

HIV/AIDS through the lens of Christianity: Perspectives from a South African urban support group



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ABSTRACT

HIV is one of the most obscure viruses that humankind has had to face in recent times. Compounding this obscurity are often contesting perspectives on what it means to be HIV infected, and these perspectives are largely constituted by people's rationalisation of complex situations or experiences. Using qualitative research methods and ethnography in particular, this paper reflects on a broad understanding of what it means to live with HIV in the context of Christianity, using research participants' perspectives in an urban support group setting. Two fundamental patterns are evident in this paper: (1) as support group members rationalise their HIV infection, they continuously construct and reconstruct their identities; and (2) support group members rationalise their HIV infection to enhance their coping abilities, using Christianity and the Bible in particular, as a reference. Whilst rationalising HIV infection, three viewpoints emerge. The first viewpoint perceives HIV infection as an affliction by Satan; the second viewpoint sees it as originating from God; while the last viewpoint interprets HIV infection as a negotiated settlement between God and Satan. The paper is intended to trigger debate, and hopefully also to seek and provide answers from various sectors of society, and religious communities in particular, in order to help other HIV positive people in similar situations better manage their HIV condition.

Key words: HIV and AIDS; support groups; Christianity; community; rationalisation

RÉSUMÉ

Le VIH est un des virus les plus obscures auxquels la race humaine a du récemment faire face. Cette obscurité se trouve souvent amplifiée par la concurrence de perspectives sur ce que signifie d'être séropositif. Ces perspectives sont largement originaires des justifications que les gens se font par rapport aux situations ou aux expériences complexes. En employant des méthodes de recherche qualitative et l'ethnographie en particulier, cette communication aborde un savoir étendu de ce que signifie vivre avec le VIH dans un contexte chrétien, en utilisant les perspectives des participants de cette recherche dans d'un groupe de soutien urbain. Deux tendances fondamentales se trouvent dans cette étude, soit, (1) pendant que les membres du groupe de soutien justifient leur infection par le VIH, ils se construisent et se reconstruisent des identités ; (2) les membres du groupe justifient leur séropositivité avec le but de mieux faire face à leur condition en se tournant vers leur foi chrétienne et surtout vers la Bible comme référence. En justifiant l'infection par le VIH, trois opinions émergent. La première perçoit l'infection par le VIH comme un malheur du diable, la deuxième opinion le perçoit comme venant de Dieu, la dernière opinion voit l'infection par le VIH comme un règlement de compte entre Dieu et le diable. Cette communication a pour but de lancer un débat et également de chercher et fournir des réponses auprès de plusieurs secteurs de la société, surtout des communautés religieuses afin d'aider d'autres malades de VIH, qui sont dans des situations pareils, à mieux gérer leur condition.

Mots clés : VIH/SIDA, groupes de soutien, la foi chrétienne, communauté, justification.

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HIV/AIDS through the lens of Christianity: Perspectives from a South African urban support group

INTRODUCTION

The tragic AIDS epidemic that is presently engulfing the sub-Saharan region is primarily spread by unprotected intimate heterosexual activities (Agha, Hutchinson & Kusanthan, 2006; Susser & Stein, 2000; Takyi, 2003). Sadly, the most infected groups in the region are young people aged 15 to 24 years (Bankole, Singh, Woog & Wulf, 2004; Gallant & Maticka-Tyndale, 2004), the majority of whom initiated sex before marriage (Bankole *et al.*, 2004), despite premarital sexual activities being condemned by the religious community (Agha *et al.*, 2006). Although a large majority of South Africans (about 79% according to 2001 census) are affiliated to Christian churches (Statistics South Africa, 2004), an epidemic fuelled by sexual behaviour remains a major challenge in the fight against AIDS (Garner, 2000). In South Africa, one in ten people aged 15 to 24 years is said to be HIV positive (Campbell, Foulis, Maimane & Sibiyi, 2005). As many people presumably contract HIV outside wedlock, it is perceived as a double-sin (Duffy, 2005). This perception is not only based on the view that premarital HIV infection suggests premarital sex, and at worst promiscuity (Duffy, 2005), but more so, given the prevailing moral judgement about the 'ungodliness' of HIV infection (Machyo, 2002), it can be viewed as a 'punishment' or curse from God (Takyi, 2003). However, there are mixed views about the relationships between 'ungodliness' and HIV infection, as well as sin or evil and diseases in general (Sanders, 2006; Wiley, 2003)

