ORIGINAL RESEARCH ARTICLE

Exploring the sexual and reproductive health needs of adolescents and young people living with vertically acquired HIV in South Africa

DOI: 10.29063/ajrh2025/v29i6.2

Bandile E. Ndlazi, David D. Mphuthi and Thinavhuyo R. Netangaheni*

Department of Health Studies, University of South Africa, Pretoria, South Africa

***For Correspondence**: E-mail: *bandile.ndlazi@yahoo.com*

Abstract

The implementation of prevention of mother-to-child HIV transmission and pediatric HIV treatment has led to infected children transitioning into adolescence. Young people living with vertically acquired HIV face complex sexual and reproductive health (SRH) concerns, including challenges in relationships with parents, dating, and accessing services. This qualitative exploratory-descriptive study involved in-depth interviews with sixteen young individuals aged 18 to 24 who have vertically acquired HIV. Conducted in three healthcare facilities in Gauteng province, South Africa, the study utilised non-probability purposive sampling and thematic analysis for data analysis. Key themes included discomfort with dating, limited family support, and negative sexual experiences. Participants were hesitant to disclose their HIV status due to fear of rejection. Family support was primarily emotional, lacking focus on SRH needs. Healthcare providers often overlook individual sexual health needs, resulting in limited client-focused services. Despite regular healthcare contact, adolescents living with vertically acquired HIV experience unmet SRH communication needs, highlighting the necessity for improved sexual communication opportunities. *(Afr J Reprod Health 2025; 29 [6]: 19-28).*

Keywords: HIV status disclosure; sexual and reproductive health; young people living with HIV

Résumé

La mise en œuvre de la prévention de la transmission mère-enfant du VIH et du traitement pédiatrique du VIH a conduit les enfants infectés à passer à l'adolescence. Les jeunes vivant avec le VIH acquis verticalement sont confrontés à des problèmes complexes de santé sexuelle et reproductive (SSR), notamment des difficultés relationnelles avec leurs parents, des difficultés relationnelles et d'accès aux services. Cette étude qualitative exploratoire-descriptive a consisté en des entretiens approfondis avec seize jeunes âgés de 18 à 24 ans, atteints du VIH acquis verticalement. Menée dans trois établissements de santé de la province du Gauteng, en Afrique du Sud, l'étude a utilisé un échantillonnage dirigé non probabiliste et une analyse thématique pour l'analyse des données. Les principaux thèmes abordés comprenaient le malaise lié aux relations amoureuses, le soutien familial limité et les expériences sexuelles négatives. Les participants hésitaient à révéler leur statut sérologique par peur du rejet. Le soutien familial était principalement émotionnel, peu axé sur les besoins en matière de SSR. Les prestataires de soins négligent souvent les besoins individuels en matière de santé sexuelle, ce qui limite les services axés sur le patient. Malgré des contacts réguliers avec les professionnels de santé, les adolescents vivant avec le VIH acquis verticalement rencontrent des besoins de communication en matière de SSR non satisfaits, soulignant la nécessité d'améliorer les possibilités de communication sexuelle.. *(Afr J Reprod Health 2025; 29 [6]: 19-28).*

Mots-clés: divulgation du statut VIH ; santé sexuelle et reproductive ; jeunes vivant avec le VIH

Introduction

With the growing access to treatment including pediatric ART, the number of infections and deaths due to HIV has steadily declined between 2010 and 2020,[1-2] resulting in exposed and infected children living longer and transitioning into adolescence.[2]

According to the 2017 South African HIV prevalence estimates and the mathematical modelling study, approximately 360,000 to 400,000 adolescents are living with HIV in South Africa.[3-7] Despite the reduction in vertical transmission rates to below 3%, there’s a growing number of adolescents and young people entering childbearing age who are living with HIV, owing to the impact of the PMTCT programme.[4] Given the growth in numbers and the heightened vulnerability of young people living with HIIV (YPLHIV), it is essential to explore and better understand gaps in sexual and reproductive health (SRH) communication. This understanding is critical for identifying holistic approaches that take gender focused issues into account for effective programming.[4]

Adolescence presents a range of developmental challenges, including physical changes, emotional advancement, cognitive awakening, and sexual awareness. During this critical transition, adolescents work on developing self-identity and understanding their sexuality.[5] For adolescents and YPLHIV, the manner of disclosing their HIV status can significantly impact their experiences. Many face heightened fears surrounding the virus, often exacerbated by misconceptions about HIV infection, stigma and discrimination. These fears can hinder their ability to access and utilise essential health services effectively.[6] Additionally, SRH issues intersect with inequalities related to gender, poverty, ethnicity, and education factors that are frequently inadequately addressed.[1]

Our study aimed to explore and describe the multifaceted self-lived communication barriers that hinder optimal SRH for young people living with vertically acquired HIV as they transition into adolescence. We focused on family dynamics and healthcare interactions to develop recommendations that could enhance support for these adolescents and facilitate better health outcomes.

