

R Roudeage tater & taxes Comp mit an end

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/caic20

Women with disabilities in hearing: the last mile in the elimination of mother-to-child transmission of HIV – a cross-sectional study from Zambia

David Chipanta, Heidi Stöckl, Elona Toska, Silas Amo-Agyei, Patrick Chanda, Jason Mwanza, Kelly Kaila, Chisangu Matome, Gelson Tembo, Amaury Thiabaud, Olivia Keiser & Janne Estill

To cite this article: David Chipanta, Heidi Stöckl, Elona Toska, Silas Amo-Agyei, Patrick Chanda, Jason Mwanza, Kelly Kaila, Chisangu Matome, Gelson Tembo, Amaury Thiabaud, Olivia Keiser & Janne Estill (2022) Women with disabilities in hearing: the last mile in the elimination of mother-tochild transmission of HIV – a cross-sectional study from Zambia, AIDS Care, 34:9, 1203-1211, DOI: 10.1080/09540121.2021.1998313

To link to this article: https://doi.org/10.1080/09540121.2021.1998313



Taylor & Francis Taylor & Francis Group

OPEN ACCESS Check for updates

Women with disabilities in hearing: the last mile in the elimination of mother-tochild transmission of HIV – a cross-sectional study from Zambia

David Chipanta ^{(b)a,b}, Heidi Stöckl ^{(b)c}, Elona Toska ^{(b)d}, Silas Amo-Agyei ^{(b)e}, Patrick Chanda^f, Jason Mwanza^f, Kelly Kaila^g, Chisangu Matome^h, Gelson Tembo ^{(b)h,i}, Amaury Thiabaud^a, Olivia Keiser ^{(b)a} and Janne Estill ^{(b)a}

^aInstitute of global Health, University of Geneva, Geneva, Switzerland; ^bJoint United Nations Programme on HIV/AIDS (UNAIDS), Geneva, Switzerland; ^cMedical Faculty, Institute for Medical Information Processing, Biometry, and Epidemiology, Ludwig Maximilians University, München, Germany; ^dCentre for Social Science Research, University of Cape Town, Cape Town, South Africa; ^eDepartment of Economics Faculty of Business and Economics (HEC), University of Lausanne, Lausanne, Switzerland; ^fSocial Work and Sociology, University of Zambia, Lusaka, Zambia; ^gDisability Inclusion Project Luapula, Internatgonal Labour Organisation, Lusaka, Zambia; ^hPalm Associates Limited, Lusaka, Zambia; ⁱEconomics and Agricultural Sciences, University of Zambia, Lusaka, Zambia

ABSTRACT

This article explored the differences in HIV testing in the elimination of mother-to-child transmission of HIV (EMTCT) between women with and without disabilities aged 16–55 years, reported being pregnant and receiving the social cash transfers (SCT) social safety nets in Luapula province, Zambia. We tested for associations between HIV testing in EMTCT and disability using logistic regression analyses. We calculated a functional score for each woman to determine if they had mild, moderate or severe difficulties and controlled for age, intimate partner sexual violence, and the SCT receipt. Of 1692 women, 29.8% (504) reported a disability, 724 (42.8%) mild, 203 (12.0%) moderate, and 83 (4.9%) severe functional difficulties (adjusted odds ratio [aOR] 1.33; 95% confidence interval [CI] 1.04–1.70). Women with moderate (aOR 2.04; 95% CI 1.44–2.88) or mild difficulties (aOR 1.66; 95% CI 1.32–2.08) or with a disability in cognition (aOR 1.67 95% CI 1.22–2.29) reported testing more for HIV than women without disabilities; Women with a disability in hearing (aOR 0.36 CI 0.16–0.80) reported testing less for HIV. Disability is common among women receiving the SCT in the study area accessing HIV testing in the EMTCT setting. HIV testing in EMTCT is challenging for women with disabilities in hearing.

Introduction

New HIV infections among children acquired through vertical transmission globally have reduced by 60% from 400,000 in 2000 to 160,000 in 2018 (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2019; UNICEF, UNAIDS and WHO, 2020). However, the target of reducing mother-to-child transmission to fewer than 20,000 new child infections worldwide by 2020 has not been met. Only 78% of women in need of elimination of mother-to-child transmission of HIV (EMTCT) services in 23 focus countries, including Zambia accounting for 86% of pregnant women living with HIV accessed it in 2018 as reported by UNAIDS, United Nations Children's Fund (UNICEF) and the World Health Organization (WHO) (Joint United Nations Programme on HIV/ AIDS (UNAIDS), 2019; UNICEF, UNAIDS and WHO, 2020). HIV counselling and testing are the entry-point to the EMTCT. The Word Health Organization affirmed that women who test HIV positive can immediately access antiretroviral therapy (ART), reducing the likelihood of transmitting HIV to the baby to less than 5%, while strengthening the mother's health (World Health Organization, 2017). A systematic review by Colombini and colleagues established factors associated with low adherence to antiretroviral therapy (ART) prophylaxis for EMTCT. These included fear of stigma and partner's reaction to HIV status disclosure, lack of male involvement, and lack of education (Colombini et al., 2014). A study in South Africa by Hatcher and colleagues identified intimate partner violence as factor which may adversely impact women's mental health leading to poor adherence to ARVs in EMTCT context (Hatcher et al., 2016).

