaction with social support, and respondents' socio-demographic characteristics were not significantly associated with non-adherence to ART
Mutumba et al., 2017	- After controlling for socio-demographic variables, daily hassles (β = 0.179, t(462) = 3.69; p < .001), negative life events (β = 0.221, t = 5.55; p < .001), HIV-related concerns (β = 0.323, t(462) = 7.40; p < .001), and stigma (β = 0.155, t(462) = 3.99; p < .001) remained statistically significant, but neighborhood insecurity (β =0.048 (p = .21)) and poverty-related hardships (beta=0.058 (p = .24) were not significantly associated with psychological distress - Adjusting for respondents' socio-demographic characteristics, frequency of praying privately was positively associated with psychological distress (β = 0.125, t(462) = 3.07; p = .002), while religious coping (β = −0.173, t(462) = −4.25; p < .001), general coping style and behaviours (β = −0.297, t(462) = −6.79; p < .001), and satisfaction with social support (β = −0.222, t(462) = −4.82; p < .001) were negatively associated with psychological distress. However, social support (beta= −0.064 (p = .17)) and optimism (beta= −0.067 (p = .12)) were not statistically significant in these analyses
Nalukenge et	- Caregivers described the causes of mental health difficulties as poverty, violence,

al., 2019	HIV-related disease, negligence, bereavement and effect of ART • Adolescents displayed a similar range of views, focusing on family illness, abuse and discrimination but also mentioning poverty and other social issues, in addition to bereavement and HIV • Both caregivers and adolescents described their source of knowledge to have come from their experiences with family members who have suffered from these mental health problems • Adolescents additionally described their source of knowledge to also include their personal experience
Nduwimana et al., 2017	• HIV-positive children were almost eight times more likely to live in foster families than unaffected children (Odds Ratio [OR] 7.88, 95 % Confidence Interval [CI] 4.45–13.93, p <.001); however, HIV-affected children were not more likely to live in foster homes (OR 1.27, 95 % CI 0.64–2.50, p = .49) than unaffected children • HIV-positive status did not predict any family factors Positive parenting: (−.03 (−.13, .08), p=0.63, psychological aggression −.03 (−.09, .10), p=0.53, physical punishment .07 (−.03, .17), p=0.15, family unity −.05 (−.17, .06), 0.37, daily hardships .05 (−.54, .65), p=0.86 • Children who were HIV-affected reported worse parenting (B = −.12 [95 % CI = −.22, −.02], p = .02), less family unity (B = −.12 [−.23, −.01], p = .03) and more daily hardships (B = .73 [.18, 1.29], p = .01)
Ng et al., 2015	• Suicidal ideation (HIV+): Yes - 46 (21.10%); unadjusted OR when compared to HIV- and unaffected: 1.17 (0.74–1.86), not statistically significant • Suicidal Behavior (HIV+): Yes: 46 (21.10%); Unadjusted OR when comparted to HIV- and unaffected: 1.85* (1.12–3.05), statistically significant at P <0.05 • Being HIV positive was not a statistically significant predictor of suicidal ideation: AOR 1.04 (0.52–2.08) p=0.91 • Being HIV positive was not a statistically significant predictor of suicidal behavior: AOR: 1.80 (0.87–3.69); p=0.11
Okawa et al., 2018	• Quantitative: Association between high scores of depressive symptoms and survey participants' socio- demographic characteristics: unsatisfactory relationships with family (Adjusted Odds Ratio [AOR] 3.01; 95% Confidence Interval [CI] 1.20–7.56), unsatisfactory relationships with health workers (AOR 2.68; 95% CI 1.04–6.93), and experiencing stigma (AOR 2.99; 95% CI 1.07–8.41 • Factors associated with non-adherence to ART: loss of mothers (AOR 3.00; 95% CI 1.05–8.58), and lack of basic knowledge about HIV (AOR 3.25; 95% CI 1.43–7.40 • High scores for depressive symptoms were not associated with non-adherence to ART AOR: 0.37 (0.13–1.01), p=0.16 • Qualitative: psychological distress was a theme in the interviews as related to challenges with ART adherence
Osok et al., 2018	• Findings indicated that younger age (F(2, 173) = 18.63; P < 0.001), unemployed (F (1, 174) = 5.49; P = 0.020), single status t(174) = 8.4; P < 0.001, living with parents t(174) = − 8.1; P < 0.001, higher monthly income (F (2, 173) = 3.42; P = 0.035), temporary housing t(174) = 4.7; P < 0.001, not receiving social support t(174) = 8.0; P < 0.001, ambivalent to negative reaction to pregnancy (F (2, 173) = 40.85; P < 0.001), having children from before t(174) = 3.7; P < 0.001, experiencing a stressful event t(174) = − 8.2; P < 0.001, those experiencing substance abuse t(174) = − 2.4; P = 0.019, not attending clinic regularly t(174) = 5.2; P < 0.001, those experiencing domestic violence t(174) = − 7.8; P < 0.001 and HIV positive diagnosis t(174) = − 4.0; P < 0.001 were significantly associated with higher depressive scores • After various iterations, when individual predictors using standardized beta scores were examined, having experienced a stressful life event (B = 3.27, P = 0.001, β =0.25), the absence of social support for pregnant adolescents (B = − 2.76, P = 0.008, β = − 0.19), being diagnosed of HIV/AIDS (B = 3.81, P = 0.004, β =0.17) and being of younger age (B = 2.46, P = 0.038, β =0.14) were the independent correlates of depression