Methods

A Qualitative exploratory-descriptive study design was conducted among young people with vertically acquired HIV infection from April to July 2018. Ethical clearance and permission to conduct the study were granted by the University of South Africa’s ethical review board under reference number HSHDC/ HSHDC/630/2017. Following approval of the research proposal by the National Health Research Database (NHRD), referenced GP_2017_RP12_180, applications were submitted to the research committees of three Gauteng health districts for review and authorisation to access healthcare facilities. All participants were between the ages of 18 and 24 and were legally able to provide informed consent to participate in the study.

Setting

The study was conducted in three urban facilities located within the metropolitan districts of Ekurhuleni, Johannesburg, and Tshwane in Gauteng Province, South Africa. The selection of these facilities was dependent on decisions made by programme managers and using convenient sampling methods. In collaboration with the district programme managers, factors such as facility size, client volume, and the presence of other ongoing studies were considered to prevent overburdening facilities. The selected healthcare facilities comprised two community health centres and one primary healthcare facility. All selected sites offered a range of general preventative and curative services for minor ailments and chronic diseases, including HIV prevention, treatment, care, and support.

Population and sampling

The inclusion criteria for the study consisted of prospective participants living with vertically acquired HIV, receiving HIV treatment, care and support from the participating clinics, aged 18-24 years, and willing to participate. Adherence to HIV treatment was not a prerequisite for inclusion in this study. Non-probability purposive sampling was applied to select information rich participants, in consultation with the clinical nurses providing HIV care and treatment services to children and adolescents. Three nurse clinicians, drawing on their extensive knowledge of clients, provided a "sample frame" of adolescents and young people living with vertically acquired HIV within their facilities. Using this sample frame, research assistants approached those individuals who had scheduled appointments and contacted those who were not scheduled via telephone. All respondents were required to sign written informed consent before participation.

Data collection

The researcher followed a phenomenological approach to create a semi-structured interview guide that included both pre-determined and probing questions for data collection, ensuring alignment with the study objectives. The primary goal was to gather comprehensive descriptions of the participants’ SRH experiences and perceptions. although the initial target sample size was 20 participants, data saturation was reached after interviewing 16 individuals. All participants were deemed eligible and capable of providing the necessary information, as confirmed through consultations with wellness clinic nurses who were familiar with the potential participants. Appointments for interviews were then scheduled to coincide with the clients' follow-up visits. Individual in-depth interviews were conducted using the semi-structured interview guide, which featured open-ended questions to facilitate rich and detailed responses. All interviews were conducted in English, although participants were allowed to code-switch to their native language if they felt it allowed for better expression. The participants were asked to discuss the following:

Their communication about sexual and reproductive with parents and guardians.

Their experiences regarding HIV disclosure with consensual partners.

Their sexual debut experiences and condom usage.

Their interactions with healthcare providers concerning SRH issues.

Interviews were conducted in a private consulting room within the clinic to ensure privacy. The researchers and research assistants utilised prompts as needed to assist and encourage participants as well as to clarify responses. With the participants' permission, interviews were recorded using an audio recorder to ensure comprehensive data capture. Additionally, field notes were taken during each interview. To enhance understanding, member checking was employed by probing further into participant's responses ensuring that their intended meanings were accurately captured. The researcher maintained strict confidentiality regarding the collected data and participants' personal information by assigning patient identifier codes on transcripts and interview guides. All collected data including field notes and signed consent forms were scanned and stored in password-encrypted computed files, while hardcopies were securely destroyed. Recorded audio data were uploaded onto a computer and saved in an encrypted format with the original recordings deleted from the tape recorder.

Data analysis

The individual interviews were audio recorded and detailed field notes were taken during the data collection. The recordings were transcribed verbatim and subsequently reviewed for accuracy to ensure fidelity to participants' narratives. Following transcription, the data was systematically organised, crosschecked for consistency and labelled. The codebook was developed collaboratively by two researchers each analysing a subset of transcripts, eight per researcher, to identify initial codes and themes. This initial analysis was followed by team discussion to reach a consensus on the final themes, enhancing the reliability and validity of the thematic analysis. A six-step coding reliability thematic approach guided further analysis, beginning with code generation based on study objectives and preliminary themes. The qualitative data was analysed by developing codes from the list generated from the study objectives and identified themes. Subsequently, the codes were categorised to facilitate effective clustering of text segments, highlighting emergent themes related to participants' SRH experiences.

