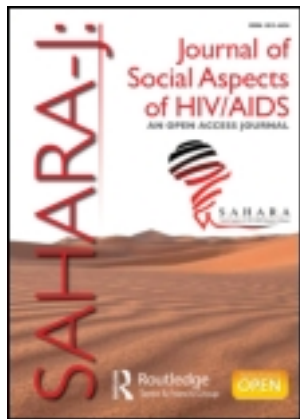


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## Social and cultural aspects of HIV and AIDS in West Africa: A narrative review of qualitative research

Helle Samuelsen\*, Ole Norgaard, Lise Rosendal Ostergaard

### Abstract

With the increasing focus on the role of social aspects of the HIV epidemic in sub-Saharan Africa, the need for an overview of existing research dealing with such issues has become more urgent. The objective of this article is to provide a thematic overview of existing qualitative research on HIV and AIDS in the West African region and to analyze the main research findings in order to identify possible gaps and recommend new research themes to inform future research-based interventions. The analysis is based on a total of 58 articles published from 2001 to 2009 in English or French identified through a literature search in seven scientific, bibliographical databases. Searches included terms related to qualitative studies combined with various terms related to HIV/AIDS. The results of this narrative review show that there was a geographical concentration on Nigeria, Ghana, Burkina Faso and Côte d'Ivoire and a strong urban bias, with most studies taking place in the capital cities of these countries. The majority of the studies focused on women or women and men; only four articles dealt exclusively with men, of which only two were on men who have sex with men. The main study groups were people living with HIV, young people or female sex workers. Sexual risk-taking and stigmatization were the themes that were most prominently explored in the articles we reviewed. We conclude that research needs to be strengthened in relation to the analysis of experiences with antiretroviral therapy and the non-optimal access to treatment in West Africa. Also, more research is needed on men and their exposure to HIV/AIDS, as well as on the role of concurrent partnership in the spread of HIV.

**Keywords:** HIV/AIDS, qualitative research, review, West Africa, risk-taking, stigmatization

### Résumé

Avec l'importance croissante du rôle des aspects sociaux de l'épidémie du VIH en Afrique Sub-saharienne, la nécessité d'une vue d'ensemble des recherches existantes traitant des questions susmentionnées est devenue plus en plus importante. L'objectif de cet article est de donner un aperçu thématique de la recherche qualitative existante sur le VIH et le SIDA dans la région ouest africaine et d'analyser les principaux résultats de recherche afin d'identifier d'éventuelles lacunes et de recommander de nouveaux thèmes de recherche pour informer, et qui à l'avenir pourraient inspirer de nouvelles interventions basées sur la recherche en question. L'analyse est basée sur un total de 58 articles publiés en anglais ou en français de 2001 à 2009 identifiés à travers une recherche documentaire dans sept bases de données bibliographiques et scientifiques. Les recherches comprenaient des termes liés aux études qualitatives combinés avec des termes variés liés au VIH/SIDA. Les résultats de cette revue narrative montrent qu'il y avait une concentration géographique sur le Nigéria, le Ghana, le Burkina Faso et la Côte d'Ivoire et un fort penchant pour les milieux urbains, avec la plupart des études se déroulant dans la capitale de ces pays là. La majorité des études ont porté sur les femmes ou les femmes et les hommes; seulement quatre articles ont traité exclusivement des hommes dont deux étaient sur des hommes ayant eu des rapports sexuels avec des hommes. Les principaux groupes d'étude étaient des personnes vivant avec le VIH, des jeunes ou des prostitués. Les prises de risques sexuels et la stigmatisation ont été les thèmes les plus explorés dans les articles que nous avons examinés. Nous concluons que la recherche doit être renforcée en ce qui concerne l'analyse des expériences avec la thérapie anti-rétrovirale et l'accès non optimal au traitement en Afrique occidentale. Additionnellement, plus de recherches sont nécessaires sur les hommes et leur exposition au VIH/SIDA, ainsi que sur le rôle du partenaire adversaire dans la propagation du VIH.

**Mots clés:** VIH/SIDA, recherche qualitative, revue, Afrique de l'ouest, prise de risque, stigmatisation

### Introduction

Epidemiological and medical research on HIV/AIDS has produced significant results, particularly in terms of the development

of life-saving antiretroviral (ARV) medicines, meaning that AIDS is no longer necessarily a fatal diagnosis but can be treated as a

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chronic disease. But research in other areas besides the purely biomedical fields is needed in order to address the many social and cultural aspects of the epidemic. There is still limited understanding of why changes in the epidemic happen and how they are perceived by population groups that have lived with HIV for decades and seen their impact on the social fabric. We also know very little about why the epidemic 'takes off' in one country but not in others that otherwise share many of the same characteristics. However, the new vision of UNAIDS – to achieve a reduction in new infections, discrimination and AIDS-related deaths – recognizes the social aspects of the epidemic and sets out a new global framework for action (UNAIDS 2011).