Gilman (2000) draws connections between sexually transmitted diseases (STDs) and religious impurity or dirtiness. He argues that stigmatisation of people suffering from STDs dates as far back as the end of the first millennium when leprosy emerged. In Europe, lepers were required to wear identifying clothes and to warn of their presence (Green & Ottoson, 1994). Like leprosy, and as a STD, the diagnosis of syphilis at the end of the 19th century evoked similar moral judgement and stigma. Despite the complexities of these inextricable connections (disease, HIV infection and sin/evil, and or dirtiness), there is no conclusive evidence that the presence of any disease, and AIDS in particular, suggests a 'punishment' from God or any sort of dirtiness (Gilman, 2000). This view recalls Jesus Christ's response in the Book of John 9: 2-3: when confronted with a question about the man born blind, and whether it was through his sins or his parents' sins

that he was blind, His response was, "Neither he nor his parents sinned. He was born blind so that the works of God might be displayed in Him" (Machyo, 2002, p. 6). Machyo further warns against the passing of premature judgement on HIV positive people, citing the unconditionality of God's love as a guiding principle.

Fatovic-Ferencic and Durrigl (2001) have documented the non-refutation of the relationship between sin or evil and disease by medieval medical authors, further presenting evidence of Christ casting out a devil from a boy suffering from epilepsy. The relationship between HIV infection and sex further complicates attempts to connect it with sin or 'punishment' from God. A search for studies that connect sin/evil and HIV infection largely unsuccessful, and we only managed to gather materials that present anecdotal connections between sin/evil and disease. Limited discussion of sex among most, if not all, religious denominations, as well as a lack of commitment in the fight against this pandemic by some religious groups, in our view further complicates existing stigma and moral judgements. Despite these multifaceted arguments, religion and spirituality remain invaluable coping resources for dealing with pain (Rippentrop, Altmaier, Chen, Found & Keffala, 2005), particularly for people living with HIV (Simoni, Martone & Kerwin, 2002; Takyi, 2003), as well as throughout life in general (Machyo, 2002; Stuckey, 2001). In a study conducted among people living with HIV/AIDS (PLWHA) in Australia, Ezzy (2000) established an increased likelihood of religiosity resulting from HIV diagnosis.

The purpose of this study is to reflect on a broad understanding of what it means to live with HIV in the context of Christianity, using research participants' perspectives in a support group¹ setting. Writing from the point of view of the research participants within the confines of a defined research setting, which Carr (1996) refers to as *emic*, is not an unfamiliar phenomenon, especially in anthropology. The paper encapsulates the various nuances of rationalisations based on differential interpretations of the Bible. We argue that support group members rationalise the HI virus, not only to make sense of their infection (Ezzy, 2000), but also to improve their coping abilities, using Christianity as a base. As much as the virus is perceived negatively in many communities of South Africa and elsewhere, the support group, as, in Carr's (1996) term

HIV/AIDS through the lens of Christianity: Perspectives from a South African urban support group

“a constructed community of need”, uses Christianity to face the hurdles of intense stigma from society.

Research background, approach and methods

Central to this paper are the two authors' overlapping ethnographic field experiences, which took place in August 2003 to January 2005 and August 2004 to May 2006, respectively. The HIV/AIDS support group which is the subject of this paper subscribes fully to, and is mainly conducted following Christian principles, while operating in a missionary hospital environment.² It was selected as a study site on the basis of its proximity to the researchers and as part of collaborative terms between two institutions (hospital and researchers' institution). Another interesting factor was that this support group is different from other support groups in that: (1) it is located in a neutral venue, far away from the participants' neighbourhood; (2) it is located in an institution which fully subscribes to Christian values. The whole support group was observed, and then 12 participants who shared information which was of interest and relevant to the topic were sampled for interviews. This made the sampling process for interviews purposive in nature.

