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Midori Yajima, Arnold van Huis, Janice Jiggins

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**Life history analysis of HIV/AIDS-affected households in rice and cassava-based farming communities in northern Malawi**

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## **Life history analysis of AIDS-affected households in rice and cassava-based farming communities in northern Malawi**

### Abstract

The 'New Variant Famine' hypothesis proposed that AIDS offers a major challenge to food security in this part of Africa by impairing the functioning of traditional support systems, leading to the collapse of 'social immunity'. This study explores the changing perceptions of HIV and AIDS and peoples' responses to its impact by eliciting life history narratives of 30 respondents in northern Malawi. We classified respondents by means gender, livelihood systems, and AIDS impact levels. Respondents reported a range of critical events, recorded in the life histories, that threatened their 'social immunity', including deaths, sicknesses, migration, marriages and divorces, and dropping out of school; i.e., a greater range of risks than AIDS alone, that need to be recognised in HIV and AIDS programming. For the respondents who were classified as 'AIDS-affected', learning about their seropositive status was found to be an important, and in some cases a positive, turning point in their lives in terms of behavioural changes, such as joining support groups and opening up to discussion of the implications of their status. The emerging social organisations could re-create social capacity and check the downward spiral proposed by the 'New Variant Famine' hypothesis. To promote this shift and to confer a higher level of 'social immunity', investments in expanding access to VCT and ART services, and assistance to community-based organisations would be essential.

Keywords: word; Malawi, HIV and AIDS, impact level, rural households, life history

## Introduction

AIDS is the leading cause of death in the age group 15-49 years in Malawi (Malawi National AIDS Commission 2003). The adult HIV prevalence was estimated in 2007 to be 12% overall, 11% in rural and 16% in urban areas (Office of the President and Cabinet 2007), i.e. it has become a generalized epidemic (U.S. Census Bureau 2000). In 2006, less than half of the population (44% male and 20% female) showed acceptance of people living with HIV and AIDS, and people generally were reluctant to disclose their serostatus (Office of the President and Cabinet and Republic of Malawi 2007).

The 'New Variant Famine' hypothesis (de Waal and Whiteside 2003; Arrehag, de Waal et al. 2006) argues that the AIDS epidemic is a major contributing factor in food insecurity in southern Africa. The hypothesis identified four causal factors: labour shortage, asset and skill loss, increasing burden of care for the sick and orphans, and malnutrition (de Waal and Whiteside 2003). The situation is regarded as an exceptional challenge for food security and overall welfare of the affected (de Waal and Tumushabe 2003; Arrehag, de Waal et al. 2006). AIDS has negatively impacted agricultural production, impairing food security, leading to malnutrition of children and adults (Barnett, Tumushabe et al. 1995; Topouzis 1999; Piwoz and Preble 2000; Baylies 2002; Shah, Osborne et al. 2002; de Waal and Whiteside 2003; Müller 2004). In Malawi, many small-scale farmers depend on income from *ganyu* (casual hired labour) to bridge the seasonal food gap. Hence, AIDS-affected households tend to neglect their own gardens, creating a so-called 'downward spiral' (Bryceson 2003; Drinkwater 2003), and examples of such phenomena have been reported (Robson, Ansell et al. 2007). Change in and death of spouses and displacement of orphaned children, leading to labour exploitation and trafficking (Drinkwater 2003), accelerates the erosion of small-scale farming communities' economic competence and traditional social unity.

The concept of 'social immunity' is defined as the 'ability of a collective of people, specifically the extended family, to mitigate the impact of an affliction' (Mtika 2001). The concept indicates that, when a household is struck by AIDS, it first receives assistance from the immediate and

extended family members. As the gravity increases until it reaches the threshold level, however, the traditional support and social network system becomes depleted (Mtika 2001; Beraho 2008).

The objective of this study is to understand the impact of AIDS in three livelihood systems, experiencing different levels of AIDS-related impacts. By eliciting life history narratives, the study explores people's responses and changing perceptions of HIV and AIDS. The findings are examined in light of the 'New Variant Famine' hypothesis in order to examine local responses to the impact on the basis of livelihood systems that support food security. By examining the threshold of 'social immunity' to adverse impacts of a range of risks, insight is gained into coping strategies that challenge the pessimism of the hypothesis. The implications open up new opportunities for public health programming. Since the first cases of AIDS were reported in the 1980s in Malawi, as of 2009 the respondents had lived through the transitional period: the growing public and private acknowledgement of the epidemic.

