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Reactions, beliefs and concerns associated with providing hair specimens for medical research among a South African sample: a qualitative approach

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Abstract

In order to optimize treatment outcome among antiretroviral therapy users, there is a strong imperative to engage in continued monitoring and maintenance of therapeutic drug levels in patients. The aim of this study was to document the perspectives, beliefs, and concerns of South African antiretroviral therapy users providing hair specimens to determine antiretroviral drug levels. Twenty-one women living with HIV were recruited from a community health center in the Western Cape. Interviews were recorded and transcribed, and analyzed using Atlas.ti version 6. Although participants identified several cultural beliefs influencing their decision to provide hair specimens for drug level measurement, nearly all agreed that they would be willing to do so if provided with enough information by the researcher.

Keywords

adherence; antiretroviral therapy; barriers; culture; drug testing; hair

The WHO estimated in 2010 that 68% of all persons living with HIV resided in sub-Saharan Africa, making it the region most affected by the epidemic [1]. The availability of antiretroviral therapy (ART) in suppressing viral load among persons living with HIV has resulted in significant reductions in mortality and morbidity. Yet, response to ART may differ significantly among patients, the basis of which is multifactorial. While host genetics is believed to play a significant part in the quantity of medication absorbed into circulation (bioavailability) and the rate at which the active drug is removed from the body (clearance) [2], other factors such as the influence of concurrent medication, diet, and adherence levels

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may also account for such differences [3]. Indeed, despite the roll-out of ART in South Africa in 2003, rates of adherence vary among patients [4].

Adherence to ART may be assessed through either self-report questionnaires [5,6], pill counts [5], pharmacy refill records [5–7], electronic cap-opening events [8] or the measurement of blood and urine drug concentrations [9]. Each of these methods have inherent limitations, namely, recall bias and social desirability bias may influence responses to self-report questionnaires [10,11]. Inconsistent record-keeping in HIV clinics make adherence monitoring by means of pill counts and pharmacy records difficult [10]. Signal disruption may limit the effectiveness of electronic devices such as the medication events monitoring system [8]. In addition, although plasma drug concentrations are sensitive indicators of treatment exposure, the concentration of drug levels reflected is only indicative of treatment exposure over a 1- or 2-day period, and similar to the other measures mentioned above, does not account for the interindividual bioavailability and clearance of the drug [12,13]. As a result, the measurement of plasma drug levels may not accurately predict long-term treatment outcomes. Due to the lack of a gold standard to determine therapeutic drug levels and treatment outcomes over a prolonged period of exposure, more objective and robust methods are continually sought.

Currently, virological indicators like CD4 counts and viral loads are the most widely-used predictors of treatment outcomes and adherence [14,15]. Yet, recent studies (e.g., [13,16,17]) have shown that drug levels in hair may provide an accurate indication of treatment exposure over time (weeks–months) and may better predict response to treatment than blood-level monitoring. In terms of data collection, the use of hair specimens provides several advantages over other methods such as blood sampling, as specimen-collection is essentially pain-free, and the physical integrity of hair specimen is maintained at room temperature. Further, monitoring cumulative exposure to ARVs in a single assay rather than using irregular and costly virological monitoring may have additional benefits in the context of resource-constrained settings [13,18].

Although collecting blood samples is commonplace worldwide, this practice has not been met without suspicion [19]. For example, in a study assessing the feasibility of microbicide use amongst individuals living with HIV in Mwanza, Tanzania [20], blood collection (especially the volume of blood collected) was identified as the chief concern amongst study participants, due to community rumors that blood would be sold for witchcraft purposes [20]. In other cultural contexts such as the Dinè (a Native American tribe), blood is considered a sacred fluid that carries the spirit of the Creator throughout the body, and contains the essence of a person's identity [19]. As shown by Davis and Reid [19], researchers in Native American communities had not considered local beliefs and customs surrounding bodily specimens, and as such had difficulty in obtaining cooperation from native tribe members. No doubt bodily integrity is considered sacred in many cultures [21], and the collection of body tissue, including blood, is continually met with suspicion.

It is therefore unsurprising that concerns exist around the provision of hair specimens for drug-level monitoring in various cultural contexts. In some cultural groups (Asian and African among others) hair is a symbol of maturity, strength, and power. Thus, the act of cutting hair is highly symbolic and indicates an important occurrence such as the coming of age or death of a family member [22]. Hair-cutting may invoke similar fears as those caused by obtaining blood, as traditional medicines or cultural rituals (muthi) may include personal artefacts such as hair. Such fears may limit the use of hair as a means of therapeutic drug monitoring [23]. The aim of this study was therefore to document the reactions, beliefs, and concerns associated with providing hair specimens for therapeutic drug monitoring amongst a sample of women in South Africa.