People with disabilities – defined as persons with long-term physical, mental, intellectual, or sensory

ARTICLE HISTORY

Received 6 January 2021 Accepted 18 October 2021

KEYWORDS

Antenatal clinic; EMTCT; women with disability; social cash transfers; HIV testing; disability score

CONTACT David Chipanta Chipanta@unaids.org, david.chipanta@etu.unige.ch Image: Institute of Global Health - University of Geneva, Campus Biotech, Chemin des mines 9, 1202 Genève – CH, Switzerland² Joint United Nations Programme on HIV/AIDS(UNAIDS)² 20 Avenue Appia, 1211 Geneva, 27, Switzerland This article has been corrected with minor changes. These changes do not impact the academic content of the article.

^{© 2021} The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (http://creativecommons.org/licenses/by-ncnd/4.0/), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

impairments, which may limit their equal participation in society (United Nations General Assembly, 2006) face difficulties in accessing sexual and reproductive services (United Nations Children's Fund, 2012; World Health Organization, 2009). Women with disabilities' access to sexual and reproductive health services has been studied widely. A study by Apolot and colleagues in Uganda and reports by the UNICEF and the WHO identify physical accessibility barriers - including lack of ramps, visual and hearing aids, unsuitable toilets distance to health facilities, and lack of disability-related clinical services. Poor knowledge and attitudes of health care providers, stigma, and discrimination are other barriers identified (Apolot et al., 2019; United Nations Children's Fund, 2012; World Health Organization, 2009). Apolot et al., further found that delivery and examination beds were too high for women with disabilities to climb onto. Women unable to walk had to crawl into unsanitary toilets used by non-disabled patients (Apolot et al. 2019). Studies from Botswana by Hanass-Hancock et al. (2018), Cameroon by De Beaudrap et al. (2019), Zambia by Hanass-Hancock et al. (2020), and a systematic review from sub-Sahara Africa by Ganle and colleagues support this finding (Ganle, Baatiema, Quansah, & Danso-Appiah, 2020). Few studies investigate differences in access to HIV testing between people with and without disabilities. In a study in Cameroon, Beaudrap et al. (2019) found that people with disabilities were significantly less likely than people without disabilities to have ever been tested for HIV (De Beaudrap et al., 2019). However, Beaudrap et al.'s study did not study HIV testing among pregnant women in the EMTCT context. Thus, whether disability is associated with HIV testing among women in the EMTCT context remains unexplored. This article examined the differences in HIV testing in the EMTCT context between women with and without disabilities and whether it differed by type of disabilities and severity of functional difficulties. We analysed data of a crosssection of women living in households receiving social cash transfers (SCT) social safety nets from the Government of Zambia.

Methods

Study context

The United Nations partnership on the rights of persons with disability (UNPRPD) funded project in Luapula, province, Zambia sought to provide integrated HIV, sexual and reproductive health and social protection services to adolescent girls and women with disabilities receiving the SCT. The International Labour Organisation implemented the project in collaboration with the government of Zambia and UN agencies (United Nations Partnership on the Rights of Persons with Disabilities, 2020). We collected baseline data for the evaluation of this project from August to September 2019 in Kawambwa, Mansa, Nchelenge, and Samfya districts of Luapula province, 760 kilometres north of Lusaka, Zambia's capital, which we used for this analysis.

The provinces' adult (15–49 years) HIV prevalence (7.7%; 9.9% for women and 5.4% for men) is lower than the national prevalence (11%). HIV testing and receipt of results during antenatal clinic (ANC) visits (80.3%) is also lower than the national level (82%) (Zambia Statistics Agency, Ministry of Health (MOH) Zambia, and ICF, 2019).

To reduce extreme poverty, the Government of Zambia started the SCT programme in 2010. Eligible households with a person with disability received monthly payments of ZMK360 (USD24) and ZMK180 (USD12) without a person with a disability, deemed sufficient to purchase a meal daily for a month (Government of Republic of Zambia, MCDSW, 2020).

Study population

The study sample was drawn from women aged 16–55 years who reported being pregnant at least once, answered the questions on HIV testing in ANC, and were living in households receiving the SCT. Households are eligible to receive the SCT if government authorities identify them as extremely poor (live on less than US1.25) and satisfy one of the following criteria: women-headed; headed by a person aged 65 years or older; have a member with a disability; have adult members who are unable to work, or support themselves economically and host any child below 18 years who has lost one or both parents to HIV or lives in a community affected by HIV.

