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Myths about HIV and AIDS among serodiscordant couples in Malawi

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Myths about HIV and AIDS among serodiscordant couples in Malawi

Abstract

Purpose: The paper reports on research that uncovered myths about HIV and AIDS held by serodiscordant couples in Malawi, and the sources of these myths. The paper reflects on how the myths affect serodiscordant couples' engagement with HIV and AIDS information.

Design

Van Manen's (1997) approach to analysis of phenomenological data is used to analyse data from in-depth interviews conducted in Malawi with 21 serodiscordant couples and 3 individuals who had separated from their partners because of serodiscordance.

Findings

Serodiscordant couples in Malawi believe and hold on to some inaccurate HIV and AIDS information that can be seen as 'myths'. Some of these myths are perpetuated by official HIV and AIDS information when it is translated into the local languages. Other myths derive from social norms of the societies where the couples live.

Practical implications: The findings of this paper have practical implications for how HIV and AIDS information providers should engage with target audiences to understand the origins of the myths they hold. The findings also imply that some myths have technical, religious, moral and cultural bases which need to be addressed before challenging the myth itself.

Originality/Value: Using real-life descriptions of experiences of HIV and AIDS information provided by serodiscordant couples, the authors reveal how myths can affect engagement with the information. The authors make recommendations on how to address myths in ways that contribute to a positive experience of HIV and AIDS information by serodiscordant couples.

Keywords: HIV – AIDS – Myths – Serodiscordance – Information Behaviour – Malawi

Introduction and background

This paper is based on a PhD project investigating how serodiscordant couples experience HIV and AIDS information in Malawi. A serodiscordant couple is a couple in which one partner is HIV-positive and the other is HIV-negative (World Health Organisation, 2012). One of the important findings of the study was that serodiscordant couples believed some myths about HIV and AIDS, which we argue negatively affected the intended outcomes of information campaigns. This paper presents myths identified in this study and discusses the implications for the effectiveness of HIV and AIDS information

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3 for serodiscordant couples. As Hammer and Elby (2002) argue, people have different ways of acquiring
4 knowledge about phenomena. However, it seems likely that no one would deliberately set out to
5 acquire false beliefs about phenomena in their environment (Kaphagawani and Malherbe, 1989). Jaja
6 (2014) contends that people naturally cannot bear to have unanswered questions, and that as such,
7 formulate answers that turn out to be mythical. Dickinson (2014) identifies that these answers may draw
8 on deeply-held beliefs and have more plausibility than scientific explanations.
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13 14 **The concept of “myth”**

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16 The word “myth” is rich in meaning, and can be interpreted in culturally resonant or in negative ways.
17 For example, the Oxford English Dictionary defines myth firstly as “a traditional story, typically involving
18 supernatural beings or forces, which embodies and provides an explanation, aetiology, or justification
19 for something such as the early history of a society, a religious belief or ritual, or a natural
20 phenomenon” (Oxford University Press, 2015). However, it also defines it as “a widespread but untrue
21 or erroneous story or belief; a widely held misconception; a misrepresentation of the truth”. As will be
22 identified, this coupling of the words “myth” and “misconception” occurs in the healthcare literature.
23 Misconception is in turn defined as “a view or opinion that is false or inaccurate because based on
24 faulty thinking or understanding” (Oxford University Press, 2015), clearly positioning the problem as
25 cognitive, and residing with the person who has the misconception. For example, Picou et al. (2011),
26 writing about HIV in the Caribbean, define myths as ideas or explanations that are widely believed to be
27 true but which are, in fact, untrue and based on ignorance about the subject.
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37 The word “myth” has been used in the medical and healthcare literature frequently, but often without
38 clear definition or discrimination from cognate terms. However, different usages of the term can be
39 identified. Casazza et al. (2013: 448), writing about obesity, usefully distinguish between myths (“beliefs
40 held true despite substantial evidence refuting them”), presumptions (for which there is not yet firm
41 evidence) and facts (for which there is high quality research evidence). Similarly Harrison (2008), whilst
42 not defining myth explicitly, frames myths as being such because there is substantial evidence that can
43 refute them. As already noted, the word “misconception” is often linked to “myth”. Ramos Salas,
44 Forhan, and Sharma (2014), in their study of obesity myths, simply define a myth as a misconception.
45 In some cases the words “myth” and “misconception” or “misperception” are introduced and then
46 implicitly treated as synonyms. An example is Cagle et al. (2016) who test citizens’ knowledge of
47 hospice care, and then use the words “myth” and “misperception” interchangeably when discussing
48 results.
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3 In contrast, the philosopher Midgley (2003: 2) defines myths as “imaginative patterns, networks of
4 powerful symbols that suggest particular ways of interpreting the world”. This interpretation differs
5 epistemologically, situating the myth (including healthcare myth) in a cultural or spiritual context, which
6 is subject to interpretation, rather than proof. Indeed Midgley (2003) proposes scientific certainty as a
7 possible contemporary myth itself.
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12 Discussions of myths specifically concerning HIV/AIDS normally associate them with misconceptions
13 and ignorance of scientific evidence. For example Kang 'ethe and Xabendlini (2014: 56) refer to
14 “Misinformation, misinterpretation, misperceptions and myths” (without distinguishing between them).
15 However, they also refer to myths as “stories that in absence of a scientific explanation try to explain
16 some of the mysteries of life. These stories can be a recipe of half-truths, mistruths, misinformation, or
17 stereotypes” (2014, 56). They explicitly link myths concerning HIV/AIDS with stigma, cultural beliefs and
18 traditions in African countries: a link that is not so commonly made in literature about the Western
19 healthcare context. Thus myths are positioned as “networks of powerful symbols that suggest particular
20 ways of interpreting the world” (as in Midgley’s definition) but with negative, rather than creative,
21 associations.
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30 **Myths about living with HIV**

