



## Elderly People and Reproductive Decisions of Couples Living with HIV in Southern Malawi

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### Author's contribution

Author BTMG designed the study, performed the analysis, wrote the protocol, and wrote the first and final draft of the manuscript. Independent researcher, JC, assisted in data analysis in order to ensure inter-rater consistency.

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### ABSTRACT

**Aims:** To explore experiences of elderly people on reproductive decisions made by couples living with HIV in rural southern Malawi.

**Study Design:** This was a qualitative exploratory descriptive research.

**Place and Duration of Study:** The informants were recruited from two districts in southern Malawi, patrilineal Chikhwawa - Ngabu area and matrilineal Chiradzulu - Ndunde area between July and December, 2010.

**Methodology:** Four focus group discussions, with thirty elderly men and women, 15 from each district, where division by gender was the criteria employed in attempts to create well-functioning and articulate groups were selected purposively. Data was analyzed concurrently with data collection using content method. The interviews, which, were transcribed verbatim were uploaded into Nvivo qualitative management software enabling a systematization and easier retrieval of data.

**Results:** Emerging themes were generation gap, defeated/ignored, lack of information and blame situation. First there was generation gap which led to the elderly people feel that their role in the community was defeated, which they indicated by being ignored in reproductive decision making. They further indicated that they lack information about current issues related to HIV, AIDS and reproductive decisions in couples living with HIV. All these led to a blame situation where the

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elderly people blamed either the couples living with HIV or health workers for the current situation.  
**Conclusion:** Older people need to be recognized, supported and educated in the fight against HIV and AIDS. The different needs, roles and responsibilities of older men and women need to be acknowledged and included in programs and policies addressing this global epidemic.

*Keywords: Couples; decisions; elderly; HIV and AIDS; Malawi.*

## 1. INTRODUCTION

In the early years of the HIV epidemic, little attention was given to the reproductive decisions among people living with HIV. This was both due to the risk of mortality and to the few options to reduce mother to child transmission [1]. In recent years, HIV-related morbidity, mortality, and mother to child transmission of HIV during pregnancy, delivery and in the newborn are declining because of antiretroviral therapy (ART) [2]. An HIV infection may now be considered a chronic illness as the antiretroviral therapy suppress HIV replication, which results in an increased CD<sub>4</sub> cell count, delayed clinical progression of AIDS and prolonged survival. Evidence emerging from research in developing countries indicates that antiretroviral therapy may encourage people living with HIV and receiving treatment to reconsider their reproductive decisions including getting married and having children [3-6].

Despite this, most of the prevention of mother to child transmission of HIV (PMTCT) efforts largely target people living with HIV and little is known about the perceptions of elderly people in the society about reproductive decisions made by couples living with HIV. The United Nations uses the age of 60 years as the dividing line between old and young cohorts of the population in demographic analysis [7]. Exploring these decisions in among people over 50 in SSA is important for a number of reasons. In sub Saharan Africa, older adults play a crucial role as educators and care givers and they remain influential community members and leaders. They also act as gatekeepers of information, playing a major role in reinforcing attitudes and normative behaviour [8]. Sefasi [9] further alludes that throughout sub-Saharan Africa, older people – particularly older women – are a key resource for combating AIDS and alleviating its impact. At household level, they are the persons who provide daily care for both AIDS patients and children left orphaned by the pandemic. These older people have taken on new roles by providing care and financial support to orphaned children, playing child-rearing roles within their

extended families and continuing their more traditional roles as advisors to their adult children and grandchildren. A South African study showed that providing HIV education workshops to older people led them; to a more positive attitude towards people living with HIV and to perceive themselves as more able to provide information and care to PLWH [10]. However, despite this fact, rarely do efforts on PMTCT involve the elderly people in a society. Hospital personnel usually have disparaging attitudes towards the role that the elders can do and do play in their communities [11].

Very little research has been conducted on experiences of elderly people about reproductive decisions made by couples living with HIV. Most studies have focused on HIV-related knowledge and attitudes among older adults in SSA [12]. Some research has been conducted in other parts of the world—particularly in developed countries for example a review of HIV attitudes among older adults in the US [13], a comparative study in Thailand on HIV knowledge and attitudinal data for those 50 years of age and older against that of young adults (20–39) [14].

In order to address these gaps, we explored experiences of elderly people on reproductive decisions made by couples living with HIV in rural southern Malawi. The scope of reproductive decision in this study is restricted to marriage and childbearing. Recognizing the significance of socio-cultural contextualisation of studies of reproduction, the research is designed to study how variations in kinship organization: Patrilineal and matrilineal descent might influence elderly people's perceptions in reproductive decisions made by people and couples living with HIV.