Data sources

Our sample size calculation assumed an intervention effect (δ) on a range of HIV services, including HIV knowledge, testing, prevalence and treatment rates of at least 0.20, a statistical significance (α) of 0.05, the statistical power of 80% and Intra-class Correlation Coefficients (p) of 0.01–0.08 as calculated by Handa and colleagues (Handa, Hoop, Morey, & Seidenfeld). In stage one we sampled CWACs using proportional probability sampling to enable sampling of CWACs with a more significant concentration of households and services to be selected. In stage 2 from each CWAC, we sampled 25 households.

We used for multi-level and longitudinal research version 3.01 written by Raudenbusg and colleagues (Raudenbush et al., 2011) to calculate a minimum sample size of 2000 households, cluster size (*n*) of 25 households, and 90 clusters (CWACs).

Procedures

We derived the questions from piloted and validated tools, including the UNAIDS HIV and Social Protection Assessment 2017, UNICEF Innocent Survey Tools, Demographic Health Survey, Population HIV Impact Assessment Survey questions, and the WGSQ (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2017; Joint United Nations Programme on HIV/AIDS (UNAIDS), 2017; UNICEF, University of North Carolina Carolina Population Center, Food and Agriculture Organisation; Washington Group on Disability Statistics, 2018; International Centre for Aids care and treatment program; The Demographic and Health Surveys Program, 2020). We translated the questions into the local language. We trained the field workers on how to effectively administer the questionnaire. They role played by them is the administration of the questionnaire to ensure clear understanding and standardized administration of the questionnaire. Before data collection, the questionnaire was piloted in a community comparable to the survey area. It worked well, and we made no changes to the questionnaire. The questionnaire contained questions on socio-demographic characteristics, maternal and HIV service use, experiences of sexual intimate partner violence, disability status, and receipt of SCT. Trained fieldworkers administered the household questionnaire to the household head and all household members aged 16 years or older in the local language of the area after obtaining consent from every respondent. They recorded the responses on Open Data Kit software templates on electronic tablets (Open Data Kit, 2021). We stored the data electronically and transferred it to a secure server.

Outcomes

The primary outcome was having tested for HIV during an ANC visit. It was operationalized as having tested for HIV during ANC visits while pregnant, coded yes, no. The primary predictor was disability. We used the Washington Group Short Questions (WGSQ) on disability, which are internationally accepted and used to understand disability among adults (Washington Group on Disability Statistics, 2018). The WGSQ asks if participants faced difficulties performing six essential daily functions: Seeing even if wearing glasses; hearing

even if using a hearing aid; walking or climbing up the stairs; cognition, that is remembering or concentrating; self-care such as washing or dressing; and communicating using usual language, for example for understanding or being understood. See Appendix 1. The response options are No, A little, A lot, and Cannot at all. The functional difficulties range from A little, to Cannot at all. Anyone answering A lot or Cannot at all on at least one of the six questions is considered disabled in the disability type they answered, each coded Not Disabled, Disabled. A composite disability variable combined reports of A lot or Cannot at all in any of the six disability type - Seeing, Hearing, Walking, Cognition, Self-care, and Communicating - also coded Not Disabled, Disabled (Washington Group on Disability Statistics, 2018) (Washington Group on Disability Statistics, 2017, October, 23).

We calculated an overall functional score for each woman by summing the following scores from all six types of disability: 0 (No), 2 (A little), 3 (A lot), and 4 (cannot at all) to determine the severity of the functional difficulties. A score of 2–5 was defined as mild, 6–8 moderate, and 9–24 severe functional difficulties. For example, a respondent reporting a little (2) difficulty in 4 of the 6 areas and "No difficulty" in 2 of the 6 areas would score 8 ($(4 \times 2 = 8) + (2 \times 0 = 0)$), falling under moderate difficulties. This followed the Washington Group Short Questions analytical guidance (Washington Group on Disability Statistics, 2018).

We included age, categorized into the age brackets 16-24, 25-34, 35-55 years and No answer; experience of sexual intimate partner violence - In the last 12 months, has your current or former partner ever physically forced you to have sexual intercourse when you did not want to? (No, Yes); and receipt of SCT in Zambian Kwachas - What is the total value of the assistance received from the SCT in the last 12 months? The amount of SCT received was reported exactly but categorized as 0-179, 180-539, 540-560, and >560. In a qualitative study in South Africa, Hatcher et al. found that intimate partner sexual violence caused depression and anxiety that led to missing medication or stopping ARV treatment for EMTCS (Hatcher, et al., 2016). In contrast, cash transfers have been known to improve access to EMTCT services, as shown by randomized control trials results in the Democratic Republic of the Congo by Yotebieng and colleagues and Nigeria by Liu and colleagues (Yotebieng et al., 2016; Liu et al., 2019).