Pantelic et al., 2017	• Internalized HIV stigma was directly associated with anticipated HIV stigma (β = .284, p < .001), depressive symptoms (β = .445, p < .001) and urban household location (β = -.014, p < .001) • Enacted HIV stigma was associated with more depressive symptoms (β = .294, p < .001) but not with anticipated HIV stigma • Abuse victimization was associated with more anticipated HIV stigma (β = .334, p < .001) and more depressive symptoms (β = .396, p < .001)
Petersen et al., 2011	• Worrying about who was going to care for them, loss of someone who loved them, as well as families fighting over them emerged as sub-themes • A common response of those who experienced emotional difficulties was distress at feeling alone in the world with the disease • A number of children's family circumstances (8) did not permit them to express their distress because of AIDS related stigma in the family • Five adolescent respondents who indicated that they received little family social support displayed either emotional numbing or reported behavioral or emotional problems, including suicidal thoughts and aggressive behavior; adolescents who had strong family social support, appeared to cope better
Sherr et al., 2018	• In multivariate models, behaviorally infected adolescents were more likely to report higher levels of depression (B = 0.456, p = 0.018), anxiety (B = 1.192 p < 0.001), internalized stigma (B = 0.41, p = 0.008), and substance use (OR = 2.99 p = 0.001) • Older adolescents were more likely to be treated less kindly at the clinic OR=0.88 p<0.001), drop out of care (OR = 0.92 p = 0.004), report depression (B = 0.09 p < 0.001), internalized stigma (B = 0.13 p < 0.001), p = 0.01), and substance use (OR = 1.43 p < 0.001), HIV-positive adolescent girls were more likely to report suicidal ideation OR = 2.43 p = 0.025 • A multivariate model of all factors and mode of infection suggests that controlling for socio-demographic factors and other physical, clinic-related and mental health experiences, behaviorally-infected adolescents are more likely to report higher rates of anxiety (OR1.13 p = 0.016), internalized stigma (OR = 2.85 p = 0.0010), and excessive substance use (OR=2.33 p= 0.011)
Smith Fawzi et al., 2016	• In bivariate analysis, nonadherence was positively associated with a number of psychological symptom dimensions, including irritability (self-report OR = 1.79, 95% CI 1.06– 3.04; caregiver report OR = 1.97, 95% CI 1.22–3.18), and conduct problems (self-report OR = 1.79, 95% CI 1.10– 2.90; caregiver report OR = 3.35, 95% CI 2.00–5.61) • Self-reported mixed anxiety/depressive symptoms were not associated with adherence (OR = 1.68, 95% CI 0.92–3.07); however, a positive association was observed through caregiver report (OR = 3.57, 95% CI 1.86–6.86) • Self-reported depressive symptoms were marginally associated with nonadherence (OR = 1.02, 95% CI 0.99–1.03), whereas caregiver report showed a significant relationship (OR = 1.02, 95% CI 1.01–1.04) • For multivariate analysis, the following relationships between mental health and nonadherence remained associated: conduct problems (as reported by caregiver) (OR = 2.90, 95% CI 1.55–5.43), and depression (as reported by caregiver) (OR = 1.02, 95% CI 1.01–1.04)
West et al., 2019	• Higher social support associated with lower depression symptomology (adjusted prevalence ratio 0.25, 95% CI 0.10–0.59) and lower anxiety symptomology (adjusted prevalence ratio 0.30, 95% CI 0.13–0.71), though no association was found with PTSD (adjusted prevalence ratio 0.47, 95% CI 0.06–3.49)
Willis et al., 2018	• Participants attributed their experiences of depression to their relationships and interactions with significant people in their lives, primarily family members and peers • A sense of being different from others was common among participants, both due to their HIV status and the impact HIV has had on their life circumstances • Participants described a longing to be important or to matter to the people in their

	lives. A sense of isolation and rejection was common, as well as grief and loss, including ambiguous and anticipated loss • Participants' idioms of distress included 'thinking deeply' ('kufungisisa'), 'pain', darkness, 'stress' or a lack of hope and ambiguity for the future. Suicidal ideation was described, including slow suicide through poor adherence • Supportive factors were also relational, including the importance of supportive relatives and peers, clinic staff and psychosocial support programs
Woollett et al., 2017	• Females scored significantly higher for depression ($p < 0.001$), anxiety ($p < 0.01$), and PTSD ($p < 0.001$) than males. Those reporting suicidality also reported significantly higher suicidality on all three mental health scales suggesting that suicidal individuals are more likely to present with higher levels of depression ($p < 0.001$), anxiety ($p < 0.001$), and PTSD ($p < 0.001$) • Being inappropriately touched increased the risk for being symptomatic for depression (RR = 2.22, p= 0.01, 95% CI), PTSD (RR = 3.08, p = 0.02, 95% CI), and anxiety (RR = 1.77, p =0.00, 95% CI) • Experiencing forced sex led to a significantly higher relative risk of experiencing depression (RR = 3.55, p = 0.02, 95% CI), anxiety (RR = 3.01, p = 0.01, 95% CI), and PTSD (RR = 2.38, p =0.04, 95% CI) • Experiencing peer violence at school increased the risk of experiencing PTSD (RR = 2.56, p =0.21, 95% CI) but not depression or anxiety • However, experiencing peer violence outside of school increased the risk of experiencing depression (RR = 2.16, p = 0.01, 95% CI), anxiety (RR = 1.62, p = 0.02, 95% CI), and PTSD (RR = 2.80, p =0.07, 95% CI) • Those that did not feel safe at home showed a significantly higher risk of all three mental health disorders – depression (RR = 5.17, p=0.00), anxiety (RR = 2.92, p =0.00), and PTSD (RR = 3.94, p =0.02) all 95% CI. This was similar (depression RR = 2.31, p =0.00; anxiety RR = 2.02, p = 0.00; PTSD RR = 3.66, p =0.01 all 95% CI) for those who reported that there was no safe place in the community for adolescents