The increasing recognition of the importance of the social and cultural aspects of the epidemic makes it relevant to reflect upon the contributions of social science to its understanding so far. In this article, we seek to identify major trends in qualitative research on HIV and AIDS in West Africa in the period from 2001 to 2009. The objective is to provide an overview of the main inputs of qualitative research in this particular region: where have the studies mainly taken place, which population groups have mostly been researched and which research themes have been most prominent? We limit ourselves to a narrative review of qualitative, empirically based studies where the aim has been to acquire an in-depth understanding of practices and perceptions related to the HIV epidemic (Collins & Fauser 2005). Furthermore, we wish to discuss new trends and needs for qualitative research in the continuous efforts to understand the epidemic and to minimize the number of people affected by it.

Several general reviews of the social science literature and HIV already exist (Nguyen, Stovel & Klot 2004), but few, if any, have been conducted on the West African countries. The reasons for choosing this particular region are three-fold. First of all, the epidemic has had a different history in West Africa than in East or Southern Africa. Infection rates have not been as high in West Africa compared with the two other regions (with North Africa having even lower infection rates), and national AIDS campaigns and the strong political focus on AIDS generally started later in many West African countries compared with East Africa. Secondly, more literature reviews have so far been conducted on the epidemic in Anglophone Africa (particularly South Africa) than in Francophone Africa. Thirdly, comparisons between countries within a specific region are more pertinent than comparisons across a whole continent.

Initially, we set out to conduct a systematic review of published qualitative research on social and cultural aspects of HIV and AIDS in West Africa. However, based on an initial scoping exercise, it was evident that the available qualitative studies were characterized by great heterogeneity and covered a very broad topic area. This may not be well suited for the narrow focus of a systematic review that is based on e.g. meta-ethnography (Britten, Campbell, Pope, Donovan, Morgan & Pill 2002). Instead, we chose to frame our study as a narrative review (Baumeister & Leary 1997) to better incorporate the broad scope of the available qualitative research.

With this review, we aim to provide an overview and reveal potential problems, weaknesses, contradictions or controversies

(Baumeister & Leary 1997) in the published qualitative research on social and cultural aspects of HIV and AIDS in West Africa.

## HIV in West Africa

HIV is less widespread in West Africa than in Southern and East Africa, with prevalence estimated to be under 2% in Benin, Burkina Faso, Gambia, Ghana, Guinea, Liberia, Mali, Mauritania, Niger, Senegal and Sierra Leone. In Côte d'Ivoire, prevalence is estimated at 3.4%, and in Nigeria at 3.6% (UNAIDS/WHO 2009). Infection is reported to take place through unprotected sex, including paid sex; in Ghana, for example, paid sex alone is estimated to be the cause of 32% of all new infections (UNAIDS 2010:30). The epidemic is typically characterized as heterosexually driven, but new indications show that sex between men is playing a significant role in the spread of the infection. Evidence from urban Senegal and Nigeria indicate that more than 20% of new infections (UNAIDS 2010:30) take place among men who have sex with men, many of whom also report having sex with women. Another major source of infection is vertical transmission from mother to newborns and breastfed infants (UNAIDS 2010).

As the likelihood of staying alive – and staying relatively healthy – with HIV increases with access to life-prolonging medicines, the number of discordant couples in the region is on the rise. Epidemiological data indicate that a large proportion of new infections are taking place among people living in stable relationships (UNAIDS/WHO 2009).

## Methods

We conducted a comprehensive literature search in seven scientific, bibliographic databases: MEDLINE, EMBASE, Cinahl, PsychINFO, FRANCIS, IBSS and POPLINE. The first six databases were searched via Ovid and POPLINE via its own interface ([www.popline.org](http://www.popline.org)).

Searches included a number of terms relevant for qualitative studies, as shown in Table 1. These terms were combined with the main terms that are expected to be present in records of articles on HIV and AIDS such as 'HIV', 'AIDS', 'human immunodeficiency virus' and 'acquired immunodeficiency syndrome'.

**Table 1. Search terms.**

Search terms	anthropolog*, attitude*, audio recording*, awareness*, behavior*, behaviour*, belief*, content analysis, ethno*, experience*, field note*, field stud*, focus group*, grounded theory, hermeneutic*, interview*, knowledge*, narrative*, participant observation*, perception*, phenomenolog*, practice*, qualitative, thematic, theme*
Countries included	Benin, Burkina Faso, Cape Verde, Cote d'Ivoire, Gambia, Ghana, Guinea, Guinea Bissau, Liberia, Mali, Mauritania, Niger, Nigeria, Senegal, Sierra Leone and Togo

\*Indicating that alternative word endings were searched.