Statistical analyses

We reported descriptive statistics for sample characteristics by disability, disability's distribution by type of

disabilities, and severity of functional difficulties. We conducted univariable and multivariable logistic regression analyses to explore the association between testing for HIV during ANC visits and disability. We controlled for age, the experience of sexual intimate partner violence and receipt of the SCT, in the multivariable analysis. We tested for association between tested for HIV during ANC visits and disability in three steps. In step 1, we tested for associations between being tested for HIV during ANC visits and functional difficulties (No limitations, No disability), Mild, Moderate, or Severe. In step 2, we examined differences between ever tested for HIV (No, Yes) by disability types - Seeing, Hearing, Walking, Remembering, Selfcare, and Communicating. In step 3, we tested for associations between tested for HIV during ANC visits and the types of disability, age, the experience of intimate partner sexual violence, and receipt of the SCT.

When conducting multiple hypothesis tests, the probability of making a Type I error (obtaining p-value that are significant by chance) is more significant. We therefore controlled p-values for multiple hypothesis testing using Michael Andersons' code for the False Discovery Rate (FDR) sharpened q's (Anderson, 2008). Thus, instead of p-values we report in this study FDR sharpened q-values. We report q-values as we would for p-values. Q-values below critical value 0.05 were considered statistically significant. Missing values if less than 5% of the sample were dropped in the analysis. Analyses were adjusted for clustering at the CWAC level and conducted in Stata/SE 14.1.

The study protocol was reviewed by the University of Zambia Humanities and Social Sciences Research Ethics Committee (IRB Approval No. 2019-April-001) and the ethics committee responsible for approving research conducted by investigators based in Geneva (no 2019-00500).

Results

The study sample comprised 1692 women aged 16–55 years who got pregnant at least once and answered they were tested for HIV during ANC visits or not. Their median age was 30 years, interquartile range of 22–44. We excluded missing data from analyses. Data were missing for less than five per cent of respondents. Of the 1692 women in the study, 29.9% (504) reported a disability, i.e., Reported difficulty of A lot or Cannot at all in at least one of the six functional domains (Table 1). A total of 724 (42.8%) respondents reported mild, 203 (12%) moderate and 83 (4.9%) severe functional difficulties. Disabilities in remembering (17.5%; n =

296), seeing (10.8%; n = 182), and walking (9.3%; n = 157) were reported most often (Annex 1).

More women with disabilities reported testing for HIV during ANC visits than women without disabilities (66.0%; n = 340) versus (57.9%; n = 681, Q = 0.001). The proportion of women with disabilities increased with age, from 18.3% (88/482) among 16–24-year-olds to 55.6% (268/482) among women aged 35–55 years. Women with disabilities received ZMK 540 or more in the past 12 months, an amount that was often more than what was reported by women with no disabilities (Table 1).

Women with disabilities (adjusted odds ratio [aOR] 1.33; 95% confidence interval [CI] 1.04–1.70), and those with moderate (aOR 2.04; 95% CI 1.44–2.88) or mild difficulties (aOR 1.66; 95% CI 1.32–2.08) were significantly more likely to report ever tested for HIV than women with no disabilities (no difficulties) even after adjusting for age, the experience of intimate partner sexual violence and level of the SCT (Table 2).

Compared to women without disabilities, women with a disability in cognition were more likely to report ever testing for HIV during ANC even after accounting for age, the experience of intimate partner sexual violence, and level of the SCT (Table 3). Women with a disability in hearing were less likely to test for HIV than women with no disabilities.

Discussion

This study examined the differences in testing for HIV in the EMTCT context between women with and without disabilities by the severity of the functional

 Table 1. Characteristics of respondents.

Variable	Disabl	ed (%)	Not disabled (%)		q-value	Total
Testing in ANC						
No	164	32.5	496	42.1		660
Yes	340	67.5	692	57.9		1032
Total	504	100	1188	100	0.001	1692
Age Groups	Total		Total			
16-24	88	17.5	441	37.1		529
25-34	126	25.0	294	24.7		420
35-55	268	53.1	435	36.6		703
Missing	22	4.4	18	1.52		40
Total	504	100	1188	100	0.001	1692
Experience of s	exual vio	lence				
No	436	86.5	998	84,0		1434
Yes	34	6.7	69	5,8		103
No answer	34	6.7	121	10,2		155
Total	504	100	1188	100	0.106	1692
Social Cash Tra	nsfer					
0-179	78	15.5	120	10.1		198
180-539	375	74.4	990	83.3		1365
540-560	28	5.6	40	3.4		68
> 560	18	3.6	27	2.4		46
Missing	5	1.0	10	0.8		15
Total	504	100	1188	100	0.01	1692

 Table 2: Differences in likelihood of HIV testing in antenatal clinic by functional severity.