Results

Participants' characteristics

A total of sixteen young people comprising 8 females, and 8 males aged 18-24 living with HIV were recruited with the assistance of healthcare workers. The participants included 4 individuals aged 18, 6 aged 19, 4 aged 20 and 2 aged 21. During the individual interviews, some participants opted out of certain questions exercising their right to decline to respond to questions they found uncomfortable.

Themes

The inductive processes adopted by the researcher resulted in the emergence of new insights relating to SRH for YPLHIV. The identified themes and sub-themes are summarised in Table 1, Four main themes were identified and extracted: support, disclosure, and sexual debut and condom use.

Parental and family support on SRH

The participants in this study reported experiencing limited parental support regarding SRH matters. This perceived lack of support and guidance was attributed to the prevailing belief that people living with HIV should not engage in sexual relationships.

Table 1: Themes and sub-themes from findings

Themes	Sub-themes
Parental and family support on SRH	SRH issues are not discussed with parents
Healthcare professional support	Nurses are not so approachable due to age difference
Sexual or intimate partner's reaction after disclosure	HIV disclosure readiness
	Fear of rejection
Imposed early Sexual debut	Peer pressure
Inconsistent and incorrect Condom usage	Lack of trust
	Poor condom negotiation

Participants elaborated further stating that:

"*…I love my parents I just wish they could be more willing to sit down and listen to me, they would have given me better advice in terms of how to handle peer pressure on the matters of sex, boys, and other common challenges such as sexual abuse*." (Participant 9, 18-year-old female)

"*…The only sex talk I've received at home was just a threat against boys and that they all run away after getting what they want which is sex*." (Participant 1, 19-year-old female)

Parental and caregiver guidance was articulated in stigmatising and controlling manners, which contributed to participants feeling different from their peers and unsuitable for engaging in intimate relationships and sexual activities. Some participants expressed:

"*…When I asked my aunt who's currently my legal guardian about sex and boys, she just said, Thobi (not her real name), you need to remember that you are not like your peers, stay away from boys and sex talk*" (Participant 4, 18-year-old female)

"*…I do get support and encouragement from my mother to take treatment, however, I do not think she understands my sexual needs as a young man. She believes that I should not have sex at all, which is impossible*"

The internet emerged as the most accessible and reliable source of information regarding sexual health, particularly in instances where they felt unable to communicate with their parents. As one participant noted:

…I have started dating but I can only rely on friends and the internet for sex education and dating. Living with the virus does not make the process that easy." (Participant 2, 21-year-old male)

Perception of healthcare professional support

Participants reported receiving great services related to HIV care and treatment, however, they expressed uncertainty about the support provided for serostatus disclosure by the facility and healthcare professionals. Many felt that they did not receive adequate guidance and support on how to disclose their status to intimate partners. As a result, they always had to devise their own strategies for disclosing their HIV status which frequently proved ineffective.

"*…I always receive great services and information about my routine HIV care from all healthcare service providers in the clinic. The question of whether I am dating has come up a couple of times if I have started having sex, on responding, yes, then I am asked if I have disclosed my status*:

…When I said no, I was asked when was I planning to because I needed to disclose. All that did not come with the how but an instruction that it is the right thing to do." (Participant 3, 20-year-old male)

As a standard practice nurses provide information on family planning and other reproductive health services, however, patients' specific sexual health needs and service preferences are unintentionally overlooked. This oversight can lead to the delivery of irrelevant messaging and information. One participant highlighted this issue stating,

"*…The nurses and staff in the clinic are great, however, none of them ever asked me about my* *additional sexual health needs and service preferences. They have no idea of the kind of health and sexual issues I experience, and I am also not able to initiate the conversation as I also fear negative statements and judgement*:

…Receiving HIV treatment is great but, there are so many questions I would like to ask and address regarding my sexual health and other challenges, but I can't." (Participant 10, 19-year-old male)

Participants noted that asking nurses questions related to SRH related questions was not always an easy task. This difficulty was primarily attributed to the age difference and the parental-like nature of the nurse-patient relationship. As one participant expressed,

"...As much as I receive a high level of HIV care from all nurses and staff in the clinic, some of the nurses are a bit old and uptight; you can't even start asking questions because they are not welcoming and feel the same way as I'm with my parents." (Participant 7, 18-year-old male)
Another participant mentioned,

"*…I once met a young friendly nurse in the facility, she just had a way of making one comfortable and feel at ease. In that case, it became easy to ask questions and was able to address all my concerns and questions and that made me feel normal and felt that I was being understood."* (Participant 5, 20-year-old male)