## 2. METHODOLOGY

This exploratory descriptive qualitative study was conducted between July and December, 2010. In order to acquire a broader understanding of the context of reproductive decisions by couples living with HIV in rural southern Malawi, the issues were explored through four focus group discussions (FGD) with men and women, where

division by gender was the criteria employed in attempts to create well-functioning and articulate groups.

Four research assistants (2 males and 2 females) two for each study site were recruited for the study. Research assistants of both sexes were present at the FGDs with the village elders who, it was envisaged, may have felt uncomfortable discussing certain issues in the presence of the opposite sex. The research assistants were Registered Nurse/Midwives trained at University level, with previous training and hands on experience in FGDs, fluency in the local language, mature in age and profession. Their recruitment was based on working at either Chikwawa or Chiradzulu District hospitals and with a recent experience, (within the past 2 months) in FGDs. These characteristics assisted in free interaction during the FGDs. Even though the research assistants had previous experience in FGDs, a meeting was arranged a week before the sessions. The aim was for them to have an understanding of the focus of the research and the sensitivity of the issue to be addressed of the study. Considerable time was spent with them to ensure that thorough comprehension was gained. The areas that were discussed included; ethical issues concerning involvement of human subjects in research, the methodological approach of the study, use of codes in identifying the informants. Their specific tasks of note taking (date, time, location, number of informants and their descriptive data – gender, occupation, general description of the group dynamics – level of participation and other observations and discussion contributions), recording the discussions on the tape recorder and organizing the venue and serving refreshments and snacks to the informants were also discussed.

The FGDs were carried out in Chichewa, the vernacular language in Malawi. Focus group discussions were useful for exploring people's knowledge and experiences and can be used to examine not only what people think but also how they think and why they think that way. Kitzinger [15] indicates some of the main advantages of using FGDs as being; not discriminating against people who cannot read or write, which was ideal with respect to the village elders. Furthermore, FGDs can encourage participation from people reluctant to be interviewed on their own or who feel they have nothing to say. Focus group discussions also encourage informants to step back and critically analyze situations, which they

themselves have been involved in and which may have affected their beliefs, values and behaviour.

Thirty village elders (chiefs, traditional birth attendants, village counsellors, religious leaders, elderly persons in terms of age) 15 from each district participated in the FGDs. Purposeful Sampling was used and informants who met the eligibility criteria were interviewed. The method was chosen to intentionally select 'information-rich cases' ([16], pp242) that would provide an in-depth understanding of the reproductive decisions of people and couples living with HIV. The strategy used for purposefully selecting the informants was maximum variation sampling. This involved conscious selection of informants with emphasis on variation of characteristics within the agreed upon inclusion criteria which in the study was by; age, level of education, religion occupation, position in the village and home area / district of origin.

The discussions started with self-introduction and using a thematic guide, focus was on their experiences in terms of couples living with HIV decisions about childbearing and marriage. The FGDs were organized with women and men separately to promote more ease in discussing sensitive issues. Ndunde key informants opted for Ndunde Court as the venue for the FGDs while the key informants from Ngabu used the ART Clinic office. Privacy, confidentiality and a relatively relaxed atmosphere were achieved in both venues. The informants showed considerable interest in the discussions and highlighted the need for the discussions to either be aired on the radio or passed on to the government officials involved in HIV and AIDS policy. They also expressed appreciation for being given the chance to discuss a topic of great concern to them. The discussions lasted between 1hour to 1 ½ hours.

The researcher and two research assistants (male and female) conducted the FGD. The researcher acted as a moderator with a role of guiding the discussions so that they remained focused while at the same time allowing for open and continuous interaction between the informants [15]. Throughout the discussions, all the informants were encouraged to get involved and contribute to the discussion. While the discussion was occurring, one of the research assistants was taking notes, while the other one was recording the discussions on a tape recorder.

After the fourth group in each study setting, it was felt that a level of saturation had been reached and based on continuous reflections and preliminary analysis, data collection was completed. To prepare for analysis all FGDs were transcribed verbatim and later translated into English to facilitate a joint analysis in the research group.