Odds	ratio (95% Confidence Interval) Wald Test-q value
	Model 1: Functional severity Unadjusted	Model 2: Functional severity Adjusted
No Limitations (0)	1	1
Disabled	1.49 (1.19 - 1.85) <i>0.001</i>	1.33 (1.04 - 1.70) <i>0.027</i>
Mild (2-5)	1.73 (1.39 - 2.15) <i>0.001</i>	1.66 (1.32 - 2.08) <i>0.001</i>
Moderate (6– 8)	2.17 (1.52 - 3.09),	2.04 (1.44 - 2.88)
Severe (9-24)	1.28 (0.82- 1.99),	1.20 (0.70 - 2.05)
N	1,692	1,637

difficulties and type of disability in four districts of Luapula province, Zambia. We found that a third of women receiving SCT attending antenatal clinic visits reported a disability in at least one of the six functional domains. Second, compared to women with no disabilities, women with disabilities in general, those with a disability in cognition, or those with mild or moderate functional difficulties, were more likely to have been tested for HIV during ANC. Women with disability in hearing were less likely to have been tested.

We found that disability was common among women receiving the SCT and attending ANC as expected, for several reasons. First, Luapula province, including the study districts has the largest concentration of people with disability in Zambia (Central Statistical Office, Ministry of Community Development and Social Services, 2018). Second, women with disabilities are among the primary focus populations of the SCT, and many cash transfers programmes in Sub-Saharan Africa. Third, contrary to widespread beliefs women with disabilities are not asexual. They are sexual, do get pregnant, and visit ANCs. In our study, all 504 women with disabilities, a third of the sample, reported being pregnant before and attended antenatal clinic for pregnancy-related care. A total of 12% of women in the sample reported moderate and 4.9% severe functional difficulties. This result is consistent with the prevalence of functional difficulties observed by Mitra and colleagues in Ethiopia, Malawi, Tanzania, and Uganda (Mitra, 2018). ANC and EMTC services need to consider the needs of diverse women with disabilities. Appropriate communication materials in large prints, simple language, small amounts of texts and pictures that women with cognitive and visual difficulties may remember and see may need to be included in EMTCT services. EMTCT providers need to partner with relevant authorities to provide mobility equipment such as tricycles, and transport to enhance women with disabilities' access to EMTCT services (World Health Organization, 2009; United Nations Children's Fund, 2012). They

Main predictor	See	ing	Неа	ring	Walk	king	Cogr	iition	Self-	care	Commu	nicating
	Unadjusted	Adjusted										
Not Disabled	-	1	-	-	-	-	-	-	-	-	-	-
Disabled	1.38	1.28	0.39	0.36	1.10	0.99	1.81	1.67	0.64	0.62	0.18	0.08
	(0.97 - 1.96)	(0.84 - 1.94)	(0.20 - 0.76)	(0.16 - 0.80)	(0.79 - 1.54)	(0.68 - 1.44)	(1.34 - 2.44)	(1.22 - 2.29)	(0.29 - 1.39)	(0.25 - 1.54)	(0.04 - 0.86)	(0.01 - 0.42)
Wald test <i>q</i> -value	0.100	0.185	0.014	0.025	0.343	0.399	0.001	0.003	0.185	0.209	0.057	0.008
	1,691	1,636	1,692	1,637	1,692	1,637	1,692	1,637	1,692	1,637	1,692	1,637

might need also to bring HIV testing to women with disabilities' homes and communities including through mobile testing.

Our second results give more nuance to two contradicting strands of evidence. One result is that women with disabilities in general access maternal health and reproductive services, including the EMTCT services. This finding is supported by results obtained from studies by Mulindwa (2003); Smith, Murray, Yousafzai, & Kasonka, 2004; Bremer, Cockburn, & Ruth, 2010; De Beaudrap, et al., (2019). Our study finds that women with disabilities in general and those with a disability in cognition, or with mild or moderate functional difficulties reported testing for HIV during ANC more than their non-disabled peers. Women with disabilities and those with mild or moderate difficulties in our study might have sought more health care relating to their condition and antenatal needs. They might have had more opportunities for HIV testing. Further, women with disabilities and those with mild or moderate difficulties and visible disabilities – as might happen for women with a disability in cognition - might have received preferential treatment at the health facility, as suggested by a qualitative study in Zambia by Yoshida and colleagues. (Yoshida, Hanass-Hancock, Nixon, & Bond, 2014).

This result contradicts previous studies that found that the severity of functional difficulties negatively impacted access to HIV services (De Beaudrap et al., 2019) and the study by Trani et al. (2011). These studies found that women with disabilities do not access sexual and reproductive health services. However, both contradictory studies support our supplementary second result which is that women with a disability in hearing reported less likely to test for HIV in EMTCT context than non-disabled peers. Difficulties in communicating between women with disabilities in hearing and health care staff are common. These difficulties might explain why women with disabilities in hearing in our study reported less likely to test for HIV. The study by Morrison and colleagues which found that health care staff often experience difficulties communicating with women with disabilities supports this argument (Morrison et al., 2014). EMTCT services need to strengthen their accommodation of women with disabilities in hearing while innovating ways to reach them with EMTCT services. Strategies to effectively reach women with disabilities in hearing include engaging them as peer educators and employing sign language interpreters. Health care providers should include short disability screening questions for women attending ANC to identify women with disabilities in hearing to offer them tailored EMTCT services.