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32 Living with HIV is an experience that involves making decisions that can make a difference between life
33 and death (Minion, 2010; Namuleme, 2013). This is even more critical for partners in serodiscordant
34 couples. HIV and AIDS information is complex, and there are many information sources available to
35 serodiscordant couples. Not all sources of HIV and AIDS information provide correct and up-to-date
36 information. Therefore, serodiscordant couples need to identify trusted sources of HIV and AIDS
37 information.
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43 Most people in Sub-Saharan Africa have heard about HIV and AIDS. For example, in Malawi, Zambia,
44 Zimbabwe and Tanzania, HIV and AIDS awareness has been described as almost universal (National
45 Statistical Office (NSO) & ICF Macro, 2011; Tanzania National Bureau of Statistics & ICF Macro, 2011;
46 Zambia Central Statistical Office et al., 2014; Zimbabwe National Statistics Agency & I. C. F. Macro
47 International, 2012). However, myths about HIV and AIDS exist in many African countries. These
48 include the belief that one can be cured of HIV after sleeping with a baby (Kang'ethe & Xabendlini,
49 2014); that mosquitoes can transmit HIV (Mwamwenda, 2015; Tenkorang, 2013); and, that HIV can be
50 transmitted through supernatural means (Tenkorang, 2013). In addition, data from most countries in
51 Sub-Saharan Africa suggest that when presented with correct and mythical information about HIV and
52 AIDS few people are able to identify correct information and dispel the myths (ICF Macro, 2015).
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3 There are many myths about diseases and illnesses. However, Midgley (2003) argues that myths are
4 not lies and are part of society. She further suggests that some patterns of thought can be useful in one
5 era and yet problematic in another. She advises that instead dropping them, they should be reshaped
6 to correct the faults. Dickinson (2013) argues that myths may be viewed as bizarre when first
7 encountered with an outsider's view. However, when understood and viewed from inside as
8 components of wider belief systems their plausibility becomes apparent.
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14 Specific to HIV and AIDS, there are two broad categories of myth that are identified in literature. The
15 first category concerns myths that exist at international and national policy levels. The debate around
16 an opinion piece by (Piot, Kazatchkine, Dybul, & Lob-Levyt, 2009a) contending that some global
17 prevention strategies for HIV and AIDS continue to be based on myths, illustrates the nature of this
18 discourse. There are several responses to Piot et al. (2009a), and Piot, Kazatchkine, Dybul, & Lob-
19 Levyt (2009b) provide an author's reply. It is notable that the authors do not accuse each other of
20 ignorance or lack of understanding, but rather present additional evidence (e.g. Starrs, 2009) or, more
21 robustly, accuse each other of vested interest (England, 2009). This discussion of myth-making is
22 taking place with a shared view of reality that can be established with reference to empirical evidence
23 and rational argument.
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31 The second category of myth concerns beliefs people hold about HIV and AIDS that are contrary to
32 medical evidence. People living with chronic conditions use various sources of information which
33 include text based information, information drawn from participation in activities, and from their bodies
34 (Lloyd, Bonner, & Dawson-Rose, 2013). These authors assert that people living with chronic illnesses
35 need information literacy skills to navigate the complex information landscape. Marshall and Williams
36 (2006) observe that information literacy programmes for health should aim at guiding people to
37 resources that are appropriate to their information needs.
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44 There is a lot of misinformation about HIV and AIDS. The expansion of access to the internet is said to
45 have exacerbated the situation (Kalichman et al., 2006). Kalichman et al. argue that people living with
46 chronic illnesses and their families often are vulnerable to misinformation on the internet. Cameron et
47 al. (2013) found that exposure to myths had no effect on the level of knowledge, and accurate recall of
48 correct information. These authors suggest that designers of health information materials should not
49 shy away from alerting information recipients about myths. However, Okpewho (1983) contends that
50 myths are an irreducible aesthetic substratum in all varieties of human cultural endeavour, reflecting
51 people's attempt to understand and explain phenomena they live with in naturalistic system.
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3 On the other hand, we might consider these alternative explanations about HIV and AIDS as people's
4 ability to think for themselves (Dickinson 2013). Dickinson (2014), based on his research in the South
5 African context, proposes a typology of myths, with underpinning theory, core beliefs, and a more
6 mutable set of myths based on the beliefs. Folk theories of HIV/AIDS link biological phenomena with
7 moral principles; for example with core traditional African beliefs or core Christian religious belief. Lay
8 theories of HIV/AIDS are developed from lay observations outside traditional or Christian belief, and
9 generally concern ways to avoid HIV/AIDS. Dickinson (2013) argues that HIV and AIDS information
10 campaigners need to appreciate these alternative ideas if scientific perspectives are to be entertained.
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17 Although myths about HIV and AIDS have been widely researched, there appears to be no study
18 previously conducted specifically on serodiscordant couples. Mwamwenda (2015) investigated myths
19 and misconceptions among university students, and Tenkorang (2013) used data from a health and
20 demographic survey which was a population wide study. Namuleme (2013) investigated the information
21 behaviour of people living with HIV and found that there were myths about HIV transmission that had to
22 be dispelled; the study participants were people infected and affected with HIV. Our study contributes to
23 the understanding of myths about HIV and AIDS by focusing on a specific group of people:
24 serodiscordant couples.
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31 **Methods**

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33 Three research approaches were considered for the study. These were ethnography,
34 phenomenography and phenomenology. As the aim of the PhD study was to describe how
35 serodiscordant couples experience HIV and AIDS information, phenomenology was found to be most
36 suited for the study. Phenomenology is a research approach that seeks to investigate the nature of the
37 everyday world as we experience it, and not as we conceptualise it (Van Manen, 1997).
38 Phenomenological interviews were used to invite serodiscordant couples in Malawi to describe how
39 they experience HIV and AIDS information. The phenomenological approach was chosen because it is
40 rigorous enough to derive in-depth understanding of how serodiscordant couples experience HIV and
41 AIDS information. Additionally, considering that people living with HIV are stigmatised, and that HIV
42 concerns couples' intimate lives, phenomenology afforded tools to achieve the level of empathy that
43 allowed serodiscordant couples to describe their experience of HIV and AIDS information. The
44 interviews lasted an average of 45 minutes each and were conducted in 2013. By the time of its
45 conclusion, fieldwork had resulted in a purposive sample of 21 couples and 3 individuals who had
46 separated from their partners because of serodiscordance.
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57 **Table 1: Demographic characteristics of the sample**

Composition	Number
HIV status	
Couples	
• Male HIV positive-Female HIV negative	10
• Male HIV negative-Female HIV positive	11
Individual partners	
• HIV positive males	1
• HIV positive females	1
• HIV negative females	1
Age	
• 25-44	29
• 45-64	13
• 65+	3
Education	
• No formal education	9
• Primary school education	23
• Secondary school education	12
• University education	1

During the interviews, serodiscordant couples were asked to describe how they experienced HIV and AIDS information. Throughout the description, couples were encouraged, using probing questions, to give specific examples of experiencing HIV and AIDS information. When these examples were given, the participants were encouraged to reflect on them and describe what the experience was like. All interviews were audio recorded and transcribed verbatim.

The interview data were analysed using Van Manen's (1997) approach to the analysis of phenomenological data to derive descriptions and interpretations of experiences. This approach has six interplaying activities which were applied in the study.

Activity 1: Turning to the nature of lived experience

This was undertaken by identifying the phenomenon of interest (HIV and AIDS information), and formulating the research question. In addition, a purposive sample of mutually disclosed serodiscordant couples was drawn. Serodiscordant couples were first contacted by managers of HIV and AIDS management organisations or coordinators of HIV and AIDS support groups. The researcher met only couples that agreed to participate in the interviews.

Activity 2: Investigating lived experience as we live it

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3 This was done by conducting in-depth interviews to invite serodiscordant couples to describe how they
4 experienced HIV and AIDS information. The interviews were conducted in Chichewa, the commonly
5 spoken local language in Malawi. Serodiscordant couples were given freedom to choose the place,
6 date and time of the interview. For all couple interviews both partners were interviewed together. This
7 ensured that partners did not experience discomfort that their spouses were disclosing information they
8 considered too private (Margolin et al., 2005). In addition, during the initial recruitment contact with the
9 gatekeepers it was clear that most couples would not commit to being interviewed for longer than 90
10 minutes because of work commitments.
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16 17 **Activity 3: Reflecting on essential themes**

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19 The first step of this activity was to listen to all the recorded interviews. The interviews were transcribed
20 verbatim and coded using Nvivo while in the local language (Chichewa).
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24 The interview data were coded by reading through the interview transcripts one at a time. As the
25 ultimate goal of the analysis was to describe how couples experience HIV and AIDS information, codes
26 were concepts that were considered as building blocks of the description. During the analysis, care was
27 taken to ensure that each concept conveyed one singular thought or idea. While reading the transcripts
28 phrases or sentences conveying a particular concept were copied in a related code. Where overlaps
29 emerged among the codes or a significant singular thought emerged within a code, we merged the
30 overlapping codes or break a code to isolate the emerging singular thought respectively.
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36 While reading the transcripts the codes were re-analysed to confirm that concepts represented the
37 couples' descriptions. The codes were also re-analysed to identify relationships among the concepts.
38 The codes were sorted according to similarities of meaning to derive themes. The process of
39 developing themes was iterative. The themes were refined by back and forth checking with the actual
40 descriptions provided by serodiscordant couples.
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45 The list of themes was further refined by conducting Free Imaginative Variation. This process was
46 carried out by picking one theme at a time and using it as a frame of reference. Specifically, we asked
47 the question: "Is the description of the experience of HIV and AIDS information complete without this
48 theme?" If the answer was 'yes' the theme was considered incidental and deleted, and when the
49 answer was 'no' it was considered an essential theme. For a complete description of the Free
50 Imaginative Variation, and themes that were identified as incidental and deleted refer to section 4.2.7.1
51 in Wella (2015).
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3 The final step in activity 3 was interpretation of the themes. The interpretive process entailed constantly
4 interrogating the themes in the context of the descriptions provided by serodiscordant couples to
5 ensure that they were true to the experience of HIV and AIDS information. Interpretation of themes was
6 carried out using Van Manen's (1997) 'structures of the life-world'. These are: lived body, lived space,
7 lived others, and lived time.
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10 11 **Activity 4 & 5: Phenomenological writing, and maintaining a strong and oriented relation to the** 12 **phenomenon** 13 14

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16 Writing was undertaken as part of the analysis of data and interpretation of the findings.
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19 **Activity 6: Balancing the research context by considering parts and whole** 20

21 This was undertaken through the process of reflexivity in order to maintain orientation to the research
22 question.
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25 The research was granted ethical approval from University of Sheffield Ethic Committee. Additional
26 ethical approval was obtained from University of Malawi, College of Medicine Research and Ethics
27 Committee (COMREC).
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30 **Limitations of the study** 31

32 Interviewing two partners in a serodiscordant couple had some limitations. Some partners were not free
33 enough in the presence of their spouses to discuss issues they considered private to their lives.
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36 Throughout the study, we ensured that this limitation did not compromise the findings. A sample of 45
37 participants (21 couples and 3 individuals) ensured that different voices were represented in the data
38 collected and that the sample would include more couples that were open and free to discuss their
39 experiences. Further, interviewing the three individuals who had separated from their partners provided
40 an opportunity to explore HIV and AIDS information experience with them away from their spouses.
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45 The other limitation concerns interviewing in the local language and translating into English. In our
46 study, translating data from Chichewa to English had the likelihood of losing the meaning of
47 serodiscordant couples' descriptions. In order to minimise the impact of translation on the integrity of
48 the findings, the data were analysed in the local language, and only the quotations that were used in
49 writing up the results were translated. In addition, all translations were validated by a language expert
50 from the University of Malawi, Centre for Language Studies.
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Findings

The outcome of the analysis was a description and interpretation of how serodiscordant couples experience HIV and AIDS information. The findings of our study show how HIV and AIDS information was constituted, consumed and acted upon within the life-world of the serodiscordant couples. In this study, five structures of the life-world were identified. Four of these are the structures identified by Van Manen (1997): the lived body (the existence of the couples in the world in bodily form), lived space (the space the couples occupied at any particular time), lived time (subjective time), lived others (the couples were in the world with others). A fifth structure was identified through the research reported here: spirituality (the couples' belief in God and ancestral spirits). In addition, the couples were found to have lay theories about HIV and AIDS which were mythical.

Myths, and HIV and AIDS information

The findings of our study showed that general awareness of HIV and AIDS among the serodiscordant couples was good. However, there was also evidence that the couples believed some myths about HIV and AIDS. Some myths influenced them to ignore information that was provided by health workers. In some cases, the myths appeared to be strengthened by the imprecision of the explanations about serodiscordance provided by health workers. In addition, mythical information appeared to originate from religion and culture. Our study identified five myths about HIV and AIDS among serodiscordant couples in Malawi.

Myth 1: Mosquitoes can transmit HIV

During the interviews, one couple explained that they believed the HIV positive partner was infected through mosquito bite. Findings of this study suggest that serodiscordant couples believed their risk of being infected with HIV was low because they were in a stable marriage. As such, some couples used myths to explain the origin of the HIV infection.

...sometimes they say on the radio that the virus can come from injections that are not sterilised, sometimes through blood transfusion, even mosquitoes, okay, when it bites an infected person, it can go and infect another person... (HIV- Male partner, Couple #13)

This myth in itself is not surprising because HIV is blood borne like other diseases transmitted by mosquitoes like malaria. However, the context in which this myth was mentioned suggests that transmission by mosquitoes takes away the shame and stigma that is associated with sexual transmission of HIV. The couple were trying to justify that the HIV positive partner had not been promiscuous.

Myth 2: If I shake my husband's hand I will be infected

Similar to myth 1, some serodiscordant couples believed that their HIV positive partners could infect them through physical contact such as a handshake. As stated earlier, couples got some HIV and AIDS information from everyday talk in their communities. One respondent remarked:

Yes, they were just talking; saying that when someone is HIV positive we should avoid getting closer to them because they can transmit the virus to you. That distressed me because I eat from the same plate with my husband (HIV- Female partner, Couple # 21).

This interview excerpt suggests that this myth was widely held in the community. Furthermore, our study indicates that these myths created a culture of stigma and discrimination against people living with HIV. A telling example was an HIV negative partner who was encouraged to divorce her husband.

She said:

When they talk about this disease, they talk to discourage me. Some ask me, like what I told you earlier, 'we hear that you husband was found with the virus? ...and they ask me; 'what encourages you to stay on with that man?...why don't you divorce him?'

This myth brings to fore the association of contamination with being infected with HIV. The interview excerpts appear to suggest that the virus is all over the body of the infected person and mere contact could result into transmission. This is consistent with our everyday association of illness and germs.

Myth 3: If my spouse is HIV positive then I am also positive

Most serodiscordant couples correctly identified unprotected sex as one of the major means through which HIV is transmitted. However, based on that knowledge, they did not believe that two partners in a marriage relationship, with regular sexual contact, can have different HIV statuses.

...information for people like us, serodiscordant couples, it is very few. Information is very few so many people don't believe that one partner can be positive and the other negative (HIV- Male partner, Couple #17).

The result is that when one partner is found to be HIV positive, the other partner resigns to their fate and declares him- or herself to be likewise positive. Our findings suggest that with the belief that they are infected, most HIV negative partners, particularly men, refused to use condoms. This is demonstrated in the following interview excerpt:

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3 *"In my mind I had already established it; there is no need to use condoms, am already infected,*
4 *the virus is just hiding, you see, I did not have enough information when all this was*
5 *happening..." (HIV- Male partner, Couple #17)*
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9 Part of the reasoning in this interview excerpt was based on HIV and AIDS information provided by
10 health workers in voluntary counselling and testing (VCT) centres. Among the reasons given by health
11 workers for the different HIV statuses was that virus in the HIV negative partner might have been
12 hiding. Believing that they are infected, and that the virus was only hiding, most serodiscordant couples
13 found no reason to use condoms.
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18 This myth also identifies the contradiction that exists in HIV and AIDS information. For serodiscordant
19 couples this contradiction was a major issue because unprotected sex was identified as the primary
20 means through which HIV is transmitted. Being in a marriage relationship, the two partners were in
21 frequent sexual contact yet they had different HIV test results.
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24 25 **Myth 4: If I reach orgasm faster than my wife I will not get infected**

26
27 While this myth was only mentioned by one respondent, it provided an insight into men's way of
28 thinking that can have an impact on the lives of women in serodiscordant couples. Evidence from
29 conversation with this respondent suggests that the myth was influenced by sexism. He said:
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33 *... a man should be fast when doing things; if you are slow you will get infected....in bed I always*
34 *make sure I get there before her. (HIV- Male partner, couple #19)*
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37 The respondent believed that if he ejaculates before his wife reaches orgasm he would not contract the
38 HIV virus. In addition, he indicated in his remarks that men need not let women overpower them and
39 infect them with the HIV virus.
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43 *...when you know that this is your wife you should teach her that I am the man and she is a*
44 *woman (HIV- Male partner, Couple #19).*
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47 The language used in this interview excerpt is figurative and idiomatic. This is characteristic of most
48 African languages. Figurative language and proverbs were used when making reference to issues of
49 sexual nature, human genitalia and pregnancy. For example during the interviews a male partner in
50 couple #12 used the word 'sleeping' to refer to sexual intercourse, and 'protector' for condom. Similarly,
51 the male partner in couple #19 used the expression 'a man should not be slow' to mean 'a man should
52 reach orgasm first'. In some interview conversations, it took careful probing to decipher the meanings of
53 such language usage.
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3 Myth 4 also demonstrates the socio-cultural constructions of the position of men in society. This is
4 reflected in the interview excerpt from an HIV positive male partner who thought he was a victim of
5 violence by his wife because of his HIV status. He said:
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9 *We have nowhere to go with our problems.... We face gender-based violence...when you*
10 *speak out people laugh, they say; 'can a man be treated like that? When he is a man? No that*
11 *can't happen because he is a man' (HIV+ Male partner, couple #6)*
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14 **Myth 5: Condoms have a hole through which the virus can pass**

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16 This myth concerns the acceptability of the condom as a means for preventing HIV transmission on the
17 one hand, and its religious acceptability for use by married couples on the other hand. Our study
18 findings suggest that some religious organisations perpetuated myths about condoms in order to
19 convince their followers that abstinence is the only viable means of preventing HIV transmission. One
20 serodiscordant couple said:
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25 *...those condoms, we are told that they have some form of air that can enter your body... They*
26 *told us that condoms are not 100% perfect they were made for people who don't listen to*
27 *advice (HIV+ Male partner, couple #7).*
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31 Most serodiscordant couples were religious and held in high esteem the support provided by religious
32 organisations. However, they believed that health workers provide correct HIV and AIDS information.
33 Some couples claimed that health workers were not convincing when countering this myth.
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37 In analysing the myths held by serodiscordant couples in Malawi, the myths appear to fall into two
38 broad categories. The first category is of myths that are grounded in the broader regime of advocacy for
39 good health. Our study reveals the interplay between general health messages, and HIV and AIDS
40 information. For instance, health information on malaria describes how, when mosquitoes suck blood
41 from a person with malaria and bite a healthy person, the malaria is transmitted. This message makes
42 some people believe that mosquitoes can also transmit HIV since like malaria it is blood-borne. This
43 example suggests that some information that is considered mythical is based on some scientifically
44 correct health information but is not related to HIV and AIDS. In the same category is information
45 considered mythical which was provided by advocacy campaigns sanctioned by the State.
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53 The second category of myth concerns views held by serodiscordant couples based on culture and
54 moral values. Serodiscordant couples were found to hold on to some beliefs about HIV and AIDS that
55 were contradictory to medical research evidence. Evidence from interview conversations with the
56 couples suggest that these myths had cultural, religious and moral bases. Our findings show the
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3 underlying dynamics of experiencing HIV and AIDS information by serodiscordant couples. Comments
4 made by some participants demonstrated that HIV and AIDS information is not consumed in a vacuum.
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6 The correct HIV and AIDS information interacts with other contradictory information that is based on
7
8 cultural, religious and moral beliefs.
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11 Evidence from interview conversations with serodiscordant couples illustrates that although HIV and
12 AIDS information from health workers was identified as most reliable, couples in practice relied on
13 personal informal sources. These included family, friends, and peers living with HIV. Everyday talk in
14 the communities serodiscordant couples lived included discussion about HIV and AIDS. Some talks
15 about HIV and AIDS in these communities were sensational and based on misinformed opinions which
16 influenced serodiscordant couples to make wrong decisions. The following interview excerpt
17 demonstrates how men talk amongst themselves about condoms:
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23 *Yes, when we were playing bawo¹ people talk, they bring those things just to fool us, those*
24 *condoms, I don't use them, I refuse to use those things, I just throw away in the toilet. [He was]*
25 *talking like that publicly yet we know he has that problem (HIV- Male partner, Couple #13).*
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29 However, some couples made good decisions after consulting other people in their communities. One
30 respondent described how a friend living with HIV allayed her fear of getting infected by her HIV
31 positive husband.
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35 *But I heard from someone. I had heard that she is HIV positive, she is on ARVs. I talked to her;*
36 *'Hey you, people say you were found with HIV?' And she said; 'Yes'. 'And you are on ARVs?'*
37 *She said; 'Yes, why are you asking me that question?' Then I told her that; 'things are not okay at*
38 *home, here is the situation, and in fact I am devastated by this issue', She told me that; 'you*
39 *should not be devastated, it's a minor issue; just follow what you were told at the hospital'; I said;*
40 *'are you serious?'; she enlightened me, and since that time I put aside all my anxiety (HIV-*
41 *Female partner, Couple #22).*
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48 Our findings suggest that HIV and AIDS information including the associated myths are socially
49 constructed. People's conceptions of HIV and AIDS were influenced by interactions and conversations
50 with others.
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58 ¹ Bawo is board game usually played by men.
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Discussion

Significant linkages of the myths with the five structures of the life-world are evident, exemplified by repeated references to the body, other people, and religious beliefs. In this paper we observe that what are called myths are HIV and AIDS information the serodiscordant couples find believable because it is delivered through the structures of their life-world. This is consistent with findings of the study by Dickinson (2014) and his typology of myths, as described above. Dickinson (2014: 48) further argues that myths about HIV and AIDS are not random acts of ignorance, but lay theories that are both more plausible and more palatable, generated from traditional belief systems. It is argued that people are less likely to believe information that is inconsistent with their worldview (Lewandowsky, Ecker, Seifert, Schwarz and Cook 2012).

Myth 4 presented in this paper resonates with the lived body as a structure of the life-world. Serodiscordant couples appeared to have lay understanding of how their bodies work and how different diseases are transmitted. That knowledge was used to form theories about HIV transmission. Dickinson (2014) observes that some communities in South Africa had a lay physiological explanation of HIV transmission from women to men through the penis sucking vaginal fluids. This explanation is behind the idea that a man cannot get infected by HIV when he ejaculates before his wife reaches orgasm. Similarly, some myths are concerned with lived others. Serodiscordant couples were aware of the contagion of other people's bodies and formed lay theories about the threat.

Most respondents who mentioned the myths presented in this paper were HIV negative. In addition, the findings of our study indicate that most HIV negative partners were not actively seeking HIV and AIDS information. This suggests that these myths thrive on lack of correct HIV and AIDS information delivered through the structures of the life-world of the couples. Many HIV and AIDS information services that were available to serodiscordant couples were for people living with HIV. As such, HIV negative partners in serodiscordant couples have difficulties in finding HIV and AIDS information. Gombachika, Chirwa, Malata, Sundby and Fjeld (2013) observe that even couples in which both partners are HIV positive face difficulties in finding reproductive health information.

Some of the myths presented in this paper aroused fear in the HIV negative partners. However, most of the fear was exacerbated by lack of correct facts about serodiscordance and HIV transmission. Cao, Sullivan, Xu, and Wu (2006) observes that in many rural areas people know very little about HIV and

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3 how it is transmitted. Because of myths, people unknowingly put themselves at risk of HIV infection and
4 infecting others. In addition, myths also help to perpetuate stigma and discrimination against persons
5 living with HIV (Picou et al. (2011). Cao et al. (2006) further argue that increasing awareness by
6 providing people with correct HIV and AIDS information can reduce stigma.
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10 As noted by Picou et al. (2011) the danger of myths is that people put themselves at the risk of being
11 infected by HIV. This is true for serodiscordant couples. Our study findings suggest that when one
12 partner is HIV positive the other partner resigns to fate, which increases transmission of HIV among
13 serodiscordant couples. Studies have shown that couples in which both partners participate in
14 counselling consistently use condoms and prevent HIV transmission to the HIV negative partner (Allen
15 et al., 1992; Curran et al., 2012). However, studies conducted in Kenya and Uganda found that myths
16 about serodiscordance were common among health care providers. Common explanations for
17 serodiscordance were that the HIV negative partner was already infected, but the virus had not reached
18 detectable levels. Other health workers were found to believe that the HIV negative partner was
19 immune (Bunnell et al., 2005; Ngure et al., 2012). These studies, taken together with our findings,
20 suggest that there is need for improvement of access to HIV and AIDS information by health workers,
21 especially in developing countries. On the other hand Dickinson (2014), in his study of HIV and AIDS
22 peer educators in South Africa describes how the peer educators had difficulties to reconcile their
23 medical knowledge with their beliefs. Dickinson observes that although the peer educators were
24 recruited to transmit scientifically correct HIV and AIDS information to their peers, they also had belief
25 systems on which they based their everyday decisions.
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38 In our study, some male partners treated their spouses as inferior to them in terms of decision making
39 about their own or their spouse's illness. As presented in the findings, this attitude is indicative of male
40 ego which marginalises women, making them unable to act on HIV and AIDS information. The finding is
41 consistent with previous studies. For example, Mbweza, Norr, and McElmurry (2008) reported that
42 women believed that they should respect their husbands because God created them first, and that
43 decisions about sex were dominated by husbands. This myth, and male dominance on decision making
44 regarding sex in serodiscordant couples, have implications for the prevention of HIV transmission for
45 women. It is therefore important for women to be empowered to participate in making decisions that are
46 favourable to their circumstances.
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53 On the other hand, our study flags up the violence men suffer in silence in order to protect their ego.
54 Most literature that is available on HIV related violence among couples portrays men as perpetrators. It
55 is undeniable that the proportion of women, as compared to men, facing gender based violence is high.
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3 However, as observed by Adebayo (2014) most men do not report gender based violence for fear of
4 bruising their ego. Adebayo further argues that even if they report it, they would not be believed and
5 would be suspected to be perpetrators.
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9 Previous studies have found that the issue of condom use for married people is a divisive one. There is
10 a divergence of views about condom use in Malawi with the government and the faith-based
11 organisations on opposing sides (Rankin, Lindgren, Kools, & Schell, 2008). Accordingly, the
12 government promotes the use of condoms while the faith-based organisations are against this. Our
13 study found that in an attempt to convince their followers not to use condoms, some faith-based
14 organisations used myths to demonise the condom. For serodiscordant couples the situation is different
15 from that of other couples and the general population; because their situation means that they cannot
16 do without condoms, the myths create a sense of guilt in them.
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23 Although HIV and AIDS awareness in Malawi is considered to be universal (National Statistical Office
24 (NSO), and ICF Macro., 2011) that knowledge exists alongside myths that negatively impact on the
25 intended outcomes of HIV and AIDS information campaigns. While believing that HIV negative partners
26 in serodiscordant couples can remain negative indefinitely if they consistently use condoms, and the
27 positive partner adheres to ART, government agencies and non-governmental organisations promote
28 condom use. However, our study has shown that some faith-based organisations perpetuate myths to
29 discourage their followers from using condoms.
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36 One of the major findings of our study (see Wella (2015)) was that HIV and AIDS information was
37 socially constructed. When describing their experience of HIV and AIDS information, serodiscordant
38 couples also described that of the community they lived in. Conrad & Barker (2010) observe that in the
39 first place all illnesses are socially constructed based on experiential realities for living with the
40 illnesses. This is corroborated by Sifunda et al. (2006) who found that knowledge about HIV and
41 sexually transmitted diseases (STD) were socially constructed. The study conducted among Nguni
42 inmates in South Africa observed that conceptualisations about HIV and STDs were shared among
43 men of the same age group.
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50 Since HIV and AIDS information is socially constructed, our opinion is that the approaches used to
51 dispel HIV and AIDS myths needs to be in resonance with social constructions of knowledge. Other
52 studies have highlighted the challenge of using the myth/fact message format which is based on the
53 scientific epistemology. Lewandowsky et al. (2012) observe that when people are presented with
54 information materials that use the myth/fact format, they tend to correctly identify the myths immediately
55 after reading the material. However, Lewandowsky et al. argue that after some time, people only retain
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3 familiarity with the materials and not the details. A study conducted by Ramos Salas, Forhan and
4 Sharma (2014) found that the myth/fact message format was not sufficient to change deeply rooted
5 myths about obesity. However, these authors argue that defusing deeply rooted myths requires
6 multilevel intervention. In their paper, they also identify circumstances where fact-only messages would
7 not work.
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12 Casazza et al. (2013) blame "repeated exposure to the claims" as the force that reinforces myths. In
13 addition, contradictory messages create cognitive dissonance that prevents people from abandoning
14 beliefs they hold despite correct information being provided. Evidence from our study suggests that
15 cognitive dissonance also affects HIV and AIDS information campaigns. Everyday talk about HIV and
16 AIDS creates a community belief system that is in dissonance with public health messages. pproaches
17 that focus on repeated discrediting of false claims can have the reverse of the desired effect, as people
18 remember the claim, and from that familiarity remember the false claim as being true (Skurnik, Yoon,
19 Park, & Schwarz, 2005). Our study of serodiscordant couples found that false claims are part of
20 everyday talk, and repeated in most conversations. In addition, the false claims had strong relevance to
21 the life-world of the serodiscordant couples. The relevance comes from the fact that such claims are
22 based on cultural, religious, and moral conceptions of illness. Dickinson (2014) argues that myths that
23 circulate through everyday talk have a greater influence on the population than those that make
24 headlines in the media.
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34 **Conclusion and recommendations**

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37 The ability to access up-to-date health information, and use it in good time, is important for
38 management of HIV infection. Unfortunately, there are also myths about HIV and AIDS that are difficult
39 to tell apart from the facts. This paper has identified some of these myths and considered some
40 implications for the health literacy of serodiscordant couples.
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45 This paper demonstrates that dissonance of HIV and AIDS messages provided by different
46 stakeholders makes efforts to dispel some myths difficult. Specifically, for serodiscordant couples, the
47 divergence of messages on condom use provided by faith-based organisations on one side, and
48 government agencies and non-governmental organisations (NGO) on the other, is not helping matters.
49 The problem occurs when conceptions about illness, specifically HIV and AIDS, are mediated by culture
50 and religion.
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3 Our study findings suggest that serodiscordant couples were exposed to mythical but persuasive
4 information about HIV and AIDS through media, music and everyday talk. The information included
5 religious arguments against condom use, and claims about HIV cure. Casazza et al. (2013 p.452)
6 observe that sometimes people believe myths because of repeated exposure to “persuasive yet
7 fallacious arguments”. Another important finding of our study concerns the effects of overly emphasized
8 negative aspects of HIV and AIDS. Most of these messages, though mythical, were troubling to
9 serodiscordant couples, especially the HIV negative partners. On the other hand, health workers use
10 scientific information to negate the risks portrayed in these messages. The negation does not help
11 matters either. As argued by Betsch and Sachse (2013) strong risk negation can paradoxically make
12 people perceive the risk as greater.
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21 In conclusion, we wish to make some recommendations. As argued by Dickinson (2013), usually
22 research on HIV and AIDS myths does not bear intended results because it is approached with
23 attitudes that label myths as ignorance and backwardness. As a result, respondents do not tell the
24 truth. We therefore recommend that research into myths, and HIV and AIDS information, should adopt
25 approaches that allow people experiencing HIV and AIDS to be heard and honoured. In this paper, we
26 have demonstrated that information that is labelled as mythical is based on experiential realities of
27 living with the illness. On the other hand, medically correct HIV and AIDS information is based on
28 protocols that are developed at international and national level with little or no regard for local contexts.
29 As Dickinson (2014) points out, focussing on each myth individually can be misleading. Myths need to
30 be “viewed in totality as a body of knowledge...that are used to interpret the AIDS
31 epidemic...”.(Dickinson, 2014) Therefore, instead of focussing on discrediting one myth, efforts should
32 be put into addressing the core idea on which a group of myths are built.
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42 Based on the findings of our study, we suggest that HIV and AIDS information materials should be
43 moderated through the structures of the life-world. In this approach, HIV and AIDS information would be
44 tailored to specific communities in order to draw on aspects of lived spaces people in the community
45 occupy. The information will also use experiences of specific people in the community who would give
46 examples from their bodies as examples of living with HIV. In a similar fashion HIV and AIDS
47 information can draw on aspects of lived time, lived others and spirituality. This approach may
48 encourage people in their communities to internalise correct information and talk about it more. A good
49 example of this approach is proposed by Mchombu, Bruton, Cocks, and Evans (2002). They propose
50 the use of radio and cassette listening clubs. In the context of our study, HIV and AIDS information
51 would be targeted at specific groups of people such as serodiscordant couples through the listening
52 clubs. Delivery of information would then be done in steps. The first step would be at group level. At this
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3 level people would listen to the radio or cassette, or watch some video and discuss the contents. The
4 discussion would draw some action plan to be followed through by couples or individuals. During the
5 discussions, couples or individuals would be encouraged to use lived experiences and their bodies as
6 examples of effective management of HIV infection. At couple or individual level members of the club
7 would be encouraged to put into practice lessons acquired from the discussions.
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12 To the best of our knowledge, HIV and AIDS counsellors in Malawi do not have standard information
13 materials they can use or give out to special groups such as couples. Therefore, we recommend that
14 information materials should be in different formats to suit the information needs of different people. "In
15 order to reach the 2015 global AIDS targets, getting the right information to the right people at the right
16 time is necessary" (Joint United Nations Programme on HIV/AIDS, 2014, p. 287). Considering that most
17 HIV and AIDS information, and the associated myths, are shared through word of mouth there is a
18 need to work with specific communities and groups when designing information materials. Hepworth,
19 Grunewald, and Walton (2014, p. 1045) argue that users of information services are "experts of their
20 reality", and they should be considered "partners" when designing the services.
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