Methods

Participants

The sample consisted of 21 ($n = 21$) Xhosa-speaking women living with HIV recruited from a community health center in South Africa. This study formed part of a larger project investigating the influence of pharmacogenetic traits and ARV drug levels in hair on treatment outcomes in women living with HIV.

Procedures

We made initial contact with the head of the community health center who then permitted the principal investigator to approach nurses involved in monthly adherence-checks and pill-refills amongst patients receiving ART. Clinic nurses were asked to give female patients attending monthly appointments a flyer inviting them to participate in an interview with a member of the study team. When a patient expressed interest in the study, she was escorted by the researcher to a private interview room. The purpose of the study was to document the cultural influences or barriers female patients expressed in response to a request to contribute a hair specimen for medical testing that may be used to monitor their own ARV drug exposure in an attempt to improve their treatment. Interviews were conducted in English, Afrikaans, or Xhosa, based on the language preference of the participant. Interviewers (two students who had received extensive training in qualitative interviewing) asked open-ended questions to understand participants' perspectives and attitudes towards providing a sample of their hair for medical testing. The core areas covered in the interviews were (i) personal beliefs associated with contributing a hair specimen for research purposes, (ii) reactions to such a request, (iii) information participants regarded as necessary to minimize fears associated with beliefs, and (iv) whether providing hair specimens for laboratory analysis may be preferred to providing blood or urine specimens. Examples of questions asked include, "How would you react if a researcher asked you whether you would be willing to provide a sample of your hair for ARV monitoring?", "Can you describe any cultural issues or certain beliefs in your community that would influence your decision to provide a sample of your hair for ARV monitoring?", "What sort of information would you require to make it easier to provide a sample of your hair for ARV monitoring?"

Ethical procedures

Ethical approval for the study was obtained from the Human Research Ethics Committee of Stellenbosch University, and permission to conduct the study was granted by the Department of Health of the Western Cape. All participants provided written informed consent prior to the interviews. All names have been changed to protect the confidentiality of respondents.

Data analysis

The interviews were tape recorded, transcribed, and entered into the Atlas.ti version 6 [24] computer program. Atlas.ti assists in the analysis of qualitative data by allowing for textual data to be coded, annotated, and compared with other important segments found through careful thematic selection. Codes that emerged as thematically similar were grouped together into a family. Subsequently, several families of themes emerged from the data and were interpreted as an overall network.

Results

Several themes emerged in response to a request to provide hair for ARV drug-level monitoring. The themes ranged from cultural beliefs about providing hair specimens, to concerns about what would happen to the hair once it has been cut.

Beliefs against providing hair specimens

One of the chief concerns participants shared about providing a hair specimen was the potential conflict it would cause with either their own beliefs or the beliefs shared by others. Despite knowing that only a few strands (20 strands) of hair would be used for analysis, many participants indicated resistance to providing hair.

Blown away by the wind—Some participants believed that if their hair was cut, it would blow away in the wind, be picked up by others and used to hurt them. As Alida*, a 35-year-old participant, reported,

“About the hair, some people say that when you cut (your hair) and the wind blows it and someone picks it up then it’s almost like people that can hurt you with your hair.”

For this participant and others there was a fear that her hair may not be well-protected and kept from the malicious intentions of others once it had been cut. Added to this was the credibility bestowed on the notion that cut hair could be used by another person to harm the patient.

Hair picked up by animals—When asked about stories involving hair several participants stated that hair could be picked up by animals such as birds or horses. They expressed concern that if used by animals to build a nest or as food, this might result in the patient ‘going mad’. Jeane*, a 26-year-old participant reported that, “you must not let your hair lay around. The birds pick it up and make nests. You become mad.” Several participants referred being afraid of “going mad” when discussing the possibility of their hair being picked up by animals. Such fears are related to the previously identified fear of hair blowing away and not being properly protected. Participants indicated that they would like to know exactly what would happen to the hair and how it would be stored.

Burning hair—Two participants referred to burning hair once it had been cut, and that the consequence of not doing so, or not doing so at the correct time, would result harm to the person. As Judith* mentioned,

“Then we put fire on them the following day because we’ve been told that if you cut today and you put fire the same day you are going to have a headache.”