The general principles and procedures for qualitative data content analysis described by Graneheim & Lundman [17] were used. In the study, the transcripts were read through several times to obtain a sense of the whole. Then the text about the experiences was extracted and brought together as one text which constituted the unit of analysis. In order to ensure inter-rater consistency, once the research team (comprised of the researcher and an expert in qualitative research) independently analysed each transcript, 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 the transcripts were re-analysed resulting into fine-tuning of the coding and interpretations. Once the codes were agreed upon, the underlying meaning of the different categories of the codes was formulated into sub themes and the main theme. All the data from digitally – recorded IDIs that was transcribed verbatim was typed. NVivo version 9 was used to organize the data.

### 3. RESULTS

This study sought to explore experiences of elderly people on reproductive decisions made by couples living with HIV. Emerging themes, which are a vicious cycle, see Fig. 1, from the discussions were generation gap, defeated/ ignored, lack of information and blame situation. These themes are elaborated in the following sections.

#### 3.1 Generation Gap

Some of the informants in the FGD's complained that the generation gap affected their relationships as such they viewed continued marriage and childbearing by the couples living with HIV and AIDS in their communities as a sign of being disobedient and disrespectful. Common phrases were: 'Old practices and beliefs', 'old fashioned advice', 'uneducated'.

They were often heartbroken and felt that the couples living with HIV and AIDS did not fully understand the situation their families were in and that they were selfish i.e. they only cared about themselves and what they wanted. As a result, they thought the desire to give advice should take a backseat.

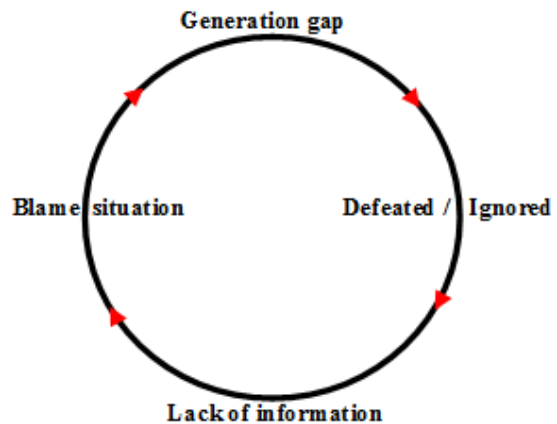


Fig. 1. Emerging themes in a vicious cycle

*"So in such situations what can you do, you just stand back and observe." Elderly woman from matrilineal community.*

*"With such remarks would you be willing to advise them next time?" Elderly woman from matrilineal community.*

*"I just tell them that; 'Okay you can go but do not ever come back to me once you are in trouble.'" Elderly man from patrilineal community.*

However, some of the informants indicated that those who come for advice come late as narrated below:

*"The couples [couples living with HIV and AIDS] do not discuss with the elders, they just do it [decisions to get married have children] on their own. By the time they come to us, they are already pregnant....." Elderly man from patrilineal community.*

#### 3.2 Defeated

Despite the informants identified the generation gap, all of them reported that they were leaders in several community groups, and that culturally, they counselled on sexuality-related issues, child rearing, family cohesiveness and were very key

during initiation ceremonies. However, in contrast, they found that the hospital and use of media in health campaigns was defeating their cultural roles. One of the informants eloquently captured this theme by stating:

*“In those days before the rights issue came, the chiefs and we elders had powers, parents had control over their children and the children would do what their parents told them to do. However, nowadays you cannot do that. We have failed.” Elderly woman from matrilineal community.*

On the other hand the informants indicated that issues of democracy and human rights were defeating their roles in their communities. For example, one participant noted:

*“If you want to advise the young ones they say things have changed, there is democracy and people have their rights.” Elderly woman from matrilineal community.*

Another participant echoed;

*“The other big challenge that we currently have at hand is what is always on the radio ‘giving children their rights’. This is killing the nation..... how can you then advise your child because they say to us that; ‘Do not tell me that I must not remarry while living with HIV or have children; it is my right to do it.’ The government introduced the issues of rights and now they are backfiring and now the same government is coming to us for help, no, all sectors, organization must now sit down and come with solutions otherwise, we have failed to advice these couples. Elderly man from patrilineal community.*

The informants indicated fear of being jailed if they continued to caution the couples living with HIV.

*“The children are very powerful to the extent that they threaten that they can go and report to Human Rights Organisation, or to PLWH support groups who can pick us and lock us in jail. Who can then dare to continue giving the advice, we are defeated” Elderly man from matrilineal community.*

Throughout the focus group, informants indicated a need to address such cultural disharmony. Some suggested recruiting them as sex educators and reproductive health counselling for

the youth by the hospital. According to them, this would help to maintain the lost trust.

