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The church and paediatric HIV care in rural South Africa: a qualitative study

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ABSTRACT

Religion has substantial – positive and negative – influence on South Africa's HIV context. This qualitative study explored possibilities for positive church engagement in paediatric HIV care in a rural district in Limpopo Province, South Africa. Opinions, attitudes and experiences of various stakeholders including religious leaders, healthcare workers and people infected/affected with/by HIV were investigated through participant observation, semi-structured interviews and focus group discussions. During the research the original focus on paediatric HIV care shifted to HIV care in general in reaction to participant responses. Participants identified three main barriers to positive church engagement in HIV care: (a) stigma and disclosure; (b) sexual associations with HIV and (c) religious beliefs and practices. All participant groups appreciated the opportunity and relevance of strengthening church involvement in HIV care. Opportunities for positive church engagement in HIV care that participants identified included: (a) comprehensive and holistic HIV care when churches and clinics collaborate; (b) the wide social reach of churches and (c) the safety and acceptance in churches. Findings indicate that despite barriers great potential exists for increased positive church engagement in HIV care in rural South Africa. Recommendations include increased medical knowledge and dialogue on HIV/AIDS within church settings, and increased collaboration between churches and the medical sector.

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HIV; religion; church; stigma; sexuality; South Africa

Introduction

South Africa has one of the world's largest HIV epidemics (World Health Organization, 2013). Although antiretroviral therapy (ART) is available, 95% adherence is required for ART to be successful (Burack, Gaur, Marone, & Petrova, 2010). Adherence is facilitated by disclosure of HIV status and influenced by healthcare seeking behaviour; both factors are influenced by religion (Alamo et al., 2012; Manzou, Schumacher, & Gregson, 2014; Mbonu, van den Borne, & De Vries, 2009; Mutwa et al., 2013; Omenka & Zarowsky, 2013).

The majority of South Africans (70%) are Christian. Approximately 30% belong to cultural churches that integrate cultural and traditional practices and Christianity (Anderson, 1999; Lubbe, 2008). Churches have played a significant role in South Africa's HIV epidemic, some fuel HIV stigma, some offer diverse forms of support (Campbell, Skovdal, & Gibbs, 2011; Haddad, 2011).

While literature focuses on possible church responses to the epidemic, limited data are available on opinions and experiences of the stakeholders at the church/HIV intersection, such as religious leaders, healthcare workers and people

infected with or affected by HIV/AIDS (people living with HIV/AIDS [PLWHA]). This study aimed to investigate these experiences and opinions, exploring how churches can support paediatric HIV care in rural South Africa.

Methods

Study setting and participants

This mixed-method case study was conducted from March to July 2013 in Mopani District in Limpopo province. Religious leaders (RLs) were approached using snowball sampling through churchgoing employees of a local NGO and churches; healthcare worker (HCW) through NGO staff at primary healthcare clinics and caregivers during their child's monthly clinic visit. Inclusion criteria were: pastoring a congregation (RLs); working in HIV clinics (HCWs) and attending an HIV clinic for an HIV-positive (foster) child (caregivers). Participants signed informed consent for participation and audio recording. Interviews and focus group discussions (FGDs) were conducted in English (or Sotho, with translator's assistance).

Table 1. Guidelines interviews and FGDs.

	Caregivers	RLs	HCWs
Interview topics	Background	Professional background	
	Experiences with caring for a child with HIV, their treatment, and adherence in daily life	Experiences with (paediatric) HIV, treatment, and adherence in the community	
	Role of one's own church	Role of churches in general	
	Relation between faith/religion and HIV	Relation between faith/religion and health	
	Collaboration between churches, clinics, DoH, and other structures; and the desired nature of HIV-related involvement of one's own church	Collaboration between churches, clinics, Department of Health, and other structures; and the desired nature of HIV-related involvement of churches in general	
FGD guidelines	<p>Adherence barriers (as identified in the research) are presented. Participants invited to share their experiences with these barriers in caring for their children living with HIV.</p> <p>Group discussion on the role of faith in personal life, experiences about the role of the church in HIV, and desires for future church involvement in HIV.</p>	<p>Each participant comes up with three barriers to (paediatric) treatment adherence.</p> <p>Barriers are grouped to the structure where they are believed to be influenced most: home, church, or clinic.</p> <p>Barriers are prioritised based on their applicability for church involvement.</p> <p>Brainstorming on how such involvement could be achieved for each of the prioritised barriers.</p>	

Study procedures

Participant observation in local clinics and churches – based on convenience sampling – served to better understand the study setting. Topic lists for interviews and FGDs were drawn from observations' field notes (Table 1). Interviews – identifying in-depth information and experiences – and FGDs – identifying shared experiences and (dis)agreement – were conducted at RLs' churches or homes, local clinics and the NGO's office. The principal author collected data, with an NGO nurse translating where applicable. At the FGD with caregivers two clinic counsellors were present.

Two of the authors (WN, MK) transcribed crude data and inductively identified five coding categories using a constant comparative method of analysis (Pope, Ziebland, & Mays, 2000), coding the transcripts and copied written FGD products. Inter-rater reliability was obtained through continuous comparing and discussing of codes between the coders. Coded transcript fragments were grouped, subcoded more specifically, and analysed noting similarities, contrasts, depth and stakeholder group.

Ethics statement

University of the Witwatersrand Johannesburg provided ethical approval (ref: M130203).

Results

General findings

Data collection initially focused on the church's role in paediatric ART adherence yet shifted towards general

HIV care in response to participants' input. All stakeholders were willing to participate, and shared their views on interactions between churches and HIV care (Table 2). Participants were convinced of the positive role RLs could and should play in improving HIV care, identifying barriers and opportunities to achieve this (Tables 3 and 4).

Barriers to HIV church engagement with HIV

Stigma and disclosure

A main reason for caregivers to disclose their (child's) HIV status in church was to obtain support (emotional; spiritual) from the pastor or congregation. Fear of stigmatisation and exclusion inhibited disclosure:

[With] the chain prayer, [...], maybe they may not touch her hand because they know that she is HIV positive. (Caregiver 6, translator)

Rather than personal experience seemed other people's stories about exclusion to fuel this fear.

RLs understood the importance of confidentiality and privacy, aiming to be discrete in identifying congregants in need of support. Non-disclosure hindered them providing support. RLs and HCWs indicated RLs lacked knowledge, skills and sensitivity to safeguard the confidentiality and privacy of their congregants:

I can go to the pastor for certain problems. And the pastor is having a wife, and the wife got her friends and the pastor got friends: it's a person! It's not God. You may find that your status is known by the whole church. [...] Some [...] say: those who are HIV positive they

Table 2. Characteristics of stakeholder groups – interviews and FGDs.

Category	Type	Characteristic	Number
Religious leaders	Interview	Participants ^a	7
		Male	7
		Female	0
		Religion	
		Pentecostal/charismatic/evangelical ^a	4
	Uniting reformed church	1	
	Apostle church	1	
	Anglican	1	
	FGD	Participants ^a	9
		Male	7
Female		2	
Religion			
Pentecostal/charismatic/evangelical ^b		9	
Healthcare workers	Interview	Participants ^a	6
		Male	0
	Female	6	
	FGD (2x)	Participants ^a	12
		Male	4
Female	8		
Caregivers	Interview	Participants ^a	7
		Male	1
		Female	6
		Religion	
		ZCC	5
	Assemblies of god	1	
	Pentecostal/charismatic/evangelical	1	
	FGD	Participants ^a	1
		Male	1
		Female	6

Notes: FGD, focus group discussion

and ZCC, Zionist Christian Church, the largest cultural church in the Limpopo province.

^aThe gender division in the participant groups is a reflection of the gender-bias present in these societal and professional groups.

^bSeveral pastors started their own congregations without being connected to another church or specific denomination. They described themselves as a mixture of Pentecostal, charismatic and evangelical, yet did not want to restrict themselves to either one of these denominations in particular.

Table 3. Barriers for church dynamics in HIV care.

Barrier	Negative consequences of the barrier
Stigma and disclosure	Stigma reduces willingness to disclosure Fear of exclusion Lack of support due to non-disclosure Difficulty to identify PLWHA in need of support due to non-disclosure
Association HIV with sexuality	Lack of confidentiality, skills and knowledge among RLs One-sided, prevention-focused concept of HIV support Increased stigma Discouragement of condom use
Interaction beliefs and practices with ART	Church as inappropriate place to discuss sexuality and therefore HIV Prayer leading to non-adherence, refusing or discontinuing ART Increased stigma of ART use because it is considered as lack of faith ART interactions with religious healing substances Religious practices and beliefs not promoting adherence and health care seeking behaviour

Table 4. Opportunities for integration of churches with HIV care and support.

Opportunity	Explanation
Holistic care and collaboration	Need for complementary medical and spiritual care for PLWHA Collaboration allows for increased reach in the community Collaboration allows for increased medical knowledge in religious settings
Wide social reach of the church	The church has a strong social position and organisational structure Many people (also those missed by the health system) attend a church Wider and integrated health care services can reach those not attending a clinic yet attending the church
The church as a safe place	The church has authority: community accepts its messages Church atmosphere as welcoming and respectful The church and pastors providing support and encouragement The church as a place of love, not stigma

must come and stand in front so that I can pray for them. You see. He can disclose. (HCW 5)

Sexuality

According to participants, in church settings, HIV is particularly associated with sex. Extramarital sex specifically (considered non-biblical or sinful) was identified as main mode of transmission, stigmatising PLWHA. Several caregivers and RLs indicated embarrassment and fear inhibited discussion on sexuality:

This is holy ground, you cannot talk about these things. (RL 7).

Despite following the Abstain, Be faithful, Condomise approach, discussing sex(uality) and condomising – perceived to encourage “sleeping around” – remained difficult for RLs, partly because of age and gender diversity within congregations.

Inviting HCWs to churches to provide information – including information on different modes of HIV-transmission – to age and gender-specific groups – already established in the majority of churches – was a suggested solution.

Beliefs and practices

Participants indicated that religious beliefs and practices influenced healthcare seeking behaviour. Prayer and pastors' encouragement were reported to support ART adherence. RLs explained that some religious settings discouraged the use of medication, reinforcing stigma:

If you are taking your medication, they [pastors and churches] condemn you for lack of faith: you have a small faith. (RL 8)

Religious practices observed in cultural churches (fasting; using healing substances such as holy tea or holy water) were mentioned as potentially interfering with ART (adherence). HCWs reported some patients starting ART ascribed health improvements to prayer and discontinued treatment.

Opportunities for church engagement with HIV

Holistic care

All participant groups emphasised the need for collaboration between clinics and churches to reach more people in the community and provide holistic HIV care:

The Department of Health is concentrating on health issues. The church [...] on the spiritual side. [...] We need each other. Since we are working with one thing: a human being. (RL 4)

Caregivers were motivated to share their experiences with HIV in their church to support fellow congregants;

HCWs were keen to share their medical knowledge in churches and RLs stated their desire to receive training from HCWs.

Social reach

Participants agreed that churches are able to reach the wider community:

The church [...] does have access [...]: when people come in the name of the church, it's like people open up. (RL 5)

HCWs particularly emphasised that including the church would reach community members missed by the health system. RLs and HCWs suggested church-based health services in this regard.

Safe place

Respondents described churches as loving, welcoming and respectful, with less stigma and more protection and freedom to disclose than other settings, making it an important, suitable actor in HIV care:

The church is a respectful place. And even everyone can be able to share what he have. (Caregiver 5)

Discussion

This study investigated barriers and potential of church involvement in HIV care in rural South Africa. One barrier found was stigma, preventing disclosure and hindering PLWHA from receiving church support. Non-disclosure reduces healthcare seeking behaviour (Wachira, Middlestadt, Vreeman, & Braitstein, 2012). In Mopani district, (perceived) stigma and disclosure differed substantially between patients and churches, as also observed in Mozambique (Mukolo et al., 2013).

Another barrier recorded was the association of HIV with sexuality, increasing stigma and judgement: a finding supported by other studies in African settings (Agadjanian & Menjivar, 2011; Van Breda, 2012). Participants emphasised the need to increase comprehensive HIV knowledge in church settings, as other studies in sub-Saharan Africa suggested (Eriksson, Lindmark, Axemo, Haddad, & Ahlberg, 2013; Nachega et al., 2005; Odu & Akanle, 2008).

A third barrier noted religious beliefs and practices interfering with (paediatric) adherence and treatment mechanisms – the study's initial focus – especially in cultural churches. Kenyan research emphasised their effect on caregivers' healthcare seeking behaviour for their children (Wachira et al., 2012).

To overcome these barriers, stakeholders suggested increasing medical knowledge within churches. A review

on churches and HIV stigma advocated for the role of churches in “renegotiat[ing] understandings of HIV/AIDS in more positive, less morally charged ways that also encourage social action to tackle HIV/AIDS” (Campbell et al., 2011, p. 1215). Combining these findings underlines the need for both education and interactive dialogue on (the interpretation of) HIV knowledge to overcome the aforementioned barriers.

Opportunities included holistic (i.e., spiritual and biomedical) HIV care when increasing health-religious collaborations. The need for such integration to improve HIV care and support is in line with earlier studies (Bradley et al., 2012; Campbell et al., 2011; Charurat et al., 2010; Wachira et al., 2012). Respondents’ proactive attitudes are promising in this regard.

Another opportunity was churches’ wide social reach and access to the community. Strong organisational church structures may additionally benefit outreach to specific community groups. Churches might however have additional interests, for example, increasing membership, and improving their status with NGOs and the government (Agadjanian & Menjivar, 2011).

Lastly, churches were identified as safe and accepting places; participants who had disclosed in church reported support from their congregation. A Kenyan study confirmed these findings (Miller & Rubin, 2007). The need to actively use the safe place of churches for dialogue on HIV/AIDS is important (Campbell et al., 2011).

Strengths of this study are the diversity of methods and participants. Limitations include the inclusion of caregivers of children with HIV while PLWHA without children were excluded (due to the initial focus on paediatric care), and the lack of distinction in data analysis between data from FGDs and interviews.

The findings show great potential and support for integrating church and HIV care in rural South Africa, as is in line with findings from other settings. Future research and interventions should consider diversity within and between churches. Moreover, a holistic perspective is required to overcome stigma and move towards a broader dialogue and understanding of HIV in church settings.

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