Our study has several limitations. We did not have information on the timing of the pregnancies and HIV testing nor the duration of the disabilities. Therefore, we cannot ascertain whether intimate partner violence, disability, SCT receipt, pregnancy-related HIV testing occurred concurrently. Capturing the timing and duration of disability is challenging. Responses might have been recalled incorrectly, especially by women with cognition difficulties. The WGSQ do not measure cognition difficulties well as argued De Beaudrap et al. (2020). We could not validate responses with independent sources such as patient charts. The distribution of types of disability was low especially for women with disabilities in self-care (n = 9) and communicating (n = 24) undermining the power of this study to make inference on access to HIV testing in EMTCT context for women with disabilities in selfcare and communicating. However, we generated a crucial insight that vulnerable women with disabilities in hearing, may be among the last mile in the EMTCT, requiring EMTCT interventions that focuses on their needs.

Conclusion

Disability is common among women receiving the SCT in the study area testing for HIV in the ANC. HIV testing as the first step for EMTCT is challenging for women with disabilities in hearing. EMTCT interventions need to include the needs of diverse women with disabilities especially those with disabilities in hearing to protect their health and attain the goals of EMTCT of HIV. More data and research are required to understand effective interventions to include women with disabilities in hearing in EMTCT programmes.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Acknowledgements

We acknowledge financial support from the United Kingdom Research in Innovation (UKRI) Global Challenges Research Fund (GCRF) Accelerating Achievement for Africa's Adolescents Hub (Principal Investigator Prof. Lucie Cluver). Olivia Keiser was supported by the Swiss National Science Foundation (grant no 163878).

We acknowledge the support of the Ministry of Community Development and Social Welfare, Ministry of Health, National AIDS Council, the Global Fund to Fight AIDS TB and Malaria Zambia Country Co-ordinating Mechanism secretariat. The Joint United Nations Programme on HIV/AIDS (UNAIDS), and the International Labour Organisation, are appreciated for their support.

Funding

This work was supported by United Kingdom Research in Innovation (UKRI) Global Challenges Research Fund (GCRF) Accelerating Achievement for Africa's Adolescents Hub (Principle Investigator Prof. Lucie Cluver); Swiss National Science Foundation.

Author contributions

Conceived the study: DC, OK JE HS. Led data collection: DC, AT, MC, GT. Data analyses was performed by DC. HS, OK, ET, JE, SA, contributed towards data analysis. DC drafted the manuscript. HS, ET, OK JE, PC, JM, SA, KK, MC, GT, and PGF commented on the drafts. DC revised the draft. HS, OK, JE, ET made additional comments on the revised draft, which DC incorporated.

Disclaimer

Information in this article are the views of authors and not of UNAIDS, ILO nor other institutions listed.

ORCID

David Chipanta b http://orcid.org/0000-0002-7909-6855 Heidi Stöckl b http://orcid.org/0000-0002-0907-8483 Silas Amo-Agyei b http://orcid.org/0000-0001-9718-6363 Elona Toska b http://orcid.org/0000-0002-3800-3173 Gelson Tembo b http://orcid.org/0000-0002-8586-9631 Olivia Keiser b http://orcid.org/0000-0001-8191-2789 Janne Estill b http://orcid.org/0000-0001-9544-1447

References

- Anderson, L. M. (2008). Multiple inference and gender differences in the effects of early intervention: A reevaluation of the Abecedarian, Perry preschool, and early training projects. *Journal of the American Statistical Association*, 103(484), 1481–1495. https://doi.org/10.1198/016214508000000841
- Apolot, R.R; Ekirapa, E., Waldman, L., Morgan, R., Aanyu, C., Mutebi, A., Nyachwo, E. B., Seruwagi, G. & Kiwanuka, S. N., (2019) Maternal and newborn health needs for women with walking disabilities. "The twists and turns": A case study in Kibuku District Uganda 2019. *International Journal for Equity in Health, 18*, Article number: 43. https://doi.org/10.1186/s12939-019-0947-9
- Bremer, K., Cockburn, L., & Ruth, A. (2010). Reproductive health experiences among women with physical disabilities in the Northwest Region of Cameroon. *International Journal of Gynecology & Obstetrics 108*(3), 211–213. https://doi.org/10.1016/j.ijgo.2009.10.008
- Central Statistical Office, Ministry of Community Development and Social Services. (2018). Zambia National Disability Survey 2015. Central Statistical Office, Ministry of Community Development and Social Services, Government of the Republic of Zambia Lusaka.

- Colombini, M., Stöckl, H., Watts, C., Zimmerman, C., Agamasu, E., & Mayhew, S. H. (2014). Factors affecting adherence to short-course ARV prophylaxis for preventing mother-to-child transmission of HIV in sub-Saharan Africa: A review and lessons for future elimination. *AIDS Care*, 26(7), 914–926. https://doi.org/10.1080/09540121. 2013.869539
- Conditional cash transfers to increase retention in PMTCT care, antiretroviral adherence, and postpartum virological suppression: A randomized controlled trial. *Journal of Acquired Immune Deficiency Syndromes*, 72(Suppl 2), S124–S129. https://doi.org/10.1097/QAI.000000000001062.
- Conditional cash transfers to prevent mother-to-child transmission in low facility-delivery settings: Evidence from a randomised controlled trial in Nigeria. *BMC Pregnancy and Childbirth*, 19(32), https://doi.org/10.1186/s12884-019-2172-3.
- De Beaudrap, P. (2019). Disability and HIV/AIDS in West Africa: A combined analysis of 4 studies conducted in Burkina Faso, Niger, Guinea-Bissau and Cape Verde. Humanity and Inclusion Lyon.
- Ganle, J. K., Baatiema, L., Quansah, R., & Danso-Appiah, A. (2020, October). Barriers facing persons with disability in accessing sexual and reproductive health services in sub-Saharan Africa: A systematic review. *Plos One*, *15*(10), e0238585. https://doi.org/10.1371/journal.pone.0238585
- Government of Republic of Zambia, MCDSW. (2020). SCT First quarter report 2020, Ministry of Community Development and Social Welfare Department of Social Welfare Lusaka.
- Hanass-Hancock, J., Taukobong, D., Keakabetse, T., & Mthethwa, N. (2018). *Preventing violence against women and girls with disabilities in Botswana situation analysis.* ALIGHT BOTSWANA.
- Handa S., Hoop, T. D., Moorey, M., & Seidenfeld, D. 2021. ICC Values in International Development. Evidence across many domains in subSaharan Africa.
- Hatcher, A. M., Stöckl, H., Christofides, N., Woollett, N., Pallittoe, C. C., Garcia-Morenoe, C., & Turan, J. M. (2016). Mechanisms linking intimate partner violence and prevention of mother-to-child transmission of HIV. A qualitative study in South Africa Social Science & Medicine, 168. https://doi.org/10.1016/j.socscimed.2016. 09.013130-139
- Joint United Nations Programme on HIV/AIDS (UNAIDS). (2017). HIV and social protection assessment tool. Generating evidence for policy and action on HIV and social protection. Joint United Nations Programme on HIV/AIDS (UNAIDS), Geneva.
- Joint United Nations Programme on HIV/AIDS (UNAIDS). (2019). Start Free Stay Free AIDS Free Report Joint United Nations Programme on HIV/AIDS (UNAIDS) Geneva.
- Mitra, S. (2018). The human development model of disability, health and wellbeing. In *Disability, health and human development. Palgrave studies in disability and international development* (pp. 9–32). Palgrave Pivot.
- Morrison, J., Basnet, M., Budhathoki, B., Adhikari, D., Tumbahangphe, K., Manandhar, D., Costello, A., Groce, N. (2014). Disabled women's maternal and newborn health care in rural Nepal: a qualitative study. *Midwifery 30* (11):1132–1139. https://doi.org/10.1016/j.midw.2014.03.012.

Mulindwa, N. (2003). Study on reproductive health and HIV/ AIDS among persons with disabilities in Kampala, Katakwi and Rakai Districts. Disabled Women's Network and Resource Organisation (DWNRO).

Open Data Kit. (2021). OpenDataKit.org.

- Raudenbush, S. W., Spybrook, J., Congdon, R., & Liu, X. (2011). Optimal design software for multi-level and longitudinal research (Version 3.01).
- Smith, E., Murray, S. F., Yousafzai, A. K., & Kasonka, L.. Barriers to accessing safe motherhood and reproductive health services: The situation of women with disabilities in Lusaka, Zambia. (2004). *Disability and Rehabilitation*, 26(2), 121– 127. https://doi.org/10.1080/09638280310001629651.
- The Demographic and Health Surveys Program. Retrieved June 21, 2021, from https://dhsprogram.com/Data/: https://dhsprogram.com/Data/ 2020). *The DHS Program Data*.
- The multidimensional vulnerability of people with disability to HIV infection: Results from the handi SSR study in Bujumbura. Burundi https://doi.org/10.1016/j.eclinm. 2020.100477 Volume 25: 100477
- The Population HIV Impact Assessment Project ICAP. Columbia University New York. https://icap.columbia. edu/tools-resources/
- Trani, J. F., Browne, J., Kett, M., Bah, O., Morlai, T., Bailey, N., & Groce, N. (2011). Access to health care, reproductive health and disability: A large scale survey in Sierra Leone. *Social Science & Medicine*, 73(10):1477–1489. https://doi. org/10.1016/j.socscimed.2011.08.040
- UNICEF. University of North Carolina, Carolina Population Center, Food and Agriculture Organisation. The Transfer Project UNICEF, University of North Carolina Carolina Population Center, Food and Agriculture Organisation UNICEF Office of Research - InnocentiInnocenti. https:// www.unicef-irc.org/
- UNICEF. UNAIDS and WHO. (2020). Key considerations for programming and prioritization. Going the 'Last Mile' to EMTCT: A road map for ending the HIV epidemic in children UNICEF New York.
- United Nations Children's Fund. (2012). Women with disabilities: An essential group for MTCT elimination A note on bottlenecks and priorities for action. United Nations Children's Fund New York.