In her case, the hair could only be burned on the day after it had been cut and failure to do so would result in physical pain.

Hair used for medicines—In some cultural environments beliefs are held that if a traditional healer (sangoma) were to gain access to their hair, it might be used as an ingredient for medicine. As stated by Sandra*, a 47-year-old farm worker,

“Because the people say if somebody take(s) your hair at night in our culture people who make medicine for the sangomas something like that, because I didn’t think about that, because I know they (the researchers) want to know if the medicine work(s) in my body or not.”

This participant acknowledged that she understood that the researchers would not give her hair to a sangoma for medicinal preparation. Judy*, a 52-year-old mother of three shared similar beliefs when she stated,

“People think you’re going to take the hair, you go to a sangoma with it, they will do many things, maybe they will (make) ..., medication with your hair that will help other people, they do many things; they will ask lots of money for your hair.”

This participant indicated that if she were to contribute a hair specimen, others would think that she was contributing hair to a traditional healer for medicinal purposes so that it could be sold for large sums of money.

Other participants expressed concern that their hair would be burned and used as part of traditional medicine. Sandra*, a 31-year-old woman stated:

“They take the hair and then they make medication, the sangomas and then somebody is sick and then they say I am going to mix this with this here, they burn the hair and then it is going to help you.”

Another participant, Jessica*, agreed and stated, “They burn the hair and then make medications.”

Witchcraft—Many of the participants reported that they had heard, believed in or experienced the effects of witchcraft that had been performed with samples of human hair. For example Judith*, a 42-year old widow said,

“Say I want to do something to you... I don’t want you to move forward, you are moving too forward, I am staying behind, I want what you have. Now automatically I can just find your hair, or just take a piece of your hair from your brush, then I can take it to someone that is going to work with it. You must not get anything, you must burn, not as in burn in fire, but you must go backwards now, not forward anymore ... now our people are scared of such things.”

Statements such as these indicate that community members may be deeply concerned about the whereabouts of specimens they give to others. A participant, Mavis*, told researchers about her son and stated:

“It happened to me and also to my child; they did it to my child. My child, he is a soccer player and he got hurt. When I took him to a man that heals people, a young man, he told me they are chasing you, they are not getting you so now they are trying to get to your children.”

This participant stated that if someone in the community was jealous of the success of another, they would try to obtain that person’s hair, take it to a sangoma who would then combine it with other ingredients. The mixture would then be planted at the house of the person to be harmed. Mavis described an example as follows,

“...you don’t know that I’m envious of you, but I watch you, when you comb your hair and put your hair in the bin, I don’t go in the day to your bin, I go in the evening and I take your hair out and then take it to a sangoma, who I know will help me. That hair of yours he puts in a bottle, and he throws stuff with it, it is transparent, we have seen plenty of those, and it has happened to me to ... then plant it at your door”

While several participants indicated that they found witchcraft to be credible and potentially harmful in the manner expressed above, other participants stated they did not believe in witchcraft and that they found it strange that others did.

Superstitions—Some participants indicated reasons related to superstition for not letting others touch their hair or leave their hair lying around. As one participant said,

“Never let anyone comb your hair and never let anyone cut your hair, because the person is cutting your hair and then cutting your thread dead and then the hair doesn’t grow any more ... or he cuts your hair and then your hair falls out, and there is (sic) bald areas on your head.”

Alida was afraid of leaving hair lying around and reported that,

“Get someone you know to cut your hair and do not let anyone brush or comb your hair, because it is that time that they find the hair in your brush and then they take it away. (They) hurt you by means of your hair.”

Several participants stated that they were reluctant to leave their brushes lying around as this would make it easy for someone to gain access to strands of their hair and use it to inflict some sort of harm. Out of fear that others would gain access to their hair several participants stated that unwanted hair should be flushed down the toilet so that it would not fall into the wrong hands.

Culture—Participants indicated that their cultural backgrounds influenced their attitudes towards haircutting. Marie*, a 45-year-old domestic worker from a township near Cape Town reported, “No, because in our (Xhosa-speaking) culture we are not allowed to cut our hair.” When asked about the reasons for this, several participants stated that hair-cutting is only permitted when someone in the family has died.

Marriage—Salomie* a 42-year-old woman stated that, “if you find a man then you may not cut your hair, because then the people say we don’t want two men in the house.” In this instance, a woman with short hair was considered to be manly.