### 3.3 Lack of Information

Informants admitted that though they were gate keepers of information they lacked modern information on reproductive decisions made by couples living with HIV was poor and justified to being ridiculed as ‘old fashioned’, ‘uneducated.’ Hence they are ignored by the community including the hospital. In addition, the narratives reflected that rarely do health education efforts for people living with HIV and AIDS by the hospital involve these elderly people in a society.

*“Our views are that we have been defeated and ignored because of the educated people who are making these policies however the same government does not want to empower us with the new information about childbearing and HIV.....” Elderly man from matrilineal community.*

In situations where the couples living with HIV and AIDS seek advice from the elderly people, though late, one informant, a local counsellor, who was supported by the village chief, was quick to indicate that the information they give to them is usually not comprehensive and they usually emphasize that the couples must “report to the hospital and follow the hospital advice diligently.”

### 3.4 Blame Situation

As the informants tried to justify or explain the current reproductive decisions of couples living with HIV in their communities, a process of blaming was initiated. All the informants blamed the hospital and its PMTCT programme. Blame has been placed on the PMTCT program in this context as it particularly encourages couples living with HIV to continue having children hence those not married but living with HIV and AIDS, also decide to get married. On closely examining the phrase, “I blame the PMTCT programme” throughout each transcript, it was noted that most FGD used the word “blame” as illustrated in the following quotes.

*“We are not happy to see these couples [couples living with HIV] get pregnant or those living with HIV and AIDS getting married. This is like adding another disease. Yes it is very important to get married and*

*have children, but we have to prevent further spreading of this virus. But we blame the hospital; they initiate programmes without consulting us. Are they with us at the community with these people or couples living with HIV and AIDS, they just advice them to get married and have children and off these couples go not even consulting us. When problems arise, we suffer, the hospital does not even care they just say 'the couples did not follow the hospital advice that is why they die'. No, it is because of not asking us how we feel with their programmes before they are implemented." Elderly woman from patrilineal community.*

*".....we have been wondering where this behaviour [marriage and childbearing in people and couples living with HIV and AIDS] is emanating from. From our observations, ¾ of the couples [couples living with HIV and AIDS] in the villages are getting pregnant and further more they get married to each. Very common as such they keep on fuelling the virus. We blame the hospital." Elderly man from matrilineal community.*

*"It is very common to hear that: 'they have been found with the virus' but within a short period you hear that they have married to each other within a year you notice that the couple is pregnant. As such we tend to wonder what advice is given to these people by the hospital, I thought they are not supposed to get married and have children, we really do not know what is happening." Elderly man from patrilineal community.*

*"Couples are becoming pregnant following the advice they get from the hospital. One woman was boasting; 'I have the virus but my child does not have it.' Therefore those living with HIV and AIDS and see that their friends have babies that do not have HIV, do you think they can just sit back, no, they are also motivated to do the same and get pregnant.' So this issue, [decision to get pregnant by couples living with HIV and AIDS], is being fuelled by the hospital." Elderly woman from patrilineal community.*

In the end the elderly people are shifting the blame to the PMTCT programme and not taking responsibility in assisting couples living with HIV and AIDS in their reproductive decisions.

#### 4. DISCUSSION

The study has shown varying results regarding experiences of elderly people on reproductive decisions made by couples living with HIV and AIDS. Independent of; structural differences in kinship organization, matrilineal Chiradzulu versus patrilineal Chikwawa, and division by gender of the focus group discussions, male versus female, the themes were the same across.

The analysis of the focus group discussions revealed four themes, which are a vicious cycle. First there was generation gap which led to the elderly people feel that their role in the community was defeated, which they indicated as being ignored due to primarily reflected by their lack of information about current issues related to HIV, AIDS and reproductive decisions in couples living with HIV, which led to a blame situation where the elderly people blamed either the couples living with HIV or health workers for the current situation.

Tensions lie in the societal expectations of people and couples living with HIV and AIDS to obey the elders and also in elders' expectations on these couples in respecting their advice. In the study, there were complaints of the elderly against the couples living with HIV and AIDS that it is not following old traditions such as showing respect to the elders and it is not interested in traditional rites and rituals. This results in the generation gap that consists of feelings of mistrust between the elderly and the people and couples living with HIV and AIDS. Consequently, the author suggests that lack of opportunity to clarify and to try to understand each other would cause a lot of trouble to the elderly-people/couple relationship and further widen the generation gap.