Next we added terms related to the 16 West African countries as defined by the National Library of Medicine, also shown in Table 1. Nouns commonly used for the countries' populations, the names of capitals and alternative names of countries, as well as terms used for the region, such as Western Africa, were also included. The thesauruses of all databases were examined to ensure that all appropriate subject headings and descriptors had been included in carrying out the search. The search results were limited to records published and entered into the databases in the period from January 1999 to March 2009.

### Selecting studies for this review

The titles and abstracts (if available) were retrieved and reviewed manually by all three authors and a research assistant. First, all abstracts that were not research-based were withdrawn from the list (e.g. advocacy materials, evaluation reports, editorials, news items, opinion pieces and various journalistic articles). Secondly, all articles that were based on an exclusively quantitative approach were excluded (e.g. epidemiological research, knowledge, attitudes and practices studies and other studies using only standardized questionnaires). Thirdly, articles that were not based on empirical data (e.g. literature reviews and general discussions) were excluded. All studies using a combination of methodologies, such as a mixture of standardized questionnaires, self-report questionnaires and focus-group discussions and/or participant observation, were examined to determine whether they were predominantly quantitative or qualitative by nature. Those studies which were primarily based on quantitative methodologies were excluded.

Eligible studies were based on qualitative research, contained empirical data obtained in West African countries, focused on issues surrounding HIV and AIDS and were written in English or French. The main reason for restricting ourselves to qualitative studies is that such studies mainly aim at providing in-depth and nuanced data on the social and cultural aspects of HIV and AIDS, as opposed to quantitative studies that mainly aim at identifying common trends across a population.

More specifically, we have included empirical studies using qualitative methods such as participant observation, individual in-depth interviews, focus-group discussions and analysis of narratives and rapid assessment procedures (Dahlgren, Emmelin & Winkvist, 2004). Qualitative studies often aim at understanding the life worlds of informants from their own perspectives, thus providing, in this particular context, information about the social and cultural aspects of the HIV epidemic.

### Limitations

In order to access a manageable volume of written material, we have chosen only to include peer-reviewed articles. Admittedly, as we have focused on published scientific articles identified through the databases mentioned above, we risk missing a range of important contributions from academic books and book chapters. We have assessed each of the articles according to the methodologies used. In the process of evaluating whether an article is predominantly qualitative, we might have included or excluded articles where authors themselves might disagree.

Likewise, the so-called 'grey literature' (non-peer-reviewed reports, conference contributions, discussion papers etc.) has been excluded. Finally, we might very well have missed studies that had not been correctly indexed, as well as published studies that had not yet been indexed in at least one of the databases at the time of the search. This is clearly a limitation to this review, though the articles included are all based on scientific field studies that include original data. In addition, we have scrutinized both English and French literature identified through the literature search.

### Analysis

Using the search strategy described above, we ended up with a total of 58 articles to include in this narrative review. A database (Microsoft Access) was established containing the following categories: authors, country of study, locality of study, year of publication, source, title of publication, study group/s, sex of study group/s (males/females or both), age groups of informants, number of focus group discussions (FGDs), number of qualitative interviews, observation (whether some kind of observation was included), survey (whether any type of survey was included), other methods (mention type), quantitative method (whether any quantitative methods were included), period of study, main research questions, main findings (1–3) and recommendations (1–3). Information about each of the 58 articles was entered into this database in order to provide an overview for a thematic analysis of the articles. Finally, the articles have been subject to a content analysis where the textual information in each has been summarized. As a consequence, articles with content on, for example, civil-society organizational issues (e.g. Deniaud & Fampou-Toundji 1999; Nguyen, Stovel & Klot 2004) that was interesting and of high quality but did not directly deal with issues included in this summary were excluded.

### Findings

Based on a thematic analysis of the 58 articles using qualitative methods, we have identified the following main features:

- The studies are concentrated in a small number of countries, and many studies are based in urban areas.
- Data collection is most often based on semi-structured interviews, with only a few studies combining different qualitative methods.
- The majority of studies focus on specific groups of people such as those living with HIV or young people.
- There is a strong focus on sexuality and sexual practices, particularly on issues concerning women's and young people's behaviours, including various aspects of sexual risk-taking.
- Stigmatization is an important theme in studies concerning people living with HIV, young people and other specific groups.
- A number of studies explore aspects related to the prevention of vertical transmission from mother to child.
- Reflections on various ARV therapy programmes and the impact of other types of interventions are the focus in a number of studies.