Appendix B: Post-UTT Study Findings

Study	Key Results
Coetzee et al., 2019	• Proportion of participants who reported clinically significant symptoms; 24.6% (n=33) fatigue, 20.1% (n = 27) insomnia, 9.7% (n = 13) depression: Mean Females: 46.63 (SD:13.89), Mean Males: 42.02 (SD 9.24), adjusted t: -2.16 p=0.03; and 6.7% (n=9) anxiety: Mean Females: 45.38(SD 13.84), Mean Males: 41.84 (SD 10.92), adjusted t-score -1.59, p=0.11 • Female participants scored significantly higher (p = <.05) on insomnia, and symptoms of depression compared to male participants • **Correlation is significant at the 0.01 level (2-tailed), *Correlation is significant at the 0.05 level (2-tailed): age and depression = .174*; age and anxiety = 239**; fatigue and depression .502**; fatigue and anxiety 158; depression and insomnia .444**; depression and anxiety .514**; insomnia and anxiety .232 • Depression was a predictor of fatigue: Depression B 10.904, SE 2.675 , Beta 0.311, t 4.076, p=.000
Enane et al., 2019	• Viral suppression was lowest among hospitalized adolescents (14%). Narratives described prominent, frequent experiences of trauma, particularly for adolescents with history of disengagement • Trauma included ordeals living with HIV – such as learning one's HIV status after the death of a parent, or being hospitalized – or experiences of conflict or abuse • Limited social support experienced by these adolescents and families exacerbated trauma, resulting in isolation, disengagement from care, and even passive suicidality for both adolescents and caregivers • Mental health challenges, including isolation, depression, and alcohol abuse, were commonly described for adolescents and caregivers, particularly for those with history of disengagement; for caregivers, mental health challenges related to their own illness and history of trauma, deaths of loved ones, and experiences caring for a child with HIV • Multiple levels of stigma, interpersonal conflicts and lack of family/social support, resulted in serious mental health challenges • Suicidality and passive suicidality among caregivers and adolescents influenced disengagement from care • Despite these many difficult challenges, critical factors at the level of the adolescent and family supported retention. The motivation to be healthy and to receive HIV education were central to retention • Supportive family relationships were essential, and in most cases, caregivers or relatives were identified as primary sources of encouragement
Kagee et al., 2019	• The mean converted T-score on the RCADS Depression subscale was 44.70 (SD=12.33). The mean score was significantly lower (t=−19.05; df=133; p=0.00) than the threshold of 65, indicating the probability of clinically significant depression, and only 5.2% scored in the clinically significant range • The mean converted T-score on the RCADS Anxiety subscale was 43.9 (SD=12.78). The mean score was significantly lower (t=−19.11; df=133; p=0.00) than the threshold of 65, indicating the probability of clinically significant anxiety, and only 9.0% of the sample scored in the clinically significant range. • There were significant correlations between depression, insomnia (0.42); depression and fatigue (0.46), and between anxiety and insomnia (0.24). QOL highly and significantly correlated with insomnia (*0.57), depression (0.60), anxiety (0.43). • Regression: Anxiety (Beta 0.15, t 1.87, p=0.04) and depression (beta 0.32, t 2.03, p=0.00) predictors of QoL
Kemigisha et al., 2019	• The median CES DC depressive symptoms score was 13.5 (IQR: 8, 21) • Of the 336 adolescents, 154 (45.8%, [95% CI 40.5–51.2]) had depressive symptoms, meaning a CES DC score of 15 or more

- 42.5% of boys and 47.8% of girls had depressive symptoms
- 37.4% of those aged 10–14 years and 62.3% of those aged 15–19 years had depressive symptoms
- A total of 26 (7.7%) had thoughts of ending their own life in the last 6 months; of these, 18 (69.2%) were female and 8 (30.8%) were male; among these, 5 were classified as having no current depressive symptoms (a score of <15) and 21 with depressive symptoms in the past two weeks (score range 20–40)
- The odds of having depressive symptoms were 1.7 higher among adolescents who traveled for more than 30 min to visit the clinic compared to those who traveled for less than 30 min (AOR= 1.66 [95% CI: 1.02-2.70], *p* = 0.041)

Appendix C: Interview Guide

I will read you a series of statements. For each statement, I would like you to tell me how you would rate your agreement or disagreement with the statement. Then, I would ask if you could please try to explain for what reason or reasons you rated your agreement or disagreement with the statement.

Remember, we're interested in your opinion; there are no right or wrong answers.

1. Most people in your community would treat a person with HIV just as they would treat anyone.
2. Most people in your community feel that having HIV is a sign of poor morality.
3. Most people in your community think that a person with HIV did something to bring this condition on themselves.
4. What does it mean to be a proper woman in Botswana?

   A. Does having HIV effect a proper woman's status (in society)?
5. Most employers in your community will hire a person with HIV if he or she is qualified for the job.
6. Does gossip effect a person with HIV's ability to be a good Batswanan?
7. Most women/men in your community would be reluctant to date a person with HIV.
8. When does a woman/man typically find out that they are HIV positive?
9. Most people in your community think that resources spent treating a person with HIV would be better spent elsewhere.

Appendix D. Curriculum Vitae

OHEMAA BOATEMAA POKU, MPH

opoku1@jhmi.edu; 517-402-2774

EDUCATION

Expected May 2021

Doctor of Philosophy (PhD)
Department of Mental Health
Johns Hopkins Bloomberg School of Public Health, Baltimore, MD
Advisor: Dr. Sarah Murray
Dissertation: The Intersection of HIV Disclosure and Stigma and their Implications for HIV Prognosis and Psychosocial Outcomes for Adolescents Living with HIV in sub-Saharan Africa

January 2018

Master of Public Health
Boston University School of Public Health, Boston, MA
Concentrations: Design and Conduct of Public Health Research and Global Health
Advisors: Dr. Rachel Bonawitz and Dr. Christina Borba
Thesis: Barbadian Perspectives on What Makes a Quality Life: A Multi-Population Qualitative Study

May 2013

Bachelor of Arts in History and International Development
Mount Holyoke College, South Hadley, MA
Honors: Cum Laude
Honors Thesis: Awaawaa Tuu: "I Open My Arms and Embrace You" Addressing the Impediments on Special Education in Ghana

Spring 2012

Study Abroad
School of Oriental and African Studies
University of London, London, UK
Concentration: Development Studies