The routine activities of the support group typically began with the singing of choruses and hymns, followed by a Word of God and the prayer. After that new members were welcomed through the exchange of hugs and motivated to live positively by any confident member who had already spent a reasonable amount of time with the group. At times, an opportunity was created for other members to testify about the greatness of God over their HIV infection. The support group was started in 1999 by nine women, whose weekly meetings were facilitated by a social worker. Since then, the support group has expanded tremendously, but it is still dominated by women (approximately 90%), mostly of child-bearing age, largely because most of them are forced to face their infection during antenatal clinic visits and voluntary counselling and testing (VCT) services during pregnancy (Jackson, 2002), whereas men can deny the signs for longer.

Members who were involved in the early stages recall that the support group was – at the time – the only platform to talk about their HIV status, since the stigma was still intense. Members acquired the strength to endure the difficulties they faced in their everyday

lives through prayer. The support group were very diverse in terms of educational attainment and age, but this diversity did not appear to be a barrier to them discussing matters of common concern, nor did it result in any visible form of prejudice. All members were Black South Africans with an estimated age range from early 20s to late 40s. Weekly attendance varied widely, ranging from 50 to 90 participants, although the official records suggest a membership of over 500 since the inception of the group.³ The discrepancy between official records and weekly attendance may imply that people come and go. We personally observed that some people joined the support group for specific individual needs, and would then disappear and come back once such needs or different ones re-emerged. Others came with expectations which, if not met, resulted in their disappearance.

The overall methodological approach was qualitative, with specific use of ethnographic methods. Ethnography is a toolkit of research methods (LeCompte & Schensul, 1999) that allows researchers to learn through systematic observation in the field (Brewer, 2000). The researchers spend adequate time building a relationship of friendship and trust with the studied people (Potrata, 2005), while carefully recording what they saw and heard (LeCompte & Schensul, 1999), and learning the meanings that people attributed to what they did. Ethnographic tools used in this study included participant observation of the support group meetings, attendance at social functions organised and held by the support group, participation in and facilitation of the support group discussions when invited, in-depth interviewing of the selected support group members, and the collection of life histories. Participant observation as a process of learning through exposure to or involvement in routine activities of participants in the research setting (Brewer, 2000) became central during the data gathering process.

According to Bogdewic (1992) and Jorgensen (1989), participant observation has the advantage of accessing situations that might be hidden from the public, such as certain rituals, illegal or socially stigmatised activities, or activities that groups use to maintain a special identity. Our access to the support group confirmed this advantage, considering that support group members were protective of their space, and would generally deny HIV negative people access to their

HIV/AIDS through the lens of Christianity: Perspectives from a South African urban support group

meetings. Our presence was a negotiated special arrangement and the purpose was declared and well explained. All information gathered through observation and interviews was documented on-site in the form of detailed handwritten field notes to obtain direct quotes; and further developed and typewritten off-site. This process provided the framework for building comprehensive case material. Giving participants the assurance that their sensitive information would remain confidential formed the basis for gaining their trust, strengthening intimacy and building reciprocal relationships (LeCompte & Schensul, 1999). Hence we were regularly invited to facilitate group discussions and to attend social functions.

Confidentiality was assured through changing participants' names in the production of this paper and by using pseudonyms. Data collected from participants was kept in a safe place where only the authors could access it. All the ethnographic notes that were entered in the computer were password protected. In addition to confidentiality assurance, the study secured ethical approval from the University of KwaZulu-Natal Ethics Committee. Furthermore, support group members gave permission for the research collectively; except in the case of interviews where individual consent was given.

As an entry point to the analysis, the authors made print-outs and read through all our field materials, as a starting point to what Jorgenson (1989) and Potrata (2005) refer to as sorting, sifting and organising of the data. Throughout the reading of our field materials we were struck by the extent to which research participants drew on rationalisations entrenched in Christianity when viewing their HIV condition. After observing this trend, we then decided to select only data that added value to the subject matter, so that the analysis could be thematic (Crossley, 1997; Schonnesson & Ross, 1999) and the whole process was done manually. Jorgenson (1989) sees this process as aiming to reconstruct the data in a meaningful or comprehensible fashion.

Discussion of results

This paper uses Cohen's (1985) concept of "the symbolic construction of community", as a theoretical underpinning to discuss and understand how support group members rationalised their HIV infection. Ezzy

(2000) views this process of rationalisation as an accomplishment of the ideals of narrative theory, which, he argues, has increasingly been utilised to study subjective experiences of illness in psychology. Notwithstanding the symbolic construction of the support group, Carr (1996) sees the support group as a "constructed community of need". Like many other authors, Cohen (1985) acknowledges the difficulty of defining the concept 'community'; owing its definitions to theories which are very contentious. He argues that the concept of 'community' implies that members of a group of people have something in common with each other, which distinguishes them in a significant way from the members of other putative groups.

Cohen's implication of the 'community' is particularly relevant in the case of the support group, in which members were bound together by their HIV status, which distinguished them from the rest of the society, and which was perceived to be largely callous and prejudicial. Cohen argues that the community has its boundaries, and those boundaries are largely constituted by people in interaction, and are mainly symbolic in character. Similarly, the support group had its own boundaries, as expressed in the previously mentioned protective nature of their space. A sense of community does not, however, imply homogeneity of members' experiences, needs and aspirations, and hence at times they turn to rationalising and viewing their HIV condition differently.

Blaming responses amongst PLWHA and professionals

It was evident from our observations that, for many people, discovering that they were HIV positive, triggered blame-steered anger and fear-driven attitudes. Within the blaming response, the first thing that emerged was that they got the virus because of their wrong conduct (self-blame), especially those who indulged in premarital sex. Others moved beyond self-blame and began to point at others whom they think infected them. In the extreme cases, though only in the early stages of infection, a few blamed God and became rebellious towards Him. An educator by training, as well as a pastor and counsellor, *Isaiah*,⁴ guided by Christian faith, interestingly, did not want to start blaming, not even to worry about who infected whom, instead he accepted his and his wife's HIV condition, as he stated:

HIV/AIDS through the lens of Christianity: Perspectives from a South African urban support group

When my wife told me that she tested HIV positive on her delivery, I went to do a test which also came positive. I did not want us to worry about who infected who. I love her so much and we are focusing on living a healthy and happy life together.

Mrs. Shange, below, who claimed to have knowledge that she was infected by her husband, found it in her heart to negate the blame trap, being assisted by her Christian faith and in honour of their wedding vows:

I am a saved wife who has the virus. My husband is the one who brought it home, I was faithful to him. However, I do not hate him for that, but will always love him so that the name of God will be praised because of my love and loyalty to my husband.

Sharing the story of how much she blamed God for her infection and how she became rebellious, Nokulunga, a self-declared 'born-again' Christian young woman in her mid 20s, stated that she got infected through rape when she was a virgin and a loyal servant of God. Nokulunga initially felt a sense of betrayal and became rebellious towards God. Her biggest question was why God did not protect her from being raped, as loyal to Him as she was, but she later on viewed and interpreted her infection in affirmative terms, as captured by the statement below:

I realised that it was God's will to be in the condition I found myself in, so that I could help other people. I then refocused on God and became faithful to Him once more.

In addition to the 'blame-game', members initially found themselves preoccupied by the feeling of death. Bongani, in response to this fear, normally began his contributions with the phrase, "AIDS is not a death sentence". Understandably, the feeling of death leads to hopelessness, and thus this phrase may be seen as an attempt to eradicate fear and restore hope, especially for newly joined members. Those who are trapped in self-blame, mostly tend to concentrate on spiritually-steered behaviour change, as they cannot reverse their infection. They become metaphysical and reoriented to the 'afterlife' or 'eternity' (Stuckey, 2001) and ultimately proclaim themselves as 'saved' Christians. They view this undertaking as a sound spiritual decision, which will be well received by God, and will reward them with 'eternal' life, when they die.

One health professional, Dr. Spiritual, often tried to limit blaming during the early days of the support group:

Do not ask why it happened, but look forward.

On the other hand, Mrs. Dladla, the hospital staff member who occasionally performed some pastoral work when the hospital pastor was not available, addressed fear and self-blame in a manner that did not negate the possibility that HIV infection was a product of sin. While addressing fear and self-blame, implicit involvement of God in HIV infection and the notion of sin resonated strongly in Mrs. Dladla's statements below, thus further illustrating the ambiguities surrounding Christianity's standpoint on HIV infection:

No matter what you have done but God provides the room for change. Take your infection as if God is setting an alarm in your watch to wake up and regain your strength.