- United Nations General Assembly. (2006). Convention on the Rights of Persons with Disabilities (CRPD). United Nations Department of Economic and Social Affairs Disability.
- United Nations Partnership on the Rights of Persons with Disabilities. (2020). Promoting disability inclusion in HIV, sexual and reproductive health and social protection in Luapula Province in Zambia.
- Washington Group on Disability Statistics. (2018). *Disability* measurement and monitoring using the Washington Group Disability Questions. United Nations Statistical Commission. Washington Group on Disability statistics. Hyattsville.
- Washington Group on Disability Statistics. (2017, October 23). The data collection tools developed by the Washington Group on Disability Statistics and their recommended use. United Nations Statistical Comission Washington Group on Disability Statistics Hyattsville.
- World Health Organization. (2017). Global guidance on criteria and processes for validation: Elimination of motherto-child transmission. World Health Organization Department of HIV/AIDS Geneva.
- World Health Organization , and United Nations Population Fund. (2009). Promoting sexual and reproductive health for persons with disabilities. WHO/UNFPA guidance note. World Health Organization. https://apps.who.int/ iris/handle/10665/44207
- Yoshida, K., Hanass-Hancock, J., Nixon, S., & Bond, V. (2014). Using intersectionality to explore experiences of disability and HIV among women and men in Zambia. (2014). *Disability and Rehabilitation*, 36(25), 2161– 2168https://doi.org/10.3109/09638288.2014.894144.
- Yotebieng, M., Thirumurthy, H., Moracco, K. E., Edmonds, A., Tabala, M., Kawende, B., Wenzi, L. K., Okitolonda, E. W., & Behets, F. (2016). Conditional cash transfers to increase retention in PMTCT care, antiretroviral adherence, and postpartum virological suppression: a randomized controlled trial. *Journal of Acquired Immune Deficiency Syndromes (1999)*, 72(Suppl 2), S124 -S129. https://doi.org/10.1097/QAI.00000000001062
- Zambia Statistics Agency, Ministry of Health (MOH) Zambia, and ICF. (2019). 2018 Zambia Demographic Health Survey Report. Lusaka, Zambia. Zambia Statistics Agency, MOH, and ICF, and ICFLusaka and Rockville, Maryland.

Appendices

Annex 1: Washington Group on Disability Short Questions

VISION

[Do/Does] [you/he/she] have difficulty seeing, even if wearing glasses? Would you say ... [Read response categories] 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all.

HEARING

[Do/Does] [you/he/she] have difficulty hearing, even if using a hearing aid(s)? Would you say ... [Read response categories] 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all.

MOBILITY

[Do/Does] [you/he/she] have difficulty walking or climbing steps? Would you say ... [Read response categories] 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all.

COGNITION (REMEMBERING)

[Do/does] [you/he/she] have difficulty remembering or concentrating? Would you say ... [Read response categories] 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all.

SELF-CARE

[Do/does] [you/he/she] have difficulty with self-care, such as washing all over or dressing? Would you say... [Read response categories] 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all.

COMMUNICATION

Using [your/his/her] usual language, [do/does] [you/he/she] have difficulty communicating, for example understanding or being understood? Would you say ... [Read response categories] 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all 7. Refused 9. Don't know.

Annex 2: Distribution of types of disability

Type of Disability	Freq	%
Seeing, even if wearing glasses		
Not Disabled	1509	89,2
Disabled	182	10,8
Missing	1	
Total	1692	100,0
Hearing, even if using a hearing aid		
Not Disabled	1653	97,7
Disabled	39	2,3
Total	1692	100,0
Walking or climbing up the stairs		
Not Disabled	1535	90,7
Disabled	157	9,3
Total	1692	100,0
Cognition		
Not Disabled	1396	82,5
Disabled	296	17,5
Total	1692	100,0
Self-care, such as washing or dressing		
Not Disabled	1668	98,6
Disabled	24	1,4
Total	1692	100,0
Communicating using usual language		-
Not Disabled	1683	99,5
Disabled	9	0,5
Total	1692	100,0
Functional score (total score 24)		-
No limitation (0)	682	40,3
Mild (2-5)	724	42,8
Moderate (6-8)	203	12,0
Severe (9 - 24)	83	4,9
Total	1692	100