## Geographical focus

The geographical focus of the studies is relatively narrow, as they mostly concentrate on a limited number of countries: Nigeria (24), Ghana (7), Ivory Coast (7), Burkina Faso (7), Senegal (4), Togo (4), Mali (2), Benin (1) and Guinea (1), with one study covering both Ghana and Nigeria. Nine of the region's 16 countries have been subject to a qualitative study, with Nigeria being the most frequently studied country. Within the selection of countries, it is most frequent to find the capital or another major city as the locus of the research. This is particularly the case for Senegal and Togo, where all the identified studies were conducted in the capital, and for Ivory Coast, where six out of seven studies were conducted in the capital.

## Methods used

All the 58 studies included in this review are based on qualitative, empirical research. In total, 36 studies used interviews in data collection, the number of interviews conducted varying from 6 to 423, with an average of 81. The types of interviews used included informal conversations and interviews based on semi-structured interview guides. One study (Suleiman 2007) included as many as 423 interviews with people living with HIV using a semi-structured, interviewer-administered questionnaire. Out of the total of 58 studies, 20 used FGDs, ranging from 1 to 40 FGDs, with an average of 10. Only five studies state that they included observation or participant observation in their data collection. Five studies report other methods of data collection, such as therapy sessions, participatory rural assessment and audio-visual techniques. The total adds up to more than 58, as a number of studies have used a combination of methods.

## Combinations of methods

The majority of studies used a single method of data collection. The number of studies which combined FGDs with individual in-depth interviews is 13. Only seven combined qualitative methods with different sizes of surveys, and four studies triangulated FGDs with interviews and observations. A few studies included other methods such as analysis of hospital registers, psychological consultations and descriptions of actual implementation practices carried out by non-governmental organizations (NGOs).

## Period of study

Less than half of the studies (26) specify when the fieldwork and data collection were carried out. Of the 58 studies, 9 conducted fieldwork before 2000 (between 1993 and 2000), while a further 17 collected data between 2001 and 2006. While this review covers articles published between 2001 and 2009, it is evident that some studies are based on fieldwork carried out as early as in the 1990s.

## Study groups

The majority of studies focus on one study group, whereas a few compare different groups. The group that is most often included is people living with HIV (23), males and/or females. Eleven of these 23 studies focus on how treatment services can be improved (including the role of patient's low socio-economic status, the role of traditional healers, community-based activities and the

importance of family support). Other themes covered are adherence versus non-adherence to treatment, dilemmas related to sexual practices and risk-taking and the role of stigmatization (see Table 2 for an overview of the articles).

The second largest study group is young people (nine). Some studies focus on people under 25 with unknown serostatus, others on young people living with HIV. A variety of age definitions are used, some just referring to 'young adults', others to those aged 15–24 and others to people up to the age of 34. To the number of articles focusing on young people can be added the only two studies investigating adolescents aged 11–19. The main themes covered in these studies are young people's levels of knowledge about HIV/AIDS and their risk behaviour.

The third largest study group is female sex workers (five), based on a variety of definitions ranging from women who sell sexual services on a casual basis to women who engage in regular sex work. Finally, a number of articles focus on different groups that have a direct impact on the response to AIDS, such as health-care providers, religious leaders, traditional healers and teachers.

Nineteen studies include only women in the sample, whereas 35 include both men and women. Only four articles focus on men specifically (Allman, Adebajo, Myers, Odumuye & Ogunsola 2007; Ilika, Emelumadu & Okonkwo 2006; Izugbara 2007; Teunis 2001), all omitting women from their sample. Of these, two focus on men who have sex with men (Allman et al. 2007; Teunis 2001).

## Sexual behaviour and risk-taking

The studies which address issues of sexuality focus on how the complex relations between knowledge and social conditions inform an individual's response to HIV prevention. In the studies focusing on people living with HIV, a common theme is how social expectations on women increase their risk-taking. This is discussed generally in relation to the issue of fertility desires (own as well as socially imposed) and their perceptions of themselves as decent women (Dago-Akribi, Msellati, Yapi, Welfens Ekra & Dabis 2001). HIV-positive women retain a wish to establish a family and are willing to have unprotected sex to fulfil that desire. Following the same line, risk-taking among people living with HIV is discussed in three studies from Togo (Moore & Amey 2008; Moore & Oppong 2007; Moore & Williamson 2003). In one of these studies, professional carers report that risky sexual practices among people living with HIV are connected to women's low status, polygamy and social constructions of manhood (Moore & Williamson 2003). Moore concludes that the focus on condom promotion in many prevention programmes is too narrow to embrace the strong fertility desire of many HIV-positive individuals and young couples who have not yet had children of their own (Moore & Oppong 2007). In Painter's study, among HIV-positive and HIV-negative women, only 5 out of 117 women considered their partner to be faithful, and only two used condoms regularly (Painter, Diaby, Matia, Lin, Sibailly, Kouassi, et al. 2007). Also, the role of socio-economic factors in risk-taking is mentioned, one study finding

Table 2. Study groups and themes.