## **Methods**

### ***Research setting***

The study was conducted in Chilumba (Karonga District, northern Malawi) from April 2007 to October 2008. Surveys conducted in 1999-2001 showed the female HIV prevalence in Karonga District as 15.0% (Crampin, Glynn et al. 2003), while the estimated figure for rural Malawi was 12% (Malawi National AIDS Commission 2004).

[insert here Figure 1: map]

The Tumbuka are the dominant ethnic group in the area. The Tumbuka are patrilineal (Tew 1950), and they practise high material transfers for their mutual support through their kinship (Mtika 2003).

At the time of the research, services for voluntary counselling and testing (VCT) and antiretroviral therapy (ART) were becoming accessible in Malawi. Between 2005 and June 2007, ART coverage

increased three-fold countrywide: from 38,000 to 114,000 (Office of the President and Cabinet and Republic of Malawi 2007). In 2006, 21% of those with advanced HIV infections had access to ART in Malawi (World Health Organization 2008). However, access to medical and psychosocial support for children affected by AIDS was relatively low in the northern Malawi in 2006 (Office of the President and Cabinet and Republic of Malawi 2007).

The Uliwa trading centre is the second-largest township after Ekwendeni along the 'northern corridor', offering a convenient stopover point for traders and long-distance truck drivers. At Chilumba Jetty, steamer lines make a weekly stop on their way to and from Tanzania and southern Malawi.

### ***Sampling strategy***

The respondents were purposively selected from three locations with different livelihood systems (Fig. 1):

- (1) Mwandovi village: cassava as a subsistence crop, fishing for food and income;
- (2) Kachere village: cassava and maize as subsistence crops, some grow rice and tobacco for cash income;
- (3) Hara Irrigation Scheme: rice as a cash crop, supplemented by cassava and maize.

Ten respondents from each location (N=30) were selected, using a combination of random and reputational sampling; i.e., 15 of the respondents had participated in a related study on their agricultural practices and 15 were recruited through referral by local key informants who had been asked to identify those whom they thought might be experiencing particular hardships.

### ***Data collection***

The main information presented here is based on repeat (2-3 rounds) interviews with 30 individuals in three locations (10 in each location, Figure 1). Research assistants were hired locally, though from outside the community, and were trained in active listening techniques to encourage in-depth discussion of sensitive issues.

The data comprise a narration based on in-depth interviews (of 3 hours or more), recorded using a digital audio recorder followed by translation and transcription. The chronologies were constructed to verify the information in the narration. This was followed by a semi-structured interview focussing on HIV and AIDS (Deshpande 2005). Responses were recorded in the local language (ChiTumbuka) with the respondents' consent; written notes were maintained in English. All identities are expressed in pseudonyms.

### ***Assessing the impact levels***

We developed the following guidelines to estimate the level of AIDS impact among our respondents.

Group A (primary impact level): Respondents reported that they had had positive results from the blood test or their previous partners or their former spouses were known AIDS cases.

Group B (secondary impact level):

Respondents did not report their own serostatus, but reported known AIDS cases in their family trees.

Group C (no evident impact):

Respondents reported that either they had had a blood test with negative results, or did not report their serostatus but had no known AIDS cases in their family trees.

### ***Data analysis procedure***

All narrations (N=30) were coded using qualitative analysis software (Atlas.ti, version 5.0, Scientific Software Development 2004). The frequencies of codes were analysed using SPSS (version 16.0, SPSS 2007) and Excel (Microsoft 2007). Follow-up interviews were analysed in Excel.

### *Categorising codes into conceptual clusters*

The concepts recorded in the narratives were coded with the help of Atlas.ti. Thereafter, each code was categorised into five conceptual clusters: family structure, health problems, risk exposure, shortages/hardships and social organisation/capital (Table 1).