In some instances hair-cutting was not only bound by marriage and funeral regulations but also as a general rule. One participant stated, “in our culture nobody is allowed to touch your hair unless you go to the salon.”

Reactions to providing hair specimens for a research study

Participants were asked how they would react to a request for their hair for chemical analysis. Responses ranged from shock and confusion to neutrality and indifference. Theresa*, a 34-year-old woman stated:

“I’ll be very surprised, my hair? Why my hair? Usually they want your blood, or your saliva, and now they want my hair.”

Evidently such a request was troublesome for this participant. Lyndel*, who had already provided the researcher with a sample of her hair stated,

“As I said I did not know what. How I really feel inside me I just thought, my hair, why, for research for other students, what will they do with my hair, why my hair? There are other methods, why specifically my hair?”

Information participants would like before providing their hair for research purposes

Participants were also asked to indicate what information they would like before being asked to provide a sample of their hair for analysis. They expressed interest in knowing how the medication would affect their hair, and whether their hair would grow back once it had been cut. Salomé stated,

“Yes, another thing I would like to know is what your hair contains and how the medication affects your hair, because if it affects your blood and saliva how does it affect your hair?”

This participant felt that the more knowledge she was able to acquire about the way in which her body would be affected, the more at ease she would feel. Several other participants shared similar feelings. Most participants also stated that if the researchers provided enough information to them about why they needed to contribute a hair specimen and what would

happen with their hair once it was cut, it would make the process much more acceptable. As Sarah* stated,

“No, I was shocked firstly, I became in shock, why do you want to take my hair or you must tell me why you take my hair, then I can understand. But now already they told me why they took my hair and then I can say okay fine you can take my hair, I understand.”

This participant had met with the researcher collecting hair specimens before the interview, and was thus able to share a personal account of what she needed to know in order to feel comfortable with providing a sample of her hair for testing.

Several participants agreed that despite knowledge of the beliefs that many of their community members shared about cutting hair, they would still be willing to provide their hair for testing purposes. This willingness is expressed in the following exchange:

Participant: “Because the people say if somebody take your hair at night in our culture people who can make medicines for the sangomas something like that, because I didn’t think that. Because I know they want to know if the medicine work in my body or not.”

Researcher: “Okay, because the doctor told you it was for research you didn’t mind.”

Participant: ...didn’t mind, yes, I don’t mind.”

Hair versus other methods

Participants stated that they frequently provided blood and urine samples for analysis. They were therefore asked to decide which method they preferred. Most reported a fear of needles and that a contribution of a hair specimen would thus be preferable to blood. As Judy stated, “I am very afraid of a needle, with hair it is very easy for me.”

Summary

These results indicate that participants found a request to provide hair as a method of drug level testing to be unusual and to some extent troublesome. Certain beliefs, superstitions, and stories about hair being used to make medicine presented some level of doubt as to whether this method would be accepted. Most participants were concerned about what would happen with their hair once it had been cut and mentioned that giving people the necessary information about what would be done with the hair would enhance the likelihood of a positive response.

Discussion

To our knowledge this is the first study that describes the beliefs, feelings and reactions of ART users to providing samples of hair for monitoring drug exposure testing in HIV. Hair has become an increasingly important biological specimen in DNA testing [25], drug testing [26], and cancer screening [27], as it is regenerative and easily replenished, and has been shown to be a more useful predictor of adherence than most other measures of adherence [17]. However, hair plays an important part in the social construct of the body in many cultures. It is thus important to consider the social meanings of hair when justifying its use as a source of genetic and health information [28].

The results of this study indicate several beliefs surrounding the removal of hair for drug-level monitoring. Participants expressed concerns that their hair would get blown away, and either picked up by other people or by animals, resulting in them either being harmed or

going mad. To some extent cultural background appears to influence the relationship people have with their hair, even once it has been removed, to the extent that the person who gains access to the hair can then obtain power from it [28]. Despite these beliefs and other superstitions that arose throughout the interviews, participants indicated that they would still be willing to provide hair for drug-level testing as they were aware that it would have positive implications for their health. This is an important finding, in that it speaks to the readiness of people to make positive decisions about their health, and to act on these decisions despite cultural belief systems that might dissuade them from doing so. Our findings provide a cautionary note about reifying cultural beliefs. For example, participants stated that if given the necessary information about the reasons for a request to contribute a hair sample, they might well do so. Yet, many of the participants stated that while they would still provide hair for medical purposes, they were not sure whether other community members would feel the same way. Finally, it should be noted that participants in this study volunteered to participate in the present research and thus may be more likely than others to participate in research studies in general. This volunteer effect may have accounted for the largely positive attitude of the sample to providing hair for ARV drug-level testing.