The findings in this study echo the general existing literature that children nowadays are not as keen to consult their parents as in the past in the aspect on marriage [18]. Chow, [18], thus concluded that, the social situation has changed so much that it has often made the advice of parents irrelevant and in applicable. Bengtson & Achenbaum, [19] further assert that generation gap has been taken as an inevitable barrier for the communications between the young and the old ones. These conflicts are commonly taken as a consequence of urbanization, industrializations and family mobility.



Concurring with Rosenberg, [20]; Cattell, [21]; it seems that elders' expressions of dissatisfaction should be seen as a struggle over respect and reputation; their complaints reveal what is at stake in the so-called generation conflict. The rivalry between young and old is expressed in the older people's insistence that they lived honourable and admirable lives in a morally superior era. This assertion is a way of countering the experience of being marginalised today, through the workings of historical forces or personal neglect and mistreatment from the younger generation.

Knowing that; first, beliefs and practices take shape around the cultural traits that are passed on from one generation to the next; secondly that these practices are deeply rooted and embedded in society and thus become part of people's lifestyles and finally that they are innate and difficult to change as people have adhered to them throughout their entire lives [22], the paper has the following suggestions. Educational programs should include the elderly as peer educators, and the content of the programs should include an intergenerational emphasis that builds on effective communication. More activities can be implemented to ensure that there are positive relationships and understanding between older and younger generation. For example, intergenerational events like drama, storytelling where older and younger generation can express their feelings in order to improve communication during traditional ceremonies. During these sessions, emphasis must be made in showing how times have changed, and how important is to update, acquire new knowledge and develop new skills.

In sub Saharan Africa, older adults play a crucial role as educators and care givers and they remain influential community members and leaders. They also act as gatekeepers of information, playing a major role in reinforcing attitudes and normative behaviour [8]. However, the elderly people felt that they were ignored consequently defeated in their traditional roles. Furthermore, hospital personnel usually have disparaging attitudes towards the role that the elders can do and do play in their communities [11]. Therefore, in the rural societies of this study setting, using elders and oral tradition forum for transmitting knowledge on sexual and reproductive health, HIV and AIDS as information carriers, will provide a favourable platform because it utilizes already existing and accepted structures [23,24]. However, the promotion and

adoption of this approach in the patrilineal and matrilineal traditional settings requires that local counsellors, who in this case are the already existing village elders, be well trained by experts so that they are conversant with sexual and reproductive health, HIV and AIDS issues [25]. Finally, whenever government institutions and other agencies are discussing policy issues and strategy related to HIV and AIDS, leaders from the older generation should be consulted in order to present their positions and ensure that they are included in development plans and intervention programmes.

The 'blame' on generation gap which led to the elderly people feel that their role in the community was defeated, which they indicated as being ignored cannot primarily be placed on the younger generation and health care workers. As Fouad, [26] asserts, a change in mindset is needed to welcome older people's contributions and participation, and take a fresh view of relations between the generations. However, a possible reason for this blame could be a general lack of knowledge and skills for working with older people among the health care workers. In addition, maybe that there is a perception among health care workers that older people are unable to contribute much to the fight against HIV and AIDS because they are feeble, both physically and mentally, and thus there is no need to ask them to be a part of providing services [27]. Therefore the education sessions eluded earlier in the paper would assist in resolving the issue.

## 5. CONCLUSION

As shown in the paper, the people and couples living with HIV and AIDS and the elderly are both caught in the tension between 'new' and 'old' thinking in the society which is the primary source of generation gap. However, the elderly need to be counted, supported and educated in sexual and reproductive decisions made by people and couples living with HIV and AIDS. Their different needs, roles and responsibilities need to be acknowledged and included in programs and policies addressing this global pandemic.

Given the trends within HIV and AIDS, much more rigorous evidence is needed on how best to involve the elderly so that there is no generation gap, blame, no feelings of defeat or ignored, and that they are up to date with knowledge and skills on sexual and reproductive decisions of couples living with HIV and AIDS. In particular, which

channels of communication are appropriate are appropriate and the types of information are most appropriate for this population. Finally, it is important for the government to put extra effort in supporting research studies on exploring the elderly peoples' experiences on reproductive decisions of people and couples living with HIV and AIDS.

## CONSENT

The author declares that 'written informed consent was obtained from the informants =for publication of this manuscript.

## ETHICAL APPROVAL

Informants were recruited upon receipt of permission to conduct the study following ethical approval in Malawi (Kamuzu College of Nursing College Research Publications Committee and University of Malawi College of Medicine Research Ethics Committee (COMREC)) and Norway (Regional Committees for Medical Research Ethics (REK)).

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## COMPETING INTERESTS

Author has declared no competing interests exist.

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