[insert here Table 1]

The clustering of codes was based on the life history narrations, personal communication with local informants, and field observation. During the clustering process, it was noted that some codes could be allocated to more than one category. For example, 'death' concerns family structure, but also could be included under health problems, hardships, and risk exposure. Likewise, 'advice' could either be bad, which could be allocated to risk exposure, or good, which could be counted as social capital. The distinctions were sometimes obvious from the context, but when it was unclear, the codes were allocated in all possible categories; hence one code could be counted more than once.

## **Results**

### *Respondents' profile*

The 30 respondents comprised 19 women and 11 men, ranging from 27 to 80 years, with an average of 49 years. All respondents had married: 17 respondents were in monogamous marriages, 6 had been widowed, 5 were in polygynous marriages (involving 1-5 co-wives), and 2 had divorced. All respondents had attended school ranging from 1 to 12 years, to standard 7 in primary education on average.

### *AIDS impact levels*

Based on our guidelines, we allocated the 30 respondents into three levels of AIDS impacts: primary level, secondary level, and no evident impact. Their impact level, locations, gender, and livelihood systems are given in Table 2.



[insert Table 2 here]

The data used to provisionally assess the 'impact level' of the respondents, namely the self-reported serostatus, and AIDS deaths within the family, could not be objectively verified, and self-reporting cannot be assumed *a priori* to be accurate when there is stigma and discrimination. Therefore, the information presented here inevitably carries some degree of uncertainty and ambiguity.

#### ***Frequently cited concepts in the narrations***

In total, there were 113 concepts recorded as codes during the analysis of the life histories by Atlas.ti, with citation frequencies ranging from 205 to 1 (Table 1). 'Children' was the most frequently cited, followed by in descending order, 'school', 'death', 'money', 'marrying', 'travelling', 'husband', 'father', 'farming', and 'health problem'. The conceptual cluster with the highest frequency was "family structure" (1,066 times), followed by "risk exposure" (825), "social organisation/capital" (778), "shortages/hardships" (583), and "health problems" (387).

#### ***New terminologies related to HIV and AIDS***

The use of new, euphemistic expressions was observed in the life histories. AIDS was implied for instance by the following: "*Matenda gha sono*" (current disease), "*Matenda gha boma*" (government disease), "*Akulwala kanthukala*" (he/ she is suffering from 'that thing'), "*Alikutola kanthukala*" (he/ she has contracted 'that thing'). The research assistants in each case sought to clarify the exact meanings. For example, 'government disease' is used to indicate that AIDS is prevalent in every corner of the country - in all districts, sectors and levels - similar to the government structure (Manzunda 15/09/2008).

#### ***Critical events in the search for livelihood***

For all respondents, the death of spouses, guardians, and close-kin were expressed as critical events. Migration, marriage and divorce (including acquiring co-wives by polygynous husbands), dropping out of school (due to lack of money to pay fees, unplanned pregnancy, violence at school,

etc.), and their own sickness or that of family members were also important events. It was observed that respondents in the secondary and the non-affected category tended to show stronger fear about their risks as compared to those in the primary category, who felt themselves to have become empowered through sharing knowledge and experiences in support organisations.

For the 'affected' respondents in the primary category, learning about their own seropositive status was identified as an important turning point in their life history, leading to behavioural changes (e.g., selective use of condoms), and taking part in support organisations. The overall decisions concerning family planning remained unchanged for 6 out of 11 respondents in the primary category. Of the other five, three were widows, one was not married but had a distant partner, and, in the fifth case, the husband was staying with a second wife in a distant town. In other words, all respondents with primary impact who are in legitimate marriages are choosing to continue having children after knowing their serostatus. Some are receiving assistance from support organisations and government, such as money or advice on nutrition and sexual practices. All the respondents in the primary category said that they would not take the children out of school to help with the farm work, commenting that this would disturb the children's future.

## **Analysis**

### ***Analysis of conceptual clusters***

The findings from the Atlas.ti analysis were examined for the three variables of gender, livelihood systems and impact levels, as shown in Figure 2.

[insert Figure 2-A,B,C here]

Only 'Social organisation/capital' in Kachere village (Figure 2-B) scored significantly low compared to the other two locations ( $p \leq 0.05$ ). The frequency of conceptual clusters recorded during the narrations associated neither with gender nor impact levels.

The concepts categorised in the 'Social organisation/capital' cluster, were cited more often by the respondents in Mwandovi village and Hara Irrigation Scheme compared to Kachere village. The respondents in the two locations base their livelihoods on a rather homogeneous enterprise involving collective activities, possibly leading to relative resilience in social capital. Other contributing factors could be the presence of Hara Water Users Association in Hara Irrigation Scheme, and Farmer Field Schools (FFS) in both locations. These might constitute an enabling environment for new social relationships to emerge. In contrast, the location of Kachere village, due to its proximity to the Uliwa trading centre, on the one hand offers wider opportunities for income, but on the other hand may result in more diversified livelihood strategies and individualised decision-making behaviours compared to the other two, irrespective of AIDS impacts. A more diversified livelihood system with weaker foundations for social organisation could aggravate social immunity.

### ***Implications of new terminologies, language metaphors***

During the life history narrations, respondents reported that perceptions related to HIV and AIDS had changed over the past few years. For example, among those in the 'affected' categories, a readiness to discuss AIDS-related topics and challenges was noted, linked to their experience of deaths in the family. Other contributing factors were the increased availability of VCT and ART in the study area and observation of the consequences of certain types of behaviour within their community. The emerging metaphors on the one hand could indicate the magnitude of the AIDS epidemic; however, it could also imply that AIDS is gradually becoming a social norm. The fact that the notion of AIDS could be less stigmatizing also merits a careful attention in prevention programming and psychosocial care for children.

### ***Critical events, life choices***

It was observed that learning about their serostatus worked as a strong motive for some to join groups for assistance, to open up to discussion, and reducing their stigma. The respondents in 'affected' categories seemed to be developing higher thresholds of social immunity and demonstrating higher confidence with the help of, or by taking up leading roles in, AIDS support

organisations or by receiving therapy. These collective actions are therefore gradually taking up the conventional roles of extended families by providing support to the affected. Their life histories demonstrate awareness and control over their fate and in some cases, reaching out to others, to form new social networks that replace or augment support formerly provided through the family.

Of all the conceptual codes in their narratives, “children” was the most frequently cited. Children were considered as important assets, a significant household workforce, and an investment in future welfare. “School” was the second most frequently cited and the most frequent one in the cluster of social capital. The strong perception of children and schooling as beneficial, enhanced by increased risk awareness and perhaps also because of a certain fatalism induced by the already unstable nature of their livelihoods could be a reason why the ‘affected’ respondents were positively continuing to plan their lives.

## **Discussion**

### ***Changing environments***

While AIDS poses an enormous socioeconomic challenge, other equally challenging issues coexist in rural Malawian livelihoods, conferring social instability and uncertainties over an individual’s lifetime. Deaths from a variety of causes already were among the most serious threats in rural Malawi prior to the onset of the epidemic (Mtika 2000). These contexts, together with the importance of children and efforts to minimize migration (Ansell and Young 2004), need to be recognised in public health programming.

In the case of Malawi, inequality in accessing ART roll-out based on region, gender and age has been reported, indicating specific need for improved access in the northern region, and for men and children (Makwiza, Nyirenda et al. 2005). The access rate of ART in Karonga District was reported to be only 3% of the total projected number of HIV positive patients as of December 2005 (Makwiza, Nyirenda et al. 2006). In addition, there are concerns about ART such as drug resistance (Deeks 2003; Calmy, Klement et al. 2004; Clavel and Hance 2004), adverse effects

including hepatic steatosis (Carr 2003), adherence and scaling up in resource-poor settings (World Health Organization 2002; Manzi, Zachariah et al. 2005). In addition to debates on equity in accessing HIV and AIDS-related health services (Farmer 1999; Greener 2004; Whyte, Whyte et al. 2004), financing, institutional support, and monitoring to facilitate ART roll-out remain as major challenges (Makwiza, Nyirenda et al. 2006). Nevertheless, the availability of VCT and ART has shown positive impact in the research area. This development is strongly supported by NGOs (such as NAPHAM) and local initiatives (such as locally established CBOs). For example, some respondents in the 'affected' category reported that they were monitoring their CD4 count, following dietary recommendations and the ART instructions (if they were on therapy), and urging others to go for VCT. These respondents were willing to discuss AIDS-related experiences with confidence. The importance of children expressed in the narratives further emphasises the need for expansion of ART programmes to children as well as increased access for children to VCT services.

### *Changing perceptions*

The AIDS epidemic has stimulated reflection on traditional social, sexual norms and behaviours (Kaler 2003; Smith and Watkins 2005). In this study, access to VCT and ART services and the presence of social organisations is reported to trigger perceptual changes that help reduce stigma and an opening-up of public discussion. While those in the secondary (indirect) and especially in the non-affected impact categories tended to show fear and anxiety about their future, those in the primary (direct) impact category, as well as some in the secondary, seemed to be empowered by sharing experiences in the new social organisations triggered by the epidemic, and were starting to feel positive about their lives. This discussion leads to a new hypothesis: while traditional social immunity through extended families is collapsing, a higher threshold of social immunity could emerge through social organisation, starting, counter-intuitively, among those with higher exposure. It is these individuals - who might seem the most impacted - who are becoming involved in social organisation or community-based support groups for counselling and care, so that they have access to social institutions that are helping them to cope. We hypothesise that this

over time could reduce risks and might eventually open up possibilities for new livelihood opportunities.

## **Conclusion**

Our life history analysis provides four recommendations that are important for public health programming:

- Recognising the wide range of risks which coexist with the risk of HIV infection.
- Learning about one's own seropositive status as an important turning point in terms of behavioural changes.
- Recognising VCT and ART services and community-based organisations as supportive of behavioural changes.
- Supporting children and schooling opportunity among AIDS-affected communities as core elements.

Affected individuals, who gain an understanding of their risk exposure and strengthen their individual control over the risks by sharing knowledge and experiences through social organisation, could play central roles in emerging social organisations that over time could re-create social capacity and check the downward spiral proposed by the 'New Variant Famine' hypothesis. To promote this shift and to confer a higher level of 'social immunity', investments in expanding access to VCT and ART services, and assistance to community-based organisations would be essential.

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## TABLES

**Table 1. Conceptual clustering of codes cited during the life history narrations**

Conceptual clusters <sup>1)</sup>	Codes <sup>2)</sup>
Family structure: 28 codes	children(205) death(149) marrying(118) mother(118) husband(98) father(89) siblings(44) brother(32) co-wives(32) parents(32) relatives(31) childcare(23) divorce(22) sister(21) wife(19) unplanned pregnancy(17) orphans(15) step children(12) grandchildren(9) step mother(8) child fosterage(7) grandparents(7) guardians(6) partnership(6) uncle(6) polygyny(5) family planning(1) step-father(1)
Health problems: 18 codes	death(149) health problem(79) HIV/AIDS(25) hospital(17) herbalist(15) serostatus(15) caring the sick(14) mental problem(13) HCT(11) ART(10) medication(10) nutrition(8) doctor(5) frequent illness(5) malaria(4) TB(3) HBC(3) weight loss(1)
Risk exposure: 29 codes	death(149) money(142) travelling(115) employment(73) stop school(59) business(58) advice(31) divorce(22) conflict(21) 'bad' behaviour(20) unplanned pregnancy(17) violence(16) teacher(16) orphans(15) illicit behaviour(14) police(7) poverty(7) imprisonment(6) unfaithfulness(6) witchcraft(6) military(5) arrest(5) sex for money(3) beer brewing(3) forging IDs(3) dancing in band(2) drought(2) attacking teachers(1) partnership dissolved(1)
Shortages/ hardships: 20 codes	death(149) money(142) hardship(63) stop school(59) food(36) domestic work (22) conflict(15) clothes(15) caring for the sick(14) accident(11) house(8) hunger(8) nutrition(8) poverty(7) dowry(6) discrimination(3) funeral(3) labour loss(3) drought(2) stigma(2)
Social organisation/ capital: 33 codes	school(152) farming(85) assistance(73) employment(73) business(58) church(45) relatives(31) AIDS support group(22) vocational training(20) sports(18) CBO(17) government(17) hobby(16) FFS(12) HCT(11) friends(8) farmers club(7) volunteer work(7) fishing(6) guardians(6) partnership(6) leadership(6) political party(5) choir(5) advice(31) assets(3) HBC(3) Malawi young pioneers(3) scheme committee(3) water(2) ethnic group(1) traditional dance(2) beer brewing(3)