Article	Study groups				Themes				
	Young people	PLWA <sup>a</sup>	Sex worker	Other	Risk-taking	Stigmatization	PMTCT <sup>b</sup>	ART <sup>c</sup>	Other
Abiona et al. (2006)		*		*		*	*		
Adebayo et al. (2004)		*		*				*	
Ajala & Adejumo (2007)		*		*		*			
Allman et al. 2007				*	*				*
Alubo et al. 2002		*				*	*		
Arulogun et al. (2007)				*			*		
Baiden et al. (2007)				*		*			
Berthé and Huygens (2007)			*		*				
Bisizi and Dedobbeleer (2003–2004)	*				*				
Bosompra (2007–2008)				*					*
Castle (2003)	*								*
Castle (2004)	*					*			
Charmillot (2002)				*					*
Coulibaly Traore et al. (2003)		*					*		*
Cros (2003)	*				*				
Dago-Akribi (2001)		*					*		
Dago-Akribi et al. (2001)	*	*							*
Dago-Akribi and Cacou Adjoua (2004)	*	*							*
De Allegri et al. (2007)				*			*		
Delaunay and Vidal (2002)		*						*	
Desgrées-du-Loû and Brou (2005)				*	*				
Desgrées-du-Loû et al. (2007)				*			*		
Drescher (2007)				*					*
Enwereji (2008)		*			*				
Enwereji and Enwereji (2008)				*					*
Espirito Santo and Etheredge (2004)			*		*				
Ezumah (2003)				*	*				
Folayan, Fakande and Ogunbodede (2001)		*		*					*
Garko (2007)		*							*
Guest, Bunce, Johnson, Akumatey and Adekun (2005)				*					*
Guest et al. (2008)				*					*
Hofmann et al. (2009)				*			*		
Homaifar and Wasik (2005)			*		*				
Ilika et al. (2006)				*					*
Izugbara (2007)	*				*				
Luginaah (2008)				*	*				
Manga et al. (2009)		*							*
Mantoura, Fournier and Campeau (2003)			*						*
Moore and Williamson (2003)		*			*				
Moore and Oppong (2007)		*			*				
Moore (2007–2008)				*					*
Moore and Amey (2008)		*			*				
Mwinituo and Mill (2006)				*		*			

(Continued)

Table 2. Continued.

Article	Study groups				Themes				
	Young people	PLWA <sup>a</sup>	Sex worker	Other	Risk-taking	Stigmatization	PMTCT <sup>b</sup>	ART <sup>c</sup>	Other
Ogunjuyigbe and Adeyemi (2005)				*	*				
Ogunro et al. (2006)		*						*	
Ojo and Fasubaa (2005)	*			*					*
Oluwagbemiga (2007)		*						*	
Owolabi and Owolabi (2001)		*						*	*
Oyefara (2007)			*		*				
Painter et al. (2007)				*	*				
Perry, Davis-Maye and Onolemhemhen (2007)		*							*
Peter, Immananagha, Essien and Ekott (2004)		*							*
Samuelsen (2006)	*				*				
Smith (2007)				*	*				
Smith and Mbakwem (2007)		*						*	
Suleiman (2007)		*		*		*			
Tanner (2008)				*					*
Teunis (2001)				*	*				

<sup>a</sup>PLWA: People living with AIDS.  
<sup>b</sup>PMTCT: Prevention of mother-to-child transmission of HIV.  
<sup>c</sup>ART: Antiretroviral treatment.

that HIV-positive women in Abia State, Nigeria, are often denied access to resources by their relatives, suggesting limited care and support by the extended family, which again can push women into risky sexual practices (Enwereji 2008).

The issue of how risk perceptions and local moral worlds shape the agency of young people is taken up in a number of articles. Cros (2003) and Samuelsen (2006) found that young people in Burkina Faso are caught in a dilemma between the desire for sex and trust in their relationships on the one hand and the risk of being infected by HIV on the other. Bisizi and Dedobbeleer (2003–2004) show that, when young women manage to communicate with their partners about sexual risks, there is a tendency for safer sexual practices to be adopted (Bisizi & Dedobbeleer 2003–2004). Izugbara (2007) demonstrates the heterogeneity of social constructions and representations of sexual abstinence among young males in rural Nigeria.

A number of studies (Berthé & Huygens 2007; Espirito Santo & Etheredge 2004; Homaifar & Wasik 2005; Oyefara 2007) focus specifically on sexual risk-taking among sex workers (Berthé & Huygens (2007) include other vulnerable groups as well). The main conclusion of these articles is that women often drift into prostitution and unsafe sexual practices because of poverty and that their main priority becomes economic security rather than to sell sex with a condom. The study by Homaifar and Wasik (2005) shows that, by legalizing and monitoring sex work in Senegal, knowledge and safe sexual practices increased among female sex workers. Berthé and Huygens (2007) also report that a Communication for Behavioural Change project has been

launched to improve knowledge of safe sexual practices among the marginalized women included in the study.

### Fertility control

The issues of sexual behaviour and risk in married couples are discussed in three articles based on different fieldwork studies in Nigeria. Ogunjuyigbe and Adeyemi (2005) found that women in stable unions in Lagos have control over their sexuality to a certain extent, especially during menstruation, breastfeeding, pregnancy and sickness, whereas only a few informants claimed to be able to negotiate safe sex outside these specific situations. Desgrées-de-Lou's study from Abidjan points out that long periods of post-partum abstinence entail the risk of men seeking sex elsewhere, thus exposing themselves and their partners to STI and HIV (Desgrées-du-Loù & Brou 2005). Ezumah's study, also from Nigeria, shows that sexual networking among married men is common, and in some cases, married women are also encouraged to become involved in it by their families. This is especially the case if a couple does not have a male child (Ezumah 2003). Smith's analysis of men's extramarital sexual relations indicates that infidelity is primarily shaped by economic inequality and a search for a modern lifestyle, and he concludes that keeping up the appearance of a healthy and peaceful marriage is very important (Smith 2007). Luginaah studies how the people of the Upper West district of Ghana relate the locally brewed gin, *akpeteshie*, to the spread of HIV/AIDS (Luginaah 2008). Only two articles deal explicitly with health risks among men who have sex with men, concluding that the risks embodied within these same-sex relationships appear unacceptably high (Allman et al. 2007; Teunis 2001).

## Stigma

Many of the articles are concerned with the issue of stigmatization and the role of perceived and enacted stigma and its consequences for people living with HIV. Stigma prevents HIV-positive individuals from disclosing their status to family members and neighbours. HIV is perceived as a shameful disease because of its connotation of socially unacceptable practices such as buying or selling sex, and the diagnosis is often only revealed to no more than one or two family members (Alubo, Zwandor, Jolayemi & Omudu 2002). Seven articles address the issue of stigma directly. Three conclude that stigmatization of people living with HIV is widespread and most often rooted in misperceptions about the routes of transmission (Alubo et al. 2002; Baiden, Akanlu, Hodgson, Akweongo, Debpuur & Binka 2007; Castle 2004). Baiden et al. (2007) find that perceptions of the social transmission of HIV (sharing food, utensils and latrines) are most widespread among women, religious leaders and people with no formal education. Other articles focus on both people living with HIV and their carers, concluding that the negative attitudes of neighbours and families often lead carers to provide care in secrecy, leading to the isolation of themselves as well as the patients (Ajala & Adejumo 2007; Mwinituo & Mill 2006; Suleiman 2007). One article (Abiona, Onayade, Ijadunola, Obiajunwa, Aina & Thairu 2006) shows that social expectations on young mothers regarding infant feeding practices are so centred on breastfeeding that women who choose not to breastfeed are subject to negative labelling and often called stigmatizing names.

One study from urban Côte d'Ivoire (Dago-Akribi & Cacou Adjoua 2004) explores how 19 HIV-positive adolescents – 12 of them on ARV therapy – struggle to reconcile a desire for social integration in adult society with the perceived stigma attached to HIV. The study finds that their suffering and lack of self-esteem are fuelled by their bodily development and that they constantly subject their maturing body to self-inspection and contemplation. The study finds that the commonplace adolescent crisis of 'coming of age' is aggravated by the deteriorated body image they are confronted with in national prevention campaigns, leaving them in strong need of psychosexual and social counselling and support.

## Mother-to-child transmission

Six articles explore the role of breastfeeding in relation to mother-to-child transmission of HIV. Three of these articles are based on studies in Burkina Faso, of which two (De Allegri, Sarker, Hofmann, Sanon & Böhler 2007; Hofmann, De Allegri, Sarker, Sanon & Bohler 2009) are based on the same study and authored by the same group of researchers. These studies conclude that breastfeeding is perceived as essential to motherhood by both the mothers and society, suggesting that HIV prevention messages which do not acknowledge the importance of breastfeeding for women's status in the family and community are likely to fail. Likewise, as already noted, Abiona et al. (2006) find that not breastfeeding is stigmatized and that replacement feeding is only acceptable after the first 6 months.