Self-blame and fear in the context of Christianity were deep-seated, to the point where members questioned whether their infection was a punishment from God or a lesson to themselves and others. Although, there is documented evidence confirming that spirituality remains a great source of comfort in dealing with feelings of guilt and fear (Machyo, 2002), no definite answers are provided on the issue of blaming in the Christian context. Our results showed that, in view of individuals' specific circumstances, some people still perceived their infection as a punishment from God. The statement by Shelly below reinforced and reconstituted HIV infection as a punishment for our wickedness as human beings, and a lesson to those around us:

God saved me from being HIV infected by my late husband, but because I did not do things according to His will, I got punished. I know the number plate of the car which hit me.

Shelly stated that her late husband knowingly, suffered from HIV/AIDS related illnesses before he died, but never divulged his HIV status to her. Although she appeared not to be impressed by her late husband's secrecy, she respected his cautious protection of her by carefully avoiding any unprotected sexual contacts. By

HIV/AIDS through the lens of Christianity: Perspectives from a South African urban support group

knowing the number plate of the car which hit her, she figuratively meant she knew who infected her and she was unwavering in interpreting her infection as a punishment from God. She based her interpretation on the fact that she had an affair after the death of her husband. A newly widowed Christian having an affair still lacks acceptance in many sectors of society, including among Christians, hence she regarded her infection as a punishment from God for compromising what were perceived to be Christian norms. She then had to deal with her self-judgement (self-blame) and societal stigmatising judgments.

Although statements by *Shelly* above, and *Thabani*, *Jabulile* and *Nokulunga* below, in one way or the other suggest God's involvement in their infection, sharp contrasts emerged on God's perceived intentions regarding their infection. These contrasts were mainly captured by the phrases 'punishment from God' and 'God chose us'. *Nokulunga* explicitly viewed her infection as a direct affliction by God. Through the use of the word 'needle', *Jabulile* not only captures the reality that HIV infection brings excruciating pain, but also a sense that something as painful as a needle was necessary to remove evil:

God chose us deliberately to educate other people living with HIV/AIDS. (Thabani)

You are not infected because you misbehaved, but because God chose you. (Jabulile)

God gave me the virus for a reason ... I had to be HIV positive so that people can learn through my positive living that they can also survive and live a healthy life with the HIV. I find myself talking to people about my status and I tell them about the greatness of God's love. (Nokulunga)

God uses the needle to take out something from us. God wanted to change our lives by using the needle. (Jabulile)

Throughout the above quotations, the notion that we are imperfect sinners and that our suffering is both the price we pay for sinning, as well as a blessing from God, was evident. The fact that HIV infection remains incurable provided a sense of punishment, yet at the same time, a sense of blessing resonated through a common belief that "God chose us" which became a therapy to face fear, anger and blame and learn to forgive. These statements were also suggestive of the

way in which HIV positive people are supposed to identify themselves and experience their infection.

Rationalisation and Biblical references to HIV infection: A contested terrain

In Christianity, everything that is documented in the Bible⁵ is believed to be real, yet the manner in which it is interpreted is hugely contested. Like many other people, Pastor [pseudonym] was convinced that the existence of HIV/AIDS is a fulfilment of Biblical prophecies and marks the nearness to the end of time, as propagated by the Book of Revelation. Basing her argument on Biblical documentation, she said:

There will be a number of different illnesses which will make people ill. Some of them will be incurable.

According to *Pastor*, HIV is one of the illnesses mentioned in the Book of Revelation as incurable. Her interpretation of HIV was that prophets, through God's revelation, knew about HIV before we even experienced it, although the relationship between HIV and God is not clear. *Pastor* and some other participants dismissed suggestions that HIV was a virus sent by God, on the grounds that God was a loving God. Instead they saw Satan as the culprit, either to test their faith or as an outcome of their wickedness, while others, as discussed earlier, saw it as coming from God, either to bring them closer to Him, or as a punishment. These views clearly demonstrate that rationalisation of HIV infection is not an uncontested terrain

Reassuring that God is a loving God and a forgiver, *Pastor* stated:

Some of the things we go through are the direct results of our disobedience, but after all we need to refocus on God. There is a Biblical evidence of God as a forgiver. In the Bible, Cain killed his brother Abel and God cursed Cain for that, but later on He forgave him.