Sexual or intimate partner's reaction to disclosure

Many YPLHIV tend to avoid long-term intimate relationships, often opting for short-term or casual encounters instead. This behaviour is driven by fear of commitment and the responsibility of disclosing their status to intimate or consensual partners. As one participant stated,

"*…I find it hard to be intimate with guys because I do not want to get too close to a point where I have to disclose my status. Commitment comes with such extra responsibilities."* (Participant 11, 21-year-old female)

The perceived complications associated with serostatus disclosure to intimate partners instil fear in most YPLHIV, as it poses a threat to their relationship and the possibility of losing them. The potential repercussions of disclosure were highlighted by one participant who stated,

"*…My partner was distant and kind of afraid of me after I disclosed my status. I felt the resentment and realised that I had made a huge mistake."* (Participant 12, 20-year-old male)

YPLHIV often wish to date and form intimate relationships with HIV-negative partners. However, they encounter the daunting challenge of navigating the expectations that come with being in a discordant relationship, particularly when it comes to disclosing their serostatus. For some, the prospect of disclosure can evoke fear and discomfort primarily due to the potential for rejection. This apprehension is largely rooted in the existing stigma surrounding HIV, which is frequently linked to misconceptions about promiscuity. As one participant expressed:

"*…I don't know how to tell my partner about this HIV thing. He will think I have a shady past; that's what everyone thinks when you are HIV positive*." (Participant 6, 18-year-old female).

"*…The challenge came where we got a bit serious, and I was kind of forced to disclose my status to her and the circumstances in which I contracted HIV which I got a sense that she did not believe me."* (Participant 3, 20-year-old male)

Sexual debut

Sexual debut is often viewed as an early life experience when young individuals may lack a comprehensive understanding of dating and the dynamics of sexual encounters. Both male and female participants shared distinct experiences and perspectives regarding their first sexual encounter, yet both groups attributed significant value to it. Male participants described their sexual debut as "scoring" while the females referred to it as "giving it away". Peer pressure always played a role in eventually "giving it away or scoring". The reason male participants referred to having sexual intercourse as "scoring" is merely because it comes with a sense of having reached a certain milestone to prove one's manhood. According to a participant,

"…*There is always a lot of questions and assumptions that one is gay or weak until they "score", eventually known to be dating with the assumption that one is now engaging in sexual activities with girls"* (Participant 15, 19-year-old male)

Not engaging in sexual acts often led to a perception of being a "failure" within certain social circles. As one female participant explained,

"…My friends never take me seriously, and they still hide certain stuff from me because they believe I am a bit immature since I am not dating and not ready to 'give it away'." (Participant 9, 18-year-old female)

Condom usage

In this study, inconsistent condom use was linked to a presumption of trust or, in some cases the patriarchal nature present in the relationship regarding sexual decision making. This was noted in one participant's remarks,

"…When I asked if we could use a condom, he asked me if I am sleeping with someone else and blatantly refused to put it on. I still insist citing fear of pregnancy which he's never happy about." (Participant 8,19-year-old female)

The prevailing attitudes towards decision making around sex and sexual practices seemed to hinder young women from effectively negotiating condom usage. As one female participant expressed,

"...As a female, I always carry my condoms, however, people refer to women who carry condoms as promiscuous while men are seen as heroes when they do." (Participant 14, 20-year-old female)

In many instances, condom use during first sexual encounters was reported as not used. One contributing factor was the spontaneous nature of the encounter, which often left little opportunity to obtain condoms.

"...I did not use the condom on my first sexual encounter because it was not planned, and I had no idea that we would have sex and none of us had condoms." (Participant 16, 19-year-old female)

Participants in this study did not perceive the accessibility and availability of condoms in public healthcare facilities as a challenge. They were all aware of where to obtain condoms within the facility without needing to ask or fearing judgment from other patients and adults while collecting.

"...Accessibility of condoms at the facility is great because we get it even from the toilet, so we no longer required to ask from the nurses and other clinic staff." (Participant 13, 19-year-old male).

Discussion

This study provides an exploratory qualitative analysis of SRH needs and complexities faced by adolescents and YPLHIV. It delves into the historical narrated experiences of young individuals living with vertically acquired HIV as they transition into adolescence.

All participants demonstrated a strong ability to articulate their lived experiences concerning sexual experiences. Notably, young people living with vertically acquired HIV are not fundamentally different from their HIV negative peers. The selected participants were all active clients receiving ongoing HIV care, and according to data on TIER.net and recorded information, they were all virally suppressed.

Like all individuals living with HIV, young people living with vertically acquired HIV desire to engage intimately with their peers and be accepted as normal individuals. However, this aspiration is often hindered by the significant challenges posed by HIV related stigma.[7] Disclosure of HIV status has become a critical component of HIV prevention programs, as it facilitates support, intimate partner index testing, treatment compliance, and ultimately viral load suppression. Despite this, available data from studies indicates that intimate or sexual partner serostatus disclosure remains low among people living with HIV.[8,9] For instance, a study conducted in Zambia found that 42% of the participants were afraid to engage in intimate relationships leading to self-isolation from friends due to fear of disclosing their serostatus.[10] Often, fear of rejection serves as the basis for non-disclosure and avoidance of intimate partnerships.[7] Participants in this study perceived intimate relationships as an added burden or responsibility to disclose their HIV status, something they felt unprepared for. The uncertainty regarding a partner's reaction was frequently cited as a reason for avoiding intimate relationships altogether or refraining from disclosing their serostatus, reflecting internalised stigma.

The study explored the extent of communication between participants and their parents or guardians particularly focusing on topics discussed. Participants expressed that while their parents and guardians were open to discussing medication related issues, they were hesitant to engage in conversations about SRH related. The support and guidance provided by parents regarding SRH matters were often limited to warnings about engaging in sexual relationships at a younger age. This lack of comprehensive SRH may stem from widespread misconceptions, leading to expectations that YPLHIV should refrain from consensual relationships.[11] The findings contrast slightly with a study conducted among high school learners in Gauteng, where participants reported some level of SRH communication, albeit infrequent.[12] Many participants in this study wished for their parents or guardians to listen without judgement and provide education on certain topics. They believed that discussions about sexual matters should occur at home, however, such conversations were often avoided due to fearing assumptions that they were already sexually active. This aligns with another study indicating that young girls frequently avoid discussing sex and sexuality issues with their mothers for fear of being judged or having assumptions about their behaviour.[13] Although parents and guardians can serve as vital sources of SRH information to adolescents, they often dismiss these discussions when initiated, sometimes reacting defensively due to social norms.[9,14,15] Such negative reactions create missed opportunities for meaningful dialogues; participants felt that conversations with their parents could have provided more opportunities to ask pertinent questions and receive guidance in a safe environment. The findings highlight the need for parental training on age-appropriate communication regarding both sexual education and HIV disclosure. Additionally, it is important to consider the role of direct learning from parents alongside information gathered from peers or older siblings.[16]

The study also examined the participants 'perceptions of support from healthcare professionals. During their interviews, participants expressed that the support they received regarding HIV disclosure from healthcare providers was not clear and lacked guidance. Certain characteristics of healthcare providers sometimes acted as barriers to communication and access to SRH services, with some professionals failing to offer appropriate and non-judgemental information to adolescents living with HIV.[17] While teen clubs were regarded as valuable sources by adolescents living with HIV in Malawi, they often did not address individual needs, as some participants felt uncomfortable asking personal questions.[18] In many instances, healthcare professionals held restrictive views on adolescent sexuality, regardless of their HIV status.[9] Younger healthcare providers, particularly nurses, were perceived as more approachable and friendly compared to their older counterparts; participants found it easier to communicate with them and felt more at ease during consultation. The provision of adolescent focused services is crucial for creating safe spaces where young people can discuss their issues and concerns with professionals without fear of judgment and discrimination.[19] This underscores the importance of healthcare facilities functioning as supportive environments for adolescents living with HIV.[20] Participants noted that healthcare professionals often overlooked their sexual health needs and service preferences during history taking, opting instead to provide generalized SRH information. This highlights the urgent need for standardized training for healthcare providers on SRH topics and the promotion of patient centred care approach.

The sexual debut was primarily characterised as an experiment driven by peer pressure where individuals felt compelled to demonstrate their ability and worth to friends rather than engaging in it out of genuine desire or readiness. For male participants, this often meant proving their capacity for intimate interactions with females, while girls faced pressure to validate their maturity through sexual engagement and activities by their peers. The findings contrast with studies indicating that most respondents viewed their first sexual encounter as something they genuinely wanted, influenced by the belief that relationships were rooted in love and romance.[21,22] Additionally, other research highlighted that some individuals delayed sexual engagement due to fear of rejection, discrimination and challenges associated with disclosing their status.[7,23,24]

Condom usage remains low in the general population, this was also observed from the 2017 HIV survey where condom use was below 50% in all South African provinces with Gauteng remaining at 29.2%.[25] The current study found limited condom negotiation opportunities for young women living with HIV as suggestions were met with unfavourable responses and promiscuity accