

Reproductive decisions of couples living with HIV in Malawi: What can we learn for future policy and research studies?

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Abstract

Background

The rapid scale-up of free antiretroviral therapy has led to decline in adult mortality at the population level and reduction of vertical transmission. Consequently, some couples living with HIV are maintaining their reproductive decisions; marrying and having children. This paper analyses policies and guidelines on HIV, AIDS and sexual and reproductive health in Malawi for content on marriage and childbearing for couples living with HIV.

Methods

A qualitative study using interpretive policy analysis approach was conducted from July to December 2010 in two phases. First, data on access to HIV, AIDS and sexual and reproductive health services were collected using in-depth interviews with twenty couples purposively sampled in matrilineal Chiradzulu and patrilineal Chikhwawa communities. Secondly, data were collected from Malawi policies and guidelines on HIV, AIDS and sexual and reproductive health. The documents were reviewed for content on marriage and childbearing for couples living with HIV. Data were analysed using framework approach for applied policy analysis.

Results

Four categories emerged from each phase. From the study, we extracted health workers attitudes, weak linkage between HIV, AIDS and sexual and reproductive health services, contradictory messages between media and the hospitals and lack of information as factors directly related to guidelines and policies. Analysis of guidelines and policies showed non-prescriptiveness on issues of HIV, AIDS and reproduction: they do not reflect the social cultural experiences of couples living with HIV. In addition, there is; lack of clinical guidelines, external influence on adoption of the policies and guidelines and weak linkages between HIV and AIDS and sexual and reproductive health services.

Conclusion

This synthesis along with more detailed findings which are reported in other published articles, provide a strong basis for updating the policies and development of easy-to-follow guidelines in order to effectively provide services to couples living with HIV in Malawi.

Introduction

Worldwide there is a dramatic reduction in HIV related morbidity and mortality and consequently improvements in quality of life. One of the main drivers is the introduction of antiretroviral therapy (ARV)¹⁻³. This has resulted in an increase in the number of people living with HIV (PLWH)^{4,7}. In addition, ARVs have decreased perinatal HIV transmission

to less than 2%, thereby reducing PLWH concerns regarding HIV transmission to their infants⁸. The ability of ARVs in suppressing HIV replication, thereby increasing the CD4 cell count, delaying clinical progression of AIDS and prolonging survival, has made HIV infection to be considered as a chronic illness⁹. As a result, PLWH are reconsidering their reproductive decisions (getting married, having children)^{3,10}.

In Malawi, antiretroviral therapy was initiated in 2004 and since then, treatment is available free of charge in the public hospital facilities. The antiretroviral therapy can also be obtained at a subsidised rate from private hospital facilities¹¹. In prevention of mother to child transmission of HIV (PMTCT), Malawi started implementing an integrated antiretroviral / PMTCT programme from 2011, following adoption and adaptation of the 2010 WHO recommendations. As a result, all HIV positive pregnant women, regardless of their CD4 count, are now put on a more efficacious regime for life¹². The rapid scale-up of free antiretroviral therapy has led to decline in adult mortality at the population level¹³ and reduction of vertical transmission¹⁴. With these strides, deaths from AIDS have been averted hence, some couples living with HIV are maintaining their reproductive decisions¹⁵. Despite the demonstrated interest by PLWH in establishing marriage relationships with spouses living with HIV and having children, the medical community has continued to be slow to support and has even discouraged PLWH in pursuing their right to their decisions¹⁶. The issue is also reported across the world. Health workers perceptions, preferences and values have consciously or unconsciously determined the choices available to PLWH^{2,6,17-20}. However, there is little by way of systematic understanding of reasons for the problem.

The aim of the paper is to explore gaps in the policies and guidelines on HIV, AIDS and sexual and reproductive health in Malawi against marriage and childbearing decisions of couples living with HIV.

Methods

In exploring the reasons for policy-practice gaps in this study, the interpretive approach of policy analysis was adopted, in which events and phenomena are viewed through the lens of the interpretations of participant actors²¹. This approach relies on in-depth qualitative research methods. In addition, a qualitative approach was deemed most appropriate because there is very little existing research that has been conducted thus far. In addition, exploration of the marriage and childbearing in PLWH involves sensitive, emotive and personal topics that can be best captured through careful probing using qualitative in-depth interviews (IDI).

The approach involves four steps: identifying key components, identifying interpretive community, identifying discourses through which these meanings are communicated and identify any point of conflict that suggests that different groups attach divergent meanings to some aspect of a policy²¹. In this study, those four areas are used to inform the analysis.

Following ethical approval from the research and ethics committees in Malawi, College of Medicine Research Ethics Committee (COMREC) and Norway, Regional Committees

for Medical Research Ethics (REK), forty informants (20 couples) were recruited from ART clinics involved in the treatment and care of PLWH at two HIV and AIDS centres in southern Malawi. The centers were Ngabu Health Center, in Chikhwawa and Ndunde Health Center, in Chiradzulu. Informants who were; HIV-positive (concordant couples), had informed about each other's HIV status as a couple, in the reproductive age group of 18 to 49 years²² and had a child while living with HIV were recruited for the study. The sample size was determined based on principles of saturation and Kuzel,²³ who recommends a sample size of twelve to more data sources when trying to achieve maximum variation.

Oral consent was opted for because asking them to give a written consent would have been unethical in terms of confidentiality. To further protect confidentiality, a coding system was devised to refer to each informant. The informants who consented were assured of confidentiality and informed that they were free to withdraw from the study if they so wished. No incentive was offered for participation. During the research all, the informants were provided transport reimbursements of \$2 and snacks.

The researcher conducted in-depth interviews in the vernacular language. An interview guide was employed to ensure coherence in the study approach and to give the interview sessions a general direction concerning topics raised and discussed. The guide comprised a section on demographic characteristics. It also had an outline of topics with open-ended questions covering access to HIV, AIDS, sexual and reproductive health services. The guide was carefully translated from English to Chichewa. The quality of a translation was verified by an independent translator: who translated it back into the original language. Original and back-translated documents were then compared for consistency by the interviewer.

Ritchie & Spencer,²⁴ framework approach for applied policy analysis: familiarization; identifying a thematic framework; indexing; charting; and mapping and interpretation was used to organize and analyze the data. Apart from being recommended as an excellent tool to assess policies and procedures from the very people that they affect, the analysis also allowed the coding process to remain iterative.

Transcripts from the informants on access to HIV, AIDS and sexual and reproductive health services were read through several times in order to obtain a sense of the whole. Then text that reflected barriers to HIV, AIDS and reproductive health services were brought together as one text. We then extracted texts that were related to policy and guidelines. A two level of thematic codes was developed: emergent issues arising from informants' narratives and analytical themes based on emergent themes.

Likewise, the policies and guidelines obtained from Malawi Reproductive Health and HIV and AIDS units and the two study sites, Ngabu rural hospital and Ndunde health centre, where our study on reproductive decisions was under way were also analysed. A two level of thematic codes was developed: a priori themes drawing on the emergent issues arising from informant's narratives and analytical themes following document review.

In order to ensure inter-rater consistency, once the coding team independently analysed each transcripts and documents, tentative categories of the codes were discussed between the researchers who initially did the coding independently. When

the coding was compared, a few differences were observed. These were discussed and re-analysed resulting into fine-tuning of the coding and interpretations. NVivo version 9 was used to organize the data.

Results

Analysis of findings: study on reproductive decisions of couples living with HIV in rural Malawi

The interviews revealed several themes, which were highly interrelated, thus could naturally be located under any of the themes. The presentation below was nonetheless chosen as the best way to guide the reader through the informants' elicitation. We limit reporting our results to four main categories; health workers attitudes, weak linkage between services, contradictory messages and lack of information. These four reflected the most common themes / dominant explanations expressed by the informants. In addition, they were found to be directly related to issues of policies and guidelines.

Health workers' attitudes

Despite negative reactions from health workers on child bearing and marriage, PLWH re-marry, re-marry spouses who are also living with HIV following divorce or death of the spouse and have children in these newly established marriage relationships. One informant eloquently captured this theme by stating:

"Tiii! They [health workers] are not happy to see us re-marrying. In my case one day I was confronted by... [HIV counsellor] that he had heard that I was in a relationship with a man who is also on treatment [ARV]. He said; 'Have you already forgotten how sick you were? If you want to live longer, you must not re-marry because you will end up acquiring more viruses [HIV].' However, I told him that I was healthy and fit to re-marry, was still young by then I only had one child from my previous marriage and that I needed support since I was an orphan. We went ahead with the marriage and we also had hoped that God will see us through." Woman from matrilineal community

Informants also mentioned judgemental tones from the health workers when they could not follow the advice on pregnancy prevention.

"The doctors do not encourage it because we are told that we must not have children but when we go back home, we just do it as a couple and when we come back pregnant they shout at us." Female from matrilineal community

"The health personnel shout at us. They say that they give us condoms to use but surprisingly the women come back pregnant. They further ask us if we are really concerned with our health because anyone with HIV is not supposed to get pregnant." Man from patrilineal community

Weak linkages between services

Weak linkages or lack of synchrony of the reproductive health and ART services coupled with long travelling and waiting hours and was on itself a barrier to seek more information on which to base their decisions.

"I walk for two hours from home and Imagine I had to wait this long just for ART services what if I had also planned to go to Family planning clinic or escort my wife to the Antenatal clinic, I think I would need to spend two days here. As such I just come for the life saving drugs and off I go the other issues will be sorted out later." Man from patrilineal community

"You know, we can not go there [family planning clinic] freely because it is an embarrassing situation since we are advised that a person who has

the virus, must not become pregnant.” Man from patrilineal community
 This in turn led to follow-up losses and missed opportunities for seeking information related to living with HIV, sexual and reproductive health.

Contradictory messages

The informants depend on the media for any other significant information and news pertaining to HIV, AIDS and sexual and reproductive health. They indicated that there is a lot of information on the radio about reproductive decisions for PLWH. One of such programmes was the ‘Mungathe’ i.e., ‘It is possible’. This programme advocates that it is possible for PLWH to have HIV-negative children provided they follow stipulated guidelines. However, there was at times conflicting information between the media and the hospital as narrated by these informants;

“By then there was a policy by the government which was aired on the radio that every woman who was HIV-positive and had a child must breastfeed it up to 6 months to prevent transmitting the virus to the child. Milk supplements will be provided thereafter and that the women must rush to the hospital once they discover that they are pregnant where they will be advised on ways to follow in order to remain healthy and prevent transmitting the virus to the child. So when we got the information it was a hint to us that the government is in support of child bearing in people like us [People living with HIV]. We then went for it [conceived] but the health workers were not happy with our decision. They would always say; ‘Some couples living with HIV are not thankful. Instead of appreciating the free drugs [ARVs] and follow the hospital advice, they are getting pregnant’.” Man from patrilineal community

“There is an advert that is aired frequently on the air known as ‘MUNGATHE’ ‘We can make it’. The main message is that although a person has HIV, they can still have a child and those who really want to have a child can go and discuss with nurses at the hospital. As such, these messages act as a driving force for the couples to get pregnant. However, when you ask the nurses they shout at us and tell us that they do not offer free food supplements.” Man from matrilineal community

Hence, lack of standardized information, education and communication led to variations in advice on reproductive decisions was their biggest challenge.

Lack of information

The majority of the informants complained about lack of support, communication and understanding by the health workers on the value of marriage and child bearing during the consultations. Lack of comprehensiveness in the information they got was a problem as cited by these informants. Hence, they concluded that there was absence of overarching national guidelines as expressed by these informants.

“Information on sexual and reproductive health is given but it is not adequate, it is as if they skate around these issues, we expect that the health workers will tell us everything.” Man from matrilineal community

“They include issues about sexual and reproductive health at the antenatal clinic. Otherwise at the ART clinic that type of information is not included in the health education messages.” Woman from patrilineal community

Some informants associated absence of information as an indication that prevention of childbearing and marriage relationships in PLWH was a foreign issue imposed in Malawi by international organisations. One male informant from a matrilineal community indicated *“ndondomeko zawozo*

zimachita kuchokera kunjja” from literal translation: “Their [health workers] guidelines come from abroad.” A woman from patrilineal community narrated the same issue but in relation to breastfeeding: *“amatiuza kuti mabungwe akunja anasintha ndondomeko yoyamwitsira”* from literal translation: “They [health workers] tell us international organisations have changed guidelines on breastfeeding.”

With no clear guidelines for the health workers in place, the informants knew that they were subjected to compromised counselling and support about childbearing and marriage decisions.

Analysis of policies and guidelines

From the analysis, a number of policies and guidelines exist, however, they are influenced by WHO, function in isolation (weak linkage) and are non-prescriptive on issues of HIV and AIDS and reproduction. In addition, clinical guidelines are not available in the two study sites. Table 1 summarizes the analysis. For detailed analysis, see Supplement 1.