In many instances hair and the cutting of hair also plays a pivotal role in the rites of passage in various cultures, especially during life transitions such as marriage, mourning, and cultural rituals (e.g., [29]). Some participants mentioned that hair was only cut when someone in the family had passed away, or that they were not permitted to cut their hair when married. In many Black South African communities, when someone dies, members of the family may cut their hair to indicate a loss in the family, thus ushering a period of mourning for the deceased that typically lasts one week. The belief is that life is concentrated in the hair, that shaving it symbolizes a death, and that its regrowth indicates the rejuvenation and strengthening of life again [101].

Participants expressed concern that hair may be used by sangomas to make medicines or perform certain magic practices that may be harmful to the person whose hair has been used. It has been suggested that in certain communities hair has been considered as the ‘seat of the soul’, and that power remains in it once it has been cut. This power can then be used by those who have it in their possession for ill-intended purposes [28].

In terms of the reactions to providing hair for ART exposure testing, most participants indicated that their initial response would be one of shock or surprise. This was mainly because a request such as this was perceived as unusual, as several other methods of adherence (such as blood tests) are available. However, when asked whether a blood or hair sample for testing would be preferred, most replied that a hair specimen would be less painful and a lot easier to contribute.

Nearly all participants involved requested that they would prefer more information from researchers on how the medication works, how it becomes traceable in hair, and how the results from their hair specimen would be interpreted. Most of the participants ultimately did indeed contribute a hair specimen and indicated that they did not find a request of this nature conflicting with their cultural or spiritual beliefs.

Conclusion

In this article we have documented some of the concerns that ART users may have regarding contributing hair specimens for the purpose of medication exposure monitoring. There is a growing need to collect accurate and informative data concerning ART exposure and adherence, especially given the limitations associated with other methods such as pill counts, self-report, and electronic pill cap monitoring. The authors of this paper would like

to emphasize that although the collection of specimens may be simple in practice for medical scientists, the context in which such collection would be appropriate in different cultures needs to be strongly considered. What may seem like simple superstition can potentially have major and even dangerous implications for the conduct of scientific research. Despite some misgivings associated with cultural prohibitions, it appears that drug-level monitoring using hair specimens may have a place as part of a range of assessment methods.

Future perspective

As new technologies and treatment regimes develop, ARV monitoring in hair may become obsolete within the near future. However, medical researchers and staff will continue to collect different specimens from patients and control individuals for various reasons. Likewise it is unlikely that cultural beliefs that have been valid for ages in communities will disappear soon. Although the findings of this study cannot be generalized to other parts of Africa, studies such as this one do need to be incorporated into research protocols when researchers are unsure of how sample-taking will be interpreted by research subjects and their communities.

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Executive summary

Background

- The aim of this study was to document the perspectives, beliefs, and concerns of South African antiretroviral therapy users of providing hair specimens to determine antiretroviral drug levels.

Methods

- Twenty-one women living with HIV were recruited from a community health center in the Western Cape.
- Interviews were recorded and transcribed, and analyzed using Atlas.ti version 6. The main themes that emerged were (i) beliefs that acted as barriers to contributing hair specimens, (ii) reactions to providing hair specimens for a research study, (iii) information participants would like before providing their hair for medical or research purposes, and (iv) hair versus other methods of monitoring drug levels.

Results

- The results of this study indicate several beliefs surrounding the use of hair for drug-level monitoring in persons receiving antiretroviral therapy.
- Participants expressed concerns that their hair would get blown away, and either picked up by other people or by animals, resulting in their either being harmed or going mad.

Discussion

- To some extent cultural background appears to influence the relationship people have with their hair, even once it has been removed, to the extent that the person who gains access to the hair can then obtain power from it.
- Despite these beliefs and other superstitions that arose throughout the interviews, participants indicated that they would still be willing to provide hair for drug-level testing as they were aware that it would have positive implications for their health.
- This is an important finding in that it speaks to the readiness of people to make positive decisions about their health, and to act on these decisions despite cultural belief systems that might dissuade them from doing so.
- At the same time these results also indicate that medical researchers should be aware of and sensitive to different cultural beliefs and practices in different communities.