RESEARCH EXPERIENCE

Sept. 2019-Present

Dissertation Research
Department of Mental Health
Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

- Conduct systematic review of the association of mental health care with engagement along the HIV care continuum for adolescents living with HIV (ALWH) in sub-Saharan Africa
- Utilize latent class analysis to characterize patterns of disclosure of HIV status by ALWH in Uganda, and then examine stigma as a

mediator of the relationship between disclosure class and mental health
- Qualitatively explore gossip as a marker of HIV status and its effects on treatment adherence in Botswana

May 2020 -Present

Research Assistant
Department of Mental Health
Johns Hopkins Bloomberg School of Public Health, Baltimore, MD
Project Title: *Photographing Truth to Power*
PIs: *Dr. Sabriya Linton and Dr. Haneefa Saleem*

- Conceptualize and implement photovoice study with Baltimore youth as to the ways housing redevelopment programs affect psychosocial outcomes
- Conduct scoping review to identify approaches for community engaged research to understand the impacts of housing and neighborhood conditions on youth

Apr. 2020-Present

Research Assistant
Department of Mental Health
Johns Hopkins Bloomberg School of Public Health, Baltimore, MD
Project Title: Sustainable Technology for Adolescents to Reduce Stress (STARS) Intervention
PI: *Dr. Judy Bass*

- Adaptation of the World Health Organization STARS intervention for youth in East Baltimore to have better access to psychosocial services
- Train adolescents on qualitative data collection and analysis
- Manage data collection and analysis with adolescent participants

Apr. 2019-Oct. 2019

Research Assistant
World Health Organization Inter Agency Standing Committee, Mental Health and Psychosocial Support Reference Group
Project Title: Preparation of Field Guidance to Supplement the Inter Agency Standing Committee (IASC) Mental Health and Psychosocial Support (MHPSS) Common Monitoring and Evaluation Framework
PI: *Dr. Jura Augustinavicius*

- Expert interviews in order to identify measures for social behavior, functioning, early childhood development, substance use, and stigma for use in humanitarian settings
- IRB preparation
- Evaluation of approximately 50 measures based on accessibility, feasibility, language, and psychometrics

- Attendance of IASC expert consultation meeting in Geneva, Switzerland (July 2019) for the final evaluation of selected measures and conceptualization of guidance document
- Survey design and dissemination to WHO IASC reference group for recommended qualitative measures for mental health in humanitarian settings

May 2019-Aug. 2019 **Research Assistant**
Department of Mental Health
Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

Project Title: Baby Friendly Spaces (BFS+): Process Evaluation of an Integrative Health Approach for Lactating Women and their Babies in Humanitarian Emergencies
PI: *Dr. Sarah Murray*

- Codebook conceptualization for qualitative analysis of transcripts with women participants
- Inductive analysis of transcriptions, synthesis of results, and drafting of report for Action Against Hunger

Apr. 2018-Present **Lead Qualitative Analyst and Research Assistant**
Department of Social and Behavioral Sciences
New York University
Department of Psychiatry
University of Pennsylvania
University of Botswana
Project Title: PHMARC Stigma Study
PIs: *Dr. Lawrence Yang and Dr. Michael Blank*

- Conceptualization and preparation of R21 Grant Proposal (Awarded)
- Conceptualization and preparation for an R01 grant re-submission
- Conceptualization of items for the development of culture specific HIV stigma scale to identify how culture shapes stigma and how it protects against stigma for women- What Matters Most Cultural Stigma Scale for Women Living with HIV in Botswana
- Collaborator for adaptation of peer-based self-stigma intervention for use among pregnant women living HIV in Botswana

May 2017-May 2018 **Research Assistant**
Global Mental Health, Psychosis, and Stigma Lab
Department of Social and Behavioral Sciences
New York University, New York, NY

PI: Dr. Lawrence Yang

- Conducted inductive analysis of data on HIV and stigma for immigrants from China, Taiwan, and Hong Kong
- Prepared and successfully published co-first authored manuscript on immigrant data
- Completed and managed Institutional Review Board protocol for domestic high school mental health survey

May 2017-Apr. 2018

Research Manager and Lead Qualitative Analyst
Department of Social and Behavioral Sciences
New York University
Department of Psychiatry
University of Pennsylvania
University of Botswana
Project Title: PHMARC Stigma Study
PIs: *Dr. Lawrence Yang and Dr. Michael Blank*

- Led 4 qualitative analyst teams in weekly sessions to discuss coding and analysis strategies for study with approximately 100 participants
- Facilitated focus group and in depth interview sessions with persons living with HIV in addition to individuals from the general community in Gaborone to collect data on HIV and mental illness stigma
- Managed data collection and instrument development
- Managed group of 4 Research Assistants in Gaborone and trained all in recruitment, focus group, in depth interview, and transcription methods

Sept. 2016-Dec. 2017

Research Assistant
Global Division of Psychiatry, Massachusetts General Hospital and Boston Medical Center, Boston, MA
Project Title: Barbados Malnutrition and Behavioral Outcomes Longitudinal Study
PIs: *Dr. Janina Galler and Dr. Rebecca Hock*

- Led an explanatory mixed methods analysis of predictive factors for quality of life (QOL) outcomes for individuals of Barbadian descent to inform public health interventions for this population
- Conducted in depth semi-structured interviews with Barbadians residing in Barbados and the U.S. in addition to using SAS for the quantitative analysis of the Quality of Life Questionnaire

March 2012-May 2013

Student Researcher (Undergraduate Honors Thesis)
Department of Sociology
Mount Holyoke College, South Hadley, MA

- Conducted semi-structured interviews with teachers, caregivers, and students involved with special education programs
- Participant observation at special education programs as well as at Accra Psychiatric Hospital
- Trained 3 undergraduate research assistants to transcribe data
- Inductive coding of transcripts and synthesis of results to inform thesis

PROFESSIONAL WORK AND CONSULTANT EXPERIENCE

Aug. 2020-Present

Director of Health Equity Initiatives
Columbia-WHO Center for Global Mental Health, New York, NY

- Re-development of course curriculums for "Mental Health Policy" and "Priorities in Global Mental Health" to have intersectional lens for readings and assignments
- Design and invite speakers for monthly seminar series on mental health equity; facilitate post presentation discussions with presenters
- Conceptualize and co-facilitate Race and Mental Health Journal Clubs for students, faculty and staff

Jan. 2020-Present

Director of Global Practica and Internships
Columbia-WHO Center for Global Mental Health, New York, NY

- Development of curriculum for undergraduate summer interns on global mental health
- Design and conduct didactic seminars on global mental health
- Mentorship of 10-12 undergraduate rising seniors during the summer for 8 weeks on global mental health concepts, professional development, and academic development
- Mentorship and supervision of 2 graduate level practica students (MPH, medical, dental students) on their Columbia affiliated summer projects related to global mental health

Jan. 2014-Aug. 2016

Program Manager (October 2015-August 2016)
Columbia-WHO Center for Global Mental Health, New York, NY

- Managed the Columbia-WHO Global Mental Health Program (GMHP) intern program and supervised research assistants and student researchers
- Wrote sections of grants and budgets for projects
- Drafted editorials, manuscripts, and contributions to the mhGAP-Intervention Guide Suicide Module
- Continued responsibilities held as Program Assistant

Program Assistant (January 2014-October 2015)

- Program and project management for GMHP as well as research administration and assistance for select projects

- Managed program budget of $1,000,000 in gifts and funding, maintained day-to-day program operations and coordinated international annual meeting
- Drafted and managed budgets and contracts in addition to facilitating the process of incoming and outgoing funding for the program
- Managed operations for all meetings held in New York and abroad, correspondence with the Global Mental Health Scholars, and Columbia databases for the program
- Head coordinator for annual Global Mental Health Meetings and symposia (Jordan-2014, India-2015, South Africa-2016)
- *Specific Research Administrator Responsibilities*
    - Responsible for drafting budget, cost analysis and specific areas of content for Grand Challenges Canada application for collaboration with the Africa Mental Health Foundation
    - Responsible for draft budget and justification sections for President's Global Innovation Fund application
    - Drafting and preparation of NIH Grant submissions
- *Specific Research Assistant Duties*
    - Africa Mental Health Foundation Collaboration: research on task sharing models, conceptualization of monitoring and evaluation framework
    - Global Clinical Practice Network (WHO/ GMHP Collaboration): generate monthly reports with updated data from the network, analysis of growth and trends from network data

Aug. 2013-Dec. 2013 **Development Coordinator**
U.S. Fund for UNICEF New England Regional Office, Boston, MA

- Primary responsibilities included maintaining information and correspondence with major donors in the region, management of interns, and assistance with board meetings and special events
- Primary contributions included organizational development and strategic planning and strengthening of the intern program
- Coordinated events around the UNICEF's work on disability

Jan. 2010-May 2013 **Program Liaison** (September 2013-May 2013)
Speaking, Arguing, and Writing Center
Mount Holyoke College, South Hadley, MA

- Core liaison responsibilities included organizing and facilitating workshops and dialogues to address program challenges

Speaking and Writing Mentor (January 2010-May 2013)

- Mentoring students on writing and oral presentation

June 2011-Aug. 2011

Education Intern
U.S. Fund for UNICEF, New York, NY

- Responsibilities included providing supplementary instructional material for classroom use by elementary students and teachers as to UNICEF's education work
- Preparation of UNICEF education briefings and updating newsletters
- Major Project: Research and development for curriculum for K-12 on education, gender equality, child marriage, and female genital circumcision

Jan. 2011-May 2013

Research Associate (February 2011-May 2013)
Associates for Change, Accra Ghana

- When in Ghana, provided assistance with interviews related to studies on gender, health, and education access
- Remote responsibilities included editing sections of reports and conducting literature reviews

Research Intern (January 2011-February 2011)

- Major Responsibilities included: proposal writing, researching corporate social responsibility, out of school children initiatives, girls' education initiatives, contributing to education and fundraising strategic plans

June 2010-Aug. 2010

Development Intern
U.S. Fund for UNICEF New England Regional Office, Boston,
MA

- Major projects: research as to UNICEF initiatives in Bolivia for major donors, database entry to maintain donor list, "major" donor research, and day to day organization of files and information

CONSULTATIONS

November 2019

Consultant
International Medical Corps, Los Angeles, CA

- Conducted extensive literature review and synthesis of family based psychosocial interventions specifically for refugees and immigrants to inform grant application

June 2012-Dec. 2012

Consultant
Darling's Human Rights Development Fund
Accra, Ghana

- Consulted on increasing revenue from programs sponsored by Darling's. In addition, and when remote, contributed to a strategic plan on how to increase human resources through volunteer and internship programs

TEACHING EXPERIENCE

Jan. 2021-Present

Teaching Assistant
Department of Mental Health
Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

Course Title: Stigma and Public Health: Issues and Interventions
Instructor: *Dr. Sarah Murray*
Mentor students on:

- Stigma mechanisms and the application of theory to understand stigma processes
- Measurement of stigma
- Understanding stigma across multiple identities and health conditions, and as a social determinant of health

Oct. 2020-Dec. 2020

Teaching Assistant
Department of Mental Health
Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

Course Title: Qualitative and Quantitative Methods for Mental Health and Psychosocial Research in Low Resource Settings
Instructor: *Dr. Judy Bass*
Mentor students on:

- Qualitative and quantitative research methodology
- Research and data analysis strategies
- Academic writing

Aug. 2020-Oct. 2020

Teaching Assistant
Department of Mental Health
Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

Course Title: Stigma and Public Health: Issues and Intervention
Instructor: *Dr. Sarah Murray*

- Curriculum development:
  - Conceptualization of lectures
  - Contribute to designing class assignments

June 2020-July 2020

Teaching Assistant
Johns Hopkins Public Health Summer Institute, Baltimore, MD
Course Title: Epidemics, Pandemics, & Outbreaks
Instructor: *Anushka Aqil, MPH*
Mentored students on:

- Researching public health challenges
- Presentations
- Academic writing

March 2020-May 2020

Teaching Assistant
Department of Mental Health
Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

Course Title: Prevention of Mental Disorders: Public Health Interventions
Instructors: *Dr. Holly Wilcox and Dr. Phillip Leaf*
Mentored students on:

- Designing prevention interventions
- Academic writing

Sept. 2017-Dec. 2017

Teaching Assistant
Boston University School of Public Health, Boston, MA
Course Title: Qualitative Research Methods
Instructor: *Dr. Lisa Messersmith*

- Collaborated with faculty on the course readings, assignments, and class activities
- Facilitated in class activities and led lectures
- Held weekly office hours for additional student help/mentorship

Jan. 2013-May 2013

Africana Writing Fellow/Teaching Assistant
Department of Africana Studies
Mount Holyoke College, South Hadley, MA

- Collaborated with faculty in the Africana Studies Department to conceptualize and deliver workshops on primary and secondary research as well as the writing process for majors and minors

GUEST LECTURES

Spring 2021

Recruitment Methods for Marginalized Populations: Case Study from Botswana
Course Title: Working with Marginalized Populations –An ethical inquiry into public health research methodologies
Krieger School of Arts and Sciences
Johns Hopkins University, Baltimore, MD
Instructor: *Anushka Aqil, MPH*

Spring 2021

Structural Racism in Global Mental Health
Course Title: Priorities in Global Mental Health
Mailman School of Public Health
Columbia University, New York, NY
Instructors: Dr. Tahilia Rebello and Dr. Kathleen Pike

Spring 2021

Measurement in Global Mental Health: The Need for Qualitative and Mixed Methods
Course Title: Priorities in Global Mental Health
Mailman School of Public Health
Columbia University, New York, NY
Instructors: Dr. Tahilia Rebello and Dr. Kathleen Pike

Spring 2020

Introduction to Global Mental Health
Course Title: Global Issues in Health & Disease
University of Maryland, Baltimore County, Baltimore, MD
Instructor: *Anushka Aqil, MPH*

MENTORSHIP EXPERIENCE

Sept. 2019-Present

Student Mentor
PhD-MHS Mentorship Program
Department of Mental Health
Johns Hopkins University Bloomberg School of Public Health

- Each academic year mentor 4-5 MHS students on:
    - Course selection
    - Capstone topics
    - Further graduate studies and job seeking
        - Mentees (2020-Present):
            - Stephen Black
            - Bo Hyun Kim
            - Shireesha Patel
            - Yuki Shen
            - Alexandra Walker
        - Mentees (2019-2020):
            - Angel Gabriel, MHS
            - Ifechukwu Ofonedu, MHS
            - Ritu Dhar, MHS
            - Colleen Zarek, MHS

Sept.2017-Present

Mentor

- Zoe Martina Siegel
    - Academic writing
    - Qualitative Methods
    - Selecting and applying to graduate programs

- Haitisha Mehta, MA
    - Qualitative methods and data management for PHMARC Stigma Study
    - Selecting and applying to graduate programs

- Dai Cao
    - Qualitative methods and data management for PHMARC Stigma Study
    - Selecting graduate programs

- Victoria Leonard
    - Program management for Columbia-WHO Center for Global Mental Health
    - Selecting graduate programs

HONORS AND AWARDS

Sept. 2020-Present	**Student Fellow** *Society for the Study of Psychiatry and Culture* Fellows contribute to steering committee priorities, conference development, and receive specialized academic and professional mentorship
Sept. 2018-Present	**T32 Pre-Doctoral Fellowship in Global Mental Health** *Johns Hopkins University Bloomberg School of Public Health* T32 Predoctoral fellow focusing on study of culture and stigma as barriers to psychosocial care
April 2017	**Santander Global Health Scholarship ($4,000)** *Boston University School of Public Health* Scholarship for Boston University MPH students pursuing a Global Health Summer Practicum
May 2017	**1905 Fellowship ($6,000)** *Mount Holyoke College* Funding for research conducted by alumnae
August 2012	**Finalist, ARCHIVE Global 'Building Malaria Prevention' Design Competition** Competition to design a small home using local resources that also allowed for minimum malaria transmission. With a group of 4 other international design and public health professionals, team was selected as one of the top 20 finalists in the competition
May 2012	**Global Studies Student Fellowship ($3,500)** *Mount Holyoke College* Fellowship awarded for student-mentor collaborative research abroad by Mount Holyoke's McCullough Center for Global Initiatives
November 2011	**Truman Scholarship Nominee**

Mount Holyoke College
One of Mount Holyoke's nominees for the national scholarship recognizing leadership in public service, education and non-profit work

September 2011
Afrepreneurs of Tomorrow Scholarship ($1,000)
Scholarship for young Africans who have innovative ideas for how to give back to their fellow Africans in the future

January 2011
Almara Fellowship ($500)
Mount Holyoke College
Grant for independent student research in History

GRANTS

February 2020
Johns Hopkins Suicide Prevention Awareness, Response and Coordination (JH-SPARC) Small Grant
Johns Hopkins University Bloomberg School of Public Health
Funding for film screening and panel to discuss suicide as both an individual as well as community issue

March 2020
Diversity Networking, Mentoring, and Professional Development Program Grant, Johns Hopkins Provost's Office (March 2020)
Johns Hopkins University Bloomberg School of Public Health
Support for underrepresented minorities at the School of Public Health to organize professional development and community building activities

PUBLICATIONS AND PRESENTATIONS

PUBLICATIONS

Yang, L. H., **Poku, O. B**, Misra, S., Mehta, HT., Rampa, S., Eisenberg, M., Yang, L., Cao, D., Blank, L., Becker, TD., Link, B., Entaile, P., Opondo, PR., Arscott-Mills, T., Ho-Foster, A., Blank, MB. *(Accepted).* Structural Vulnerability and "What Matters Most" among Women Living with HIV in Botswana, 2017. *American Journal of Public Health.*

Misra, S, Mehta, HT, Eschliman, EL, Rampa, S, **Poku, OB**, Wang, W, Ho-Foster, A, Mosepele, M, Becker, TD, Entaile, P, Arscott-Mills, T, Opondo, PR, Blank, MB, Yang, LH. Identifying 'what matters most' to men in Botswana to promote resistance to HIV-related stigma. *Qualitative Health Research (Accepted).*

Poku, O., Ho-Foster, A., Entaile, P., Misra, S., Mehta, H., Rampa, S., Goodman, M., Arscott-Mills, T., Eschliman, E., Jackson, V., Benti, T., Becker, T., Eisenberg, M., Link, B., Go, V., Opondo, P., Blank, M., Yang., L. H. 'Mothers moving towards empowerment' intervention to reduce stigma and improve treatment adherence in pregnant women living with HIV in

Botswana: study protocol for a pragmatic clinical trial. *Trials* **21,** 832 (2020). https://doi.org/10.1186/s13063-020-04676-6

Yang, L. H., Ho-Foster, A. R., Becker, T. D., Misra, S., Rampa, S., **Poku, O. B**., Entaile, P., Goodman, M., & Blank, M. B. (2020). Psychometric Validation of a Scale to Assess Culturally-Salient Aspects of HIV Stigma Among Women Living with HIV in Botswana: Engaging "What Matters Most" to Resist Stigma. *AIDS and Behavior*. https://doi.org/10.1007/s10461-020-03012-y

Becker, T. D*., **Poku, O. B*.,** Chen, X., Wong, J., Mandavia, A., Huang, M., Chen, Y., Huang, D., Ngo, H., & Yang, L. H. (2020). The Impact of China-to-US Immigration on Structural and Cultural Determinants of HIV-Related Stigma: Implications for HIV Care of Chinese Immigrants. *Ethnicity & health*, 1–20. https://doi.org/10.1080/13557858.2020.1791316 **(*co-first authors)**

Poku, O. B., Becker, T. D., Ho-Foster, A. R., Rampa, S., Entaile, P., Yang, L., Mehta, L., Eisenberg, M., Blank, L., Cao, D., Opondo, P., Blank, M.,Yang, L. H. (2020). Reflections on qualitatively investigating HIV and mental illness stigma in Botswana with a multicultural and multinational team. *SAGE Research Methods Cases.* doi:10.4135/9781529742961

Ramogola-Masire, D., **Poku, O**., Mazhani, L., Ndwapi, N., Misra, S., Arscott-Mills, T., Blank, L., Ho-Foster, A., Becker, T. D., & Yang, L.H. (2020). Botswana's HIV response: Policies, context, and future directions. *Journal of community psychology*, *48*(3), 1066–1070. https://doi.org/10.1002/jcop.22316

Becker, T. D., Ho-Foster, A. R., **Poku, O. B**., Marobela, S., Mehta, H., Cao, D. T. X., Yang, L. S., Blank, L. I., Dipatane, V. I., Moeng, L. R., Molebatsi, K., Eisenberg, M. M., Barg, F. K., Blank, M. B., Opondo, P. R., & Yang, L. H. (2019). "It's When the Trees Blossom": Explanatory Beliefs, Stigma, and Mental Illness in the Context of HIV in Botswana. *Qualitative Health Research*, *29*(11), 1566–1580. https://doi.org/10.1177/1049732319827523

Scorza, P., **Poku, O.,** & Pike, K. M. (2018). Mental health: taking its place as an essential element of sustainable global development. *BJPsych international*, *15*(4), 72–74. doi:10.1192/bji.2017.22

Pike, K. M., Min, S. H., **Poku, O. B.,** Reed, G. M., & Saxena, S. (2017). A renewed call for international representation in editorial boards of international psychiatry journals. World psychiatry : official journal of the World Psychiatric Association (WPA), 16(1), 106–107. doi:10.1002/wps.20389

UNDER REVIEW

Poku, O., Rampa, S., Becker, T., Misra, S., Choe, K., Tay, C., Ho-Foster, A., Mosepele, M., Entaile, P., Arscott-Mills, T., Opondo, P., Blank, M., Yang, Y. "A Multi-stage, Mixed Methods Approach to the Culturally-Informed Development of a Self-Stigma Intervention for Pregnant Women Living with HIV in Botswana"

Holingue, C., **Poku, O**., Murray, S., Fallin, MD."A qualitative study of family experiences with having a child with autism and co-occurring gastrointestinal symptoms"

MANUSCRIPTS IN PREPARATION

Murray, SM., Lasater, M., Guimond MF., **Poku., O**., Musci, R., Fataftah, M., Kasina, L., Lwambi, M., Salaimeh, A., Falb, K**.** Raising the Bar for Monitoring and Evaluation of Gender-Based Violence Programs: Measuring Sexual Violence Stigma Across Humanitarian Contexts

Wiginton, JM., **Poku, O.,** Murray, SM., Baral, SD. Disclosure of same-sex practices and health-care stigma among cisgender men who have sex with men across five sub-Saharan African countries

Poku, O., Goldmann, E., Kretchy, I.A., Novignon, J., Osafo, J., "Factors Associated with Mental Health Service Use in Ghana: A Review"

Poku, O., Hock, R.S., Borba, C.P., Bryce, C.P., Galler, J.R., "Barbadian Perspectives on What Makes a Quality Life: A Dual Population Qualitative Study"

PRESENTATIONS

Bostswana-UPenn Partnership Journal Club (June 2020)
Presented on publications produced by the PHMARC Stigma study.