1) Clustering was based on interpretation of life history narrations, personal communication with local

informants, and observation

2) In the order of frequencies (in brackets)

Key

CBO: community-based organisation; FFS: Farmer Field Schools; HBC: home-based care; HCT: HIV/AIDS counselling and testing

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**Table 2 Respondents categorisation by location and impact levels**

	A- primary level 11 respondents		B- secondary level 9 respondents		C- no evident impact 10 respondents	
	Female: 7	Male: 4	Female: 7	Male: 2	Female: 5	Male: 5
(1) Mwandovi village	4	1	0	1	2	2
(2) Kachere village	0	2	5	0	2	1
(3) Hara Irrigation Scheme	3	1	2	1	1	2

**Key**

(1) Mwandovi Village: cassava as a subsistence crop, fishing for food and income

(2) Kachere Village: cassava as a subsistence crop, some grow rice and tobacco for cash income

(3) Hara Irrigation Scheme: based on cash income from rice production

A (primary level): He or she reported that they had had positive results from the blood test, or their previous partners or their former spouses were known AIDS cases. assumed as 'people living with

HIV/AIDS': PLWHA

B (secondary level): He or she did not report their own serostatus, but reported known AIDS cases in their family trees.

C (no evident impact): He or she reported that either they had had a blood test with negative results or did not report their serostatus but had no known AIDS cases in their family trees.