Three other studies from Nigeria focus indirectly on breastfeeding. In the two studies conducted by Aka-Dago-Akribi (Dago-

Akribi 2001; Dago-Akribi et al. 2001), the main focus is on the need for psychological support for HIV-positive women, and it is also shown that their wish for more children makes them prone to risk-taking. Arulogun, Adewole, Olayinka-Alli and Adesina (2007) investigate community gatekeepers' general awareness and perceptions of how to prevent mother-to-child transmission (PMTCT), concluding that a stronger community focus and advocacy is needed to improve utilization of PMTCT services. Coulibali's study in Abidjan focused on women's understanding of their participation in clinical trials and found that more than half of the women had not shared their test results with anyone (Coulibaly Traore, Msellati, Vidal, Ekra & Dabis 2003). Desgrées-du Lôu et al. do not focus directly on PMTCT, but investigate why some women refuse prenatal testing, emphasizing the importance of the role of the regular partner and that repeating the offer of testing is worthwhile (Desgrées-du-Lôu, Brou, Djohan & Tijou-Traore 2007).

## ARV therapy

All six articles with a specific focus on ARV therapy conclude that the direct or indirect costs of treatment (including lab-based check-ups and the treatment of opportunistic infections) cause severe problems for patients with low economic status. Owolabi and Owolabi's (2001) study from Ile-Ife in Nigeria illustrates, through four case studies, how the economic burden of treatment leaves patients with poor outcomes of treatment and unpaid hospital bills. Delaunay and Vidal (2002) show how the high cost of treatment affects both family relationships and strategies for selecting beneficiaries for care-giving programmes. Olugwagbemiga (2007) shows that some patients even have to sell their property or other economic assets in order to buy drugs, and Ogunro, Adeneye, Ogungbamigbe, Adewole, Musa and Isikwei (2006) recommend that drugs be made more affordable on the basis of a study in Nigeria, where patients have to pay US\$120 per year for ARV treatment. A study by Smith and Mbakwem (2007) argues that in the future, effective ARV programmes will demand a better understanding of the patient's life projects, which also cover marriage and childbearing. Adebayo, Irinoye, Oladoyin and Fakande (2004) draws attention to a home-based care project provided by an NGO in Osun State, Nigeria, and discusses the strengths and weaknesses of such types of intervention. One of the most important weaknesses is identified as irregular funding of the local NGO, which has direct consequences for the availability of medicines to patients.

## Discussion

The overall aim in applying qualitative methods to the study of HIV is to provide an in-depth and detailed understanding of the socio-cultural issues underlying the epidemic. The collection of studies included in this narrative review shows that the unfolding complexities of the epidemic at both the individual and community levels have been subject to academic scrutiny. While clinically based research offers important information about the patterns of different epidemics at the national and regional levels, the empirically based, qualitative studies add insights into the varieties of local situations.

Only a few of the studies we have included triangulated their methods, using two or three different tools of data collection.



The difficulty of conducting participant observation in studies of sexuality and risk-taking is recognized, but a combination of methods is particularly useful in studies where sensitive issues are investigated. It is striking how many of the articles provide little information about the actual time of data collection, even though this information would allow the reader to situate the fieldwork in the context of an epidemic that is evolving at a rapid pace.

Below, we will first discuss some of the main features identified in the review with a specific focus on research gaps. Secondly, we will discuss possible areas of enquiry which call for intensified research in the future.

One of the findings of this study is the preponderance of urban-based studies identified in a small number of countries. Most of the studies took place in 4 of the 16 West African countries (Nigeria, Ghana, Burkina Faso, Ivory Coast). We have managed to identify only one study from Benin and not a single study from Gambia, Cape Verde, Liberia, Mauritania, Niger or Sierra Leone. This does not necessarily imply that no research has been conducted in these countries, but findings have not been published in any of the scientific journals registered in the seven databases. It is not surprising that, given their large populations, Ivory Coast and Nigeria have been subject to many studies, and it is also clear that they are the countries with some of the highest HIV prevalence in the region. According to UNAIDS (2009), the latest epidemiological update estimates Nigeria to have a prevalence of 3.1% among adults, Ghana 1.9%, Burkina Faso 1.6% and Ivory Coast 3.9%.

However, we also find other West African countries with an estimated prevalence of over 1.5%, such as Togo (3.3%), Sierra Leone and Liberia (both 1.7%) and Guinea Bissau (1.8%), with only very few studies. The geographical focus of the studies is indicative of how global health research in the field of HIV is organized. Most of the epidemiological or clinically focused research in the Franco-phone countries has been funded by the USA or France and been based in Abidjan, Ivory Coast, Bobo Dioulasso, Burkina Faso or Dakar, Senegal. This research has often been conducted by groups such as the Institut National de la Santé et de la Recherche Médicale, the Institut de Recherche pour le Développement for Ivory Coast and the Population Council for Senegal. While only a small part of this research draws on qualitative methods, it has generated an important volume of quantitative data of high quality. It has probably been a source of information for other researchers, and one can hypothesize that these clinically based research stations have pulled other researchers to these locations, which also benefit from much better infrastructure than most other places in the region.