Whether *Pastor's* firm assertion that our wickedness is the main culprit in HIV infection, was perceived as being judgemental, remains unclear. However, group members' alertness on moral judgement, based on Christian values, was noticeable in the statement by *Jabulile* below. Embedded in her statement was a sense of non-denial of wickedness, yet discomfort about judgement. She argued:

HIV/AIDS through the lens of Christianity: Perspectives from a South African urban support group

It is wrong for people to judge others that they will die or they misbehaved because they are HIV infected.

Isaiah's perspective on HIV infection seemed to reflect both the view that 'it comes from God', as well as that 'it comes from Satan'. His line of argument, which we term a 'middle-line perspective', seemed to be the reconciliation of these two seemingly irreconcilable views. He saw infection as a negotiated settlement between God and Satan, drawing from Job's experience in the Bible, as he noted:

Bad things, including disease like HIV comes from Satan to ravage the flesh, but the soul belongs to God. In the Bible, Satan asked for Job from God and God gave Job to Satan on one condition that he was not going to temper with his soul. God said to Satan, you can try any temptation with Job, as long as you do not temper with his soul, you will not succeed. Satan tortured Job. He felt sick with different diseases and lost his property. Satan tortured Job until his wife asked him to humiliate God once and die. Satan asked for us from God to be infected. Our souls are not HIV positive. Satan has not touched our souls.

Similar to the above excerpt, *Mama Grace* cited the story of Lazarus from the Bible, who held onto his belief in God even in his dying moments. Consolidating her argument, *Mama Grace* stated:

We often wonder why we are sick. Is it because God does not love us? The Bible says, Lazarus loved God, but he also fell sick.

Three patterns of argument are visible in the above discussion. The first pattern of argument perceives HIV as a virus sent by Satan. The second pattern of argument views it as originating from God, while the last pattern of argument interprets HIV infection as a negotiated settlement between God and Satan. In all these arguments, people attributed the reasons for infection differently, some attributing complete optimism, while others ascribed pessimistic connotations. These particular claims are limited to the responses found in this support group and, in that way, do not fully represent the range of possible ways that Christianity might be applied to coping with infection or living with AIDS.

CONCLUSION

Two fundamental patterns emerged in this paper: (1) as support group members rationalised their HIV infection, they continuously constructed and reconstructed their identities, and (2) support group members rationalised their HIV infection to enhance their coping abilities, using Christianity and the Bible in particular, as a source of reference. The paper also mirrors a broader understanding of the multiple dimensions of living with HIV in the context of Christianity, from the research participants' point of view. In doing so, it exposes us to the manner in which people use Christianity to construct their identities, and experience their HIV infection in a manner that helps them cope with their condition. It confirms that Christianity remains one of the coping mechanisms for many people living with HIV.

However, based on the literature and the results of this study, the legitimacy of the connections drawn between sin, evil, dirtiness and HIV infection remain unresolved, and will seemingly remain the subject of intellectual discourse in the future. Although arguments for and against these connections are occasionally supported by some sound Biblical citations, they remain polarised. What is more critical is the manner in which HIV positive people identify themselves and experience their infection. Beside the fact that issues raised in this paper should trigger debate, as well as seek and provide answers from the various sectors of society and the religious communities in particular, the ways and means of packaging these diverse and vast experiences should be given attention, in order to help other HIV positive people better manage their HIV condition.

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HIV/AIDS through the lens of Christianity: Perspectives from a South African urban support group

The views in this paper are the personal views of the authors and do not necessarily represent the views of HIVAN.

Footnotes

¹Support groups are small groups that gather for support for dealing with a shared concern or experience and are often ritualistic in their conduct with established written protocols (Carter, 1994). Different support groups exist for people with different needs, and the support group which is the subject for this paper, is for people living with HIV/AIDS. HIV/AIDS support groups help people living with HIV to confront and deal with their HIV/AIDS problems and experiences as a collective.

²We have learned that the support group has recently established itself as a Non-Profit Organisation (NPO), outside the leadership of the hospital, but within proximity of less than 10 km, although this paper is developed on the materials gathered during the period of our fieldwork.

³These figures may have changed, especially given recent developments, whereby the support group acquired a new status as an NPO and breaking ties with the hospital.

⁴All the names used in this paper are pseudonyms to protect the research participants.

⁵The Bible is vulnerable to abuse to accomplish individual or group specific justifications of behaviour. Making a judgement on whose interpretation should prevail becomes a considerable challenge.

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