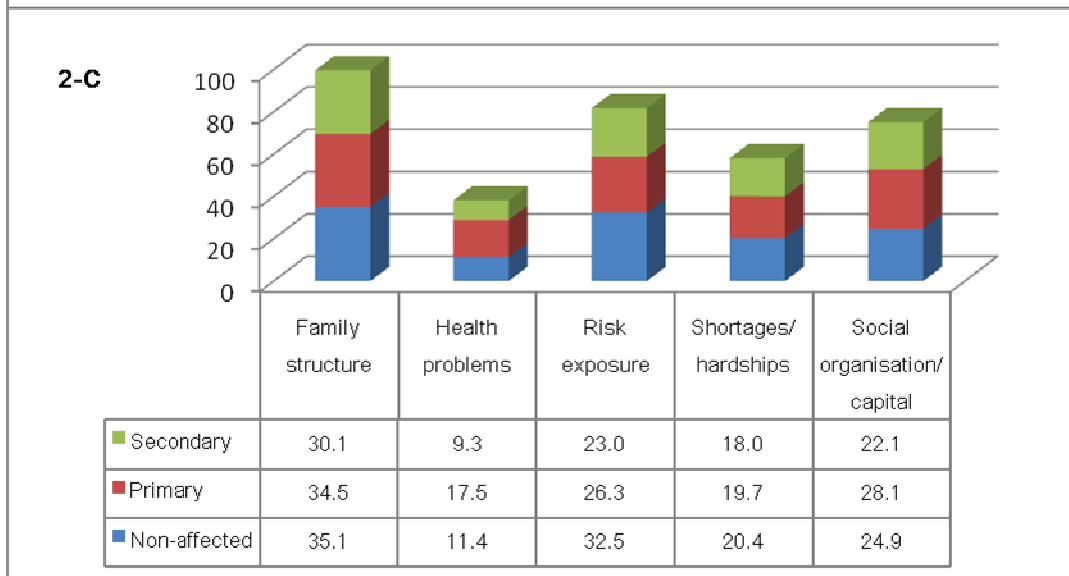
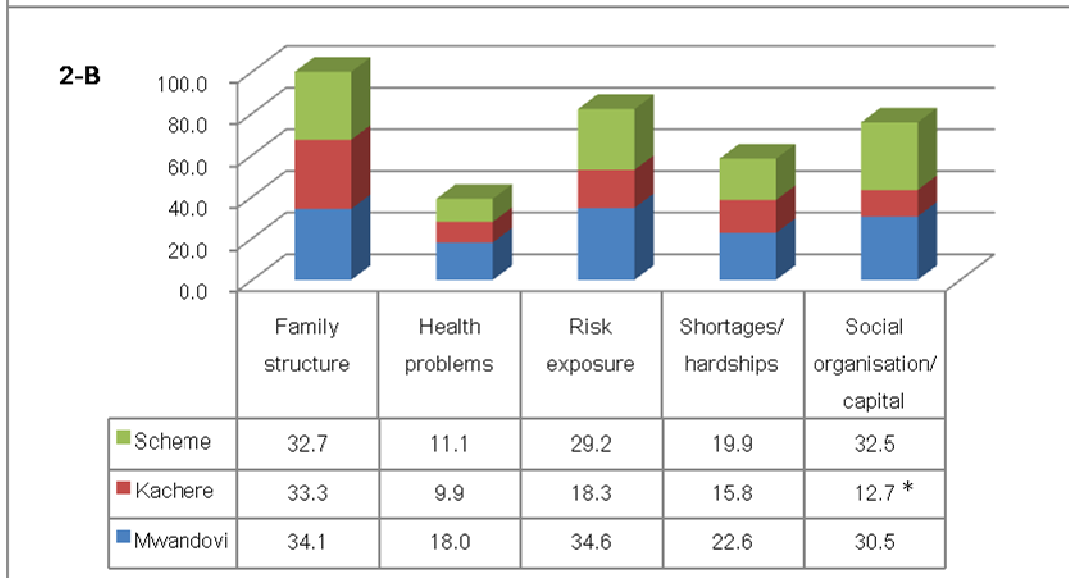
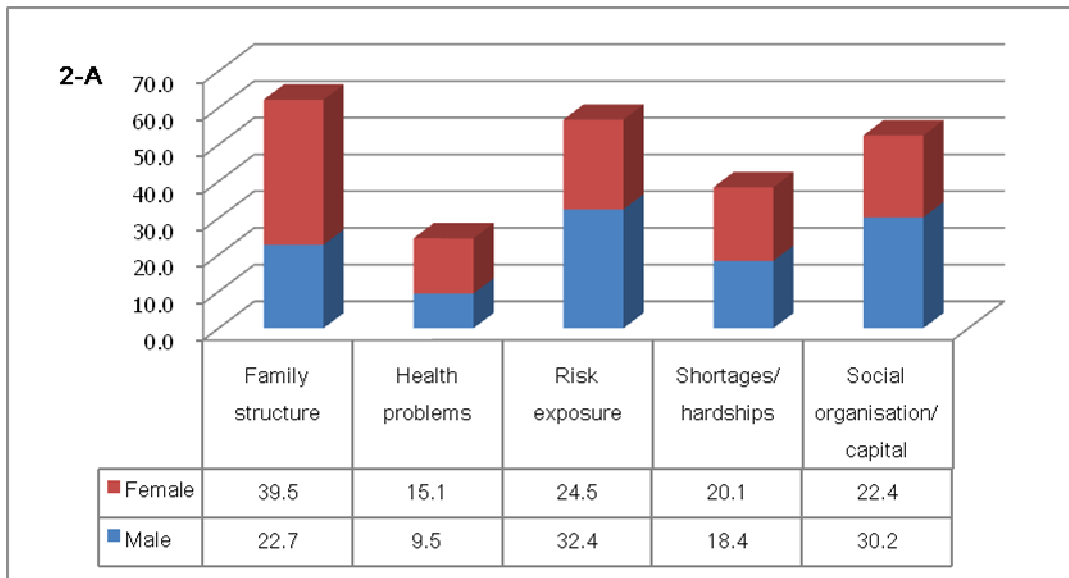
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## FIGURE LEGENDS



**Figure 1** Map of Chilumba and three locations

Source: Microsoft 2009; Harris Corp, Earthstar Geographics LLC; National Geographic Society 2009.



**Figure 2 Comparison of frequently cited concepts in narrations (expressed as a mean number of times cited per respondent) by gender (2-A), livelihood systems (2-B) (see table 2), and impact levels (2-C)**

**\* Kruswal-Wallis test : significantly different ( $P < 0.05$ ) from the other groups.**

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