Poster for International AIDS Conference (July 2020-Virtual) Ho-Foster, A., Goodman, M., Entaile, P., Rampa S., Jackson, V., Manyeagae, G., **Poku, O**., Misra, S., Opondo, P., Arscott-Mills, T., Mehta, H., Becker, T., Tadele, B., Blank, M., Yang. L., "What Matters Most enables resistance of HIV stigma: sustained effects of a novel, culturally-tailored prenatal HIV stigma-reduction intervention on stigma and depression in Botswana"

Poster for the International Society for Autism Research (May 2020-Virtual)
Holingue, C., **Poku, O.,** Murray, S,. Fallin, D. "A Qualitative Study of Family Experiences with Having a Child with Autism Spectrum Disorder and Co-Occurring Gastrointestinal Symptoms"

Poster Presentation for the Society for the Study of Psychiatry and Culture (April 2020-Virtual) Poku, O., Hock, R., Borba, C., Bryce, C., Galler, J. "Barbadian Perspectives on What Makes a Quality Life: A Bi-Fold Population Qualitative Study"

Poster for the American Public Health Association Conference (November 2019)
Blank, L., Yang, L., Blank, M., Ho-Foster, A., **Poku, O.,** Eisenberg, M., Cao, D., Mehta, H., Yang, L., Opondo, P. "HIV+ Motswana women, and their lived experience of gender-related stigma"

Poster for the Yale RebPsych Conference (September 2018)
Becker, T., Ho-Foster, A., **Poku, O**., Marobela, S., Mehta, H., Cao, D., Yang, L., Blank, L., Dipatane, V., Moeng, R., Molebatsi, K., Eisenberg, M., Barg, F., Blank, M., Opondo, P., Yang, L. "Explanatory beliefs and stigma to mental illness among HIV clinic patients and community dwellers in Gaborone – implications for integrated HIV and mental health care"

Poster for the 7th Botswana International HIV Conference (August 2018)
Becker, T., Ho-Foster, A., **Poku, O**., Marobela, S., Mehta, H., Cao, D., Yang, L., Blank, L., Dipatane, V., Moeng, R., Molebatsi, K., Eisenberg, M., Barg, F., Blank, M., Opondo, P., Yang, L. "Explanatory beliefs and stigma to mental illness among HIV clinic patients and community dwellers in Gaborone – implications for integrated HIV and mental health care"

Poster for the American Psychological Association Annual Convention (August 2018)
Mehta, H., Dai, C., Yang, L., **Poku, O**., Dishy, G., Shi, X., Xu, Y., Phillips, S., and Dr. Yang, L. "Gender differences and vulnerability to gossip in HIV positive individuals in Botswana"

Poster for the American Psychological Association Annual Convention (August 2018)
Poku, O., Yang, L., Ho-Foster, A., Marobela, S., Mehta, H., Cao, D., Blank, L., Eisenberg, M., Opondo, P., Blank, M., Dr. Yang, L. "Qualitative Assessment of Culture Specific Stigma Measures around HIV in Gaborone, Botswana"

Poster for the National Center for AIDS Research Meeting (November 2017)
Blank, L., Yang, L., Blank, M., Ho-Foster, A., **Poku, O**., Eisenberg, M., Cao, D., Mehta, H., Yang, L., Marobela, M., Morsel, M., Opondo, P. "Identifying culturally competent aspects of gendered HIV stigma in Gaborone, Botswana"

Poster for the Society for the Study of Psychiatry and Culture (April 2015)
Min S.M., Pike K.M., **Poku O.,** "Global Representation on the Editorial Boards of the Top 10 Psychiatry Journals: A Follow-Up Study"

Five College Africa Day Panelist (Fall 2012)
Mount Holyoke College, South Hadley, MA
The 2012 Five College Africa Day theme was: What's Next in African Development? Specific topic was undergraduate thesis analysis and how it aligned with the post Millennium Development Goal (MDG) era of development thinking

LEAP (Learning from Experience) Panel (Fall 2012)
Mount Holyoke College, South Hadley, MA
Presented on a panel with three other students about research design and experience in Ghana for undergraduate thesis

Five College Africa Day Panelist (Fall 2011)
Hampshire College, Amherst, MA
Presented on a panel with five students from the Five College Consortium on agriculture and development in sub-Saharan Africa; area of research focused on school feeding programs and their progress in five countries.

SERVICE

Co-Curricular Activities

March 2020-Present **Co-Founder and Doctoral Student Collaborator**

Leadership and Education in Academic Research and Networking for Enhancing Diversity (LEARNED) Program for Minority Doctoral Students and Postdoctoral Fellows
Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

- Create mentorship connections for doctoral students and postdoctoral fellows with minority faculty
- Host networking events across departments as well as with government and nonprofit organizations
- Facilitate professional development seminars on grant writing, proposal development, and job talks

July 2019-March 2020 **Co-Founder and Co-Chair**
Underrepresented Minority Support Network
Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

- A professional and social support network for doctoral students and postdoctoral fellows who self-identify as underrepresented minorities
- Host Community building events within the school of public health and professional networking opportunities

July 2019-Present **Department Representative**
Doctoral Student Council
Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

- Member of Interdepartmental Programming Subcommittee
- Advocate for the particular needs of doctoral students including needs related to student benefits, academic and graduation requirements, and funding and tuition
- Plan and host events that foster community building among the degree programs

Editorial Activities
Ad-Hoc Reviewer Qualitative Health Research

SKILLS

Software:

- Microsoft Office Suite
- NVivo
- STATA
- Qualtrics (basic)
- Experience with SAS and R

Qualitative Data Analysis:

- Semi-structured interviews

- Focus Groups
- Inducive and deductive coding
- Photovoice
- Thematic analysis
- Participant observation
- Transcribing and Coding of Interviews
- Conceptualization and management of code books

Quantitative Data Analysis:

- Factor analysis and latent class analysis

Program Management:

- Program Evaluation
- Grant Writing
- Program/Project Budgeting and Management

Certified in CITI Human Subjects Research
Valid until: January 2023

Additional Quantitative Coursework:

- EPIC (Epidemiology and Population Health Summer Institute), Columbia University, New York, NY, Certificate of Completion of Biostatistics Course (June 2014)