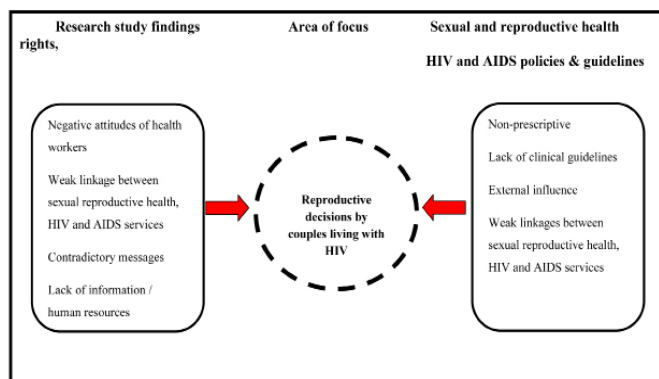
Table 1: Summary of policies and guidelines analysis

Policy and Guideline documents	External influence	Function in isolation/ weak linkage between HIV/AIDS and sexual and reproductive issues	Non-prescriptive on issues of HIV, AIDS and reproduction in couples living with HIV
National HIV and AIDS Policy 2003	√ Pages 4-5	No	√ Page 10
National Sexual and Reproductive Health and Rights (SRHR) Policy, 2009	√ Pages ii, 1	No	√
Guidelines for the use of antiretroviral therapy in Malawi 3rd Edition 2008	√ Page 5	√	√
Prevention of mother to child transmission of HIV guidelines Second Edition 2008	√ Page i	No	√ Page 23
Guidelines for HIV testing and counselling (HTC) 3rd Edition 2009	√ Page 4	√	√ Page 32
Malawi Guidelines for Clinical Management of HIV in Children and Adults 2011	√ Page 2	√	√ Pages 6, 8

Discussion

The analysis has shown that from the study, the informants indicated negative health workers attitudes, weak linkage of services, contradictory messages and lack of information influenced their reproductive decisions. Similarly, HIV, AIDS and sexual and reproductive health policies and guidelines reflect their non-prescriptiveness, absence of clinical guidelines, external influence and lack of linkage. Figure 1 shows a summary of the analysis.

Fig 1: Analysis of narratives by couples living with HIV, policies and guidelines.



Negative attitudes from health workers

The informants expressed dissatisfaction with the health workers in general; the stigma expressed with regard to PLWH child bearing and fear of disapproval. Yeatman³⁰ indicated similar issues in a study that was trying to make sense of what HIV infection means for childbearing in rural Malawians. This does not only reinforce the couples living with HIV anxiety and self-judgement that they are currently not adhering to the advice by the health workers; but also led to a critical situation where they made reproductive decisions based from information from peers. Other studies conducted among PLWH only and with both PLWH and health workers by Harries et al.³¹ Orner et al.³² have found similar behaviours. Street³³ and Oosterhoff et al.³⁴ indicate that this may arise due to cultural differences between a provider and a patient can pose serious challenges to effective communication; especially if one holds negative attitude towards the other's cultural beliefs or if the two differ in their communicative preferences and expectations for the consultation.

In Vietnam, however, Oosterhoff et al.³⁴ indicate that the health workers are apparently more supportive and never question their PLWH's desires to have children because of an understanding of the cultural implications of not having children in the society. A few published papers suggest that when patients fully disclose their concern, expectations and preferences, health workers are able to assist them more accurately and offer better advice. Furthermore, when the patients receive reproductive information that is culturally adequate and accessible by people with different educational levels, they are more likely to make better informed decisions and feel committed to implementing those decisions³⁵⁻³⁷.

Weak linkage of sexual and reproductive health services

One of the main determinants of success and potential benefits of integration of PMTCT services with other

programmes is the increased access to and utilization of services³⁸. The rationale for integration of HIV, AIDS and sexual and reproductive health services is that these services temporally coincide. However, the identified weak linkages between HIV, AIDS sexual and reproductive health services, has also previously been raised as a concern in Malawi among policy-makers³⁹ and researchers^{40,41}. They asserted that PMTCT services were being provided as vertical rather than as integrated programmes within the MCH as had originally been proposed. Even at administrative system level, overall, despite clear policies supporting integration, the two Malawi Ministry of Health units and National AIDS Commission (NAC) tend to work 'vertically' – as separate entities, with separate plans and budgets. This lack of national coordination translates into inconsistent guidance for those working at the service delivery level⁴².

Contradictory messages

There were clashes between the information from the media and the hospital policies in terms of PLWH childbearing since they were not operating from one authority. Just as in any communication process, some overlaps and gaps are bound to exist especially where multiple agencies are involved in similar programmes⁴³. In such cases, co-ordination between the main health service delivery system, Malawi Ministry of Health, and the other formal and informal communication networks before messages are produced is essential.

Non-prescriptive and lack of guidelines

It is evident that couples living with HIV reproductive decisions are creating a clash between their social-cultural expectations, practices, their own wishes and stipulated safer sexual behaviours which often mean elimination or reduction of the possibility of reproduction. However, despite these two formulated policies, national sexual and reproductive health and rights, national HIV and AIDS, that conform to international charters such as International Conference on Population and Development (ICPD), Maputo Action Plan, social-cultural expectations and practices of couples living with HIV are silent. Apart from being old, the policies do not address the sexual and reproductive needs of couples living with HIV; with the only emphasis on couple voluntary counselling and testing for PMTCT. The PMTCT programme tends to focus on the third component/prong of the strategy: preventing HIV transmission from a woman living with HIV to her infant.

Apart from the guidelines being 'silent' or non-prescriptive on sexual and reproductive health information for couples living with HIV who desire to have children, the HIV prevention paradigm is negative in so far as it seeks to limit and control sexual practice. For example, efforts to prevent the transmission of HIV typically focus on risk avoidance and harm reduction strategies. Risk avoidance models stress the value of abstinence and fidelity while harm reduction models promote condom use, needle exchange and partner reduction. The language that informs HIV infection is also negative as it may refer to stopping or avoiding⁴⁴. Underdeveloped guidance on what advice and actions to be taken by governments and health workers have also been shown in national and international documents such as the South Africa 2010 National Antiretroviral Treatment Guideline⁴⁵, Tanzania 2009 National Guidelines for the Clinical Management of HIV and AIDS⁴⁶ and WHO

reports⁴⁶⁻⁴⁹.

The guidelines may not have been followed probably due to the presence of powerful social norms and stereotyping attitudes regarding childbearing coupled with the health workers' dual loyalty pressures, attitudes and values. It may also be due to the lack of prescriptive guidelines themselves. Similarly, previous studies contend that the quality of counselling on childbearing options for PLWH for many PMTCT programmes in sub-Saharan Africa is unsatisfactory, partly because the counsellors are not always aware of the existence of the current international guidelines and lack of concrete national guidelines for implementation^{39,50}.

Nonetheless, despite the complexities and dynamics in policy formulation⁵¹ which may be due to budgetary allocations, political and cultural acceptability of discussion of issues relating to sexual and reproductive issues of couples living with HIV, human resources and issues of priority setting for HIV, AIDS and sexual and reproductive health, we still put forward our suggestion. Malawi Ministry of Health does not need to reinvent the wheel by formulating new policies relating to couples living with HIV. Rather, through the relevant departments, Reproductive, HIV and AIDS units, transparent discussions on current and priority issues must be instituted from PLWH, health workers, government and non-governmental organizations dealing directly with PLWH. The discussions be rolled out as a pilot project in few rural communities with different kinship organizations with plans of expanding to other areas. Data from the discussions would later be pooled to form a database of priority areas that can be shared widely. This database can also be a starting point for the new policy briefs.

Lack of information versus human resource constraints

Being under-staffed and concerns about time constraints by health workers were some of the reasons that the informants narrated for not getting information related to HIV, AIDS and sexual and reproductive health timely. These are not new problems, as have been indicated by other authors in their previous studies^{52,53}. Furthermore, IPPF Malawi⁴² has shown that the same practitioners work in both SRH and HIV programmes. However, this is crucial because the health care system is currently placing more responsibility on patients to be active participants in decision-making, self-care, and disease management where active participation presumes the person will have the necessary information⁵⁴.

While it appears logical to criticise the health workers for the confusion on guidance and lack of information giving, it is crucial to indicate that Malawi is one of the fifty-seven countries classified as falling below the WHO's minimum staffing recommendations in sub-Saharan Africa and Asia (49). Nearly 50% of its posts for technical staff are vacant, and some health centres do not have a single doctor or nurse^{55,56}. Therefore, training peer leaders of PLWH support groups on issues related to HIV, AIDS and reproductive decisions in order to empower couples living with HIV with knowledge and skills necessary for making informed reproductive decisions can be opted for while plans are on the way to increase the staffing levels in health facilities.

External influence

Some of the national policies and guidelines are prompted by external organisation such as UN-led Millennium Project, WHO, for example the current Malawi Guidelines

for Clinical Management of HIV in Children and Adults 2011. We are also aware that foreign academic institutions and researchers have generated much of the internationally published research done in Malawi that is also influencing HIV, AIDS and sexual and reproductive health policy and guidelines¹². These academic institutions often have the funding, time, and mandate for research and thus have the associated power in decisions about what gets done which sometimes might predominately reflect their interests hence, may not correspond with policy pressures and research needs of governments. Although these issues might be very useful in their own right, this type of research needs to be balanced by increasing the work done by local operational organisations, governmental and non-governmental⁵⁷. Although it is impossible to fully predict the ways in which HIV and AIDS research will develop in the future⁵⁸, the fact that the epidemic continues to expand independent of the efforts instituted, we recommend the kinds of approaches that focus on individuals in their local social cultural contexts by researchers.

At present, insufficient evidence base and monitoring and evaluation capabilities, guidelines or a road map for this process of moving research into policy and practice do not exist at national or international level, and the activities that happen tend to be ad hoc⁵⁹. However, the experience of integrating operational research within the Malawi National Tuberculosis Control programme by Harries et al.,⁵⁹ is an example of how these aspects can be successfully built into a national programme, and be of great value in shaping policy and practice.

Aware that poor quality research hurriedly or inadequately collected or analysed also means that the foundations of the message will be flawed⁶⁰, we therefore, echo previous researchers in urging Malawi government through the Ministry of Health for a strong and sustainable political will in terms of funding research agenda in order to achieve its goals. Currently, international agencies and organisations fund 90% of research in reproductive health in Malawi⁶¹. It should not see research as an expense or as an afterthought, but as an investment for a better, healthier future⁶². Frequent inspections at all levels by the Ministry of Health of the research activities and imposing penalties for non-compliance must be some of its main weapons. In addition, it has to ensure availability of quality policy researchers inside and outside of government, and a steady supply of suitably trained people for the research community.

With this suggested approaches to policy and guideline formulation, there can be minimal reliance on external researchers as important policy actors. Furthermore, Malawi Ministry of Health can avoid common critiques that in developing countries policy international and non-governmental actors influence formulation^{63,64}.

Limitations

Although the study that has been used to base its arguments on is informative, there are a number of methodological limitations. The nature of analysis does not claim to offer a comprehensive assessment of all the research findings on reproductive decisions in couples living with HIV, policies and guidelines in Malawi that have a direct bearing with HIV, AIDS and sexual and reproductive health. This would require a major systematic review, which is beyond the scope of the paper. Rather the aim is to identify the main entities contributing to public health policy and guidelines

development and offer recommendations that consider trends of reproductive decisions, HIV and AIDS in local communities. The study lacked information on health worker and policy makers. This information could have strengthened the results because of its ability to draw conclusions from a wider picture. However, despite the limitations a major strength is that we have shown how realities as understood and experienced by the concerned people can be used to analyse policies and guidelines.

Conclusion

This paper has shown a broad picture of the current state on issues related to reproductive decisions of couples living with HIV in Malawi on one hand and how a policy, guideline and research analysis can provide a powerful lens through which gaps can be identified, explained and understood. In addition, it shows how policies and guidelines of HIV, AIDS and sexual and reproductive health for couples living with HIV involve much more than content. Importance of marriage and childbearing in couples living with HIV, sometimes directly conflicts with public health interests. Surprisingly, the HIV, AIDS and sexual and reproductive health policy agenda in Malawi is not considering these issues and does not reflect the social cultural context in which couples living with HIV live. In addition, with wide access to ARV's, more research is required to address gaps in existing knowledge about HIV, AIDS marriage and childbearing in order to inform policy, practice, and HIV, AIDS related interventions. We believe that by including such agenda, information necessary to inform planning and intervention programmes for PLWH can be provided. It is our hope that the paper has contributed one-step toward achieving these critical global health priorities.

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