At this particular stage of the epidemic, when life-saving drugs are now available, one can argue that we need more and better research on how to improve the uptake of HIV care and services. The improved survival rates of people living with HIV means that the number of people who can transmit the virus to their partners or babies is growing, as is the number of HIV-positive individuals eligible for treatment. To respond to this new demographic situation, the delivery and effectiveness of HIV testing services need to be improved for pregnant women, as well as for most at-risk populations and for people in stable unions. Many of the

studies in this article point to the fear of stigma as a barrier to better use of HIV testing. The social exclusion that can be the harsh reality for people who are known to be HIV-positive is often presented as the result of stigma, misconceptions and prejudices among HIV-negative people in local communities. It might be relevant to go one step further and explore how existing social conflicts and tensions between different family members maybe triggered by an HIV diagnosis.

While many of the studies included in the summary in one way or another present data which show that stigmatization has been and remains a barrier to an effective AIDS response, rather few studies deal explicitly with the 'access gap'. Only a few studies focus on experiences with ARV therapy and the access gap to treatment, which could be explained by the time lag between fieldwork and publication. New studies could explore why so few people are actually tested for HIV. Apart from the fear of stigmatization, what other reasons are there for low testing rates? The access gap is also relevant in relation to access to treatment. It is estimated that only about 30% of eligible AIDS patients are receiving combination therapy in West and Central Africa, compared with 48% in East and Southern Africa (UNAIDS/WHO 2009). Of course, one reason could be the lack of medicines and health staff in the countries concerned, but there could also be other relevant barriers that could be studied from a qualitative point of view.

Our narrative review shows that most of the studies covered focus either on people living with HIV or young people. A smaller number of studies have focused on the general population or other specific groups such as sex workers, health-care personnel and traditional healers. We have identified a strong focus on women and gender issues in the studies included in this review, where 19 of the 58 studies included only women in their sample, and many studies present conclusions about the vulnerable position of many women in partnerships. However, qualitative studies could probably contribute with further analyses of factors contributing to the higher prevalence rates of women and girls compared with men. According to UNAIDS, HIV prevalence among females (6.4%) is more than twice as high as among males (2.9%). Women's vulnerability to HIV not only stems from their greater physiological susceptibility to heterosexual transmission, but is also related to their socially, legally and economically disadvantaged positions (UNAIDS/WHO 2009). Another gender-related trend documented by epidemiological survey data from five West African countries calling for in-depth qualitative studies shows that women living in the wealthiest households have higher HIV prevalence rates than other socio-economic groups of women. This suggests that future studies should include married couples and people in long-term relationships. The significant contribution of low-risk heterosexual partnerships to the sub-Saharan epidemic points to the high prevalence of sero-discordant partnerships in many countries. This suggests that we need a better understanding of the role of concurrent partnerships, especially in the spread of HIV. Likewise, it is estimated that male-male transmission has been under-reported, but we only located 2 out of the 58 studies which specifically focus on this phenomenon. It is also worth noting that very few studies have focused on children and their specific problems related to HIV and AIDS.

## Conclusion

In this narrative review covering qualitative studies published between 2001 and 2009, we have identified some common trends such as a strong geographical focus, a focus on people living with HIV and young people, as well as thematic concentrations on topics such as sexual behaviour and risk-taking, stigmatization and aspects of mother-to-child transmission. The review shows that there are certain commonalities across the West African region: the desire to establish strong social relationships and partnerships, the desire to have children despite a seropositive status, the difficulties many women face in negotiating safe sexual practices and the increased risk-taking caused by socio-economic problems. But the studies also report from very different contexts, where rooms for negotiating safe sex vary, where stigmatization is expressed in different ways and where the significance of extramarital sex varies.

While the concentration on a small number of countries might be explained by the high HIV prevalence in these countries, it also reflects how international funding and research agendas are shaped and how they prioritize support for research activities. There is inadequate research capacity in many of the countries in the region, which is hardly surprising in the poorer countries. Those countries that are under-represented certainly need to strengthen their national research capacity so they can set their own research priorities in the future.

It is our hope that this overview of existing qualitative, empirically based research on HIV/AIDS conducted in West Africa will be of interest to researchers, policy-makers and organizations directly involved in the prevention and treatment of the HIV/AIDS epidemic. Furthermore, we hope that, by pointing out certain research gaps, other researchers and funders of research will be inspired to take up some of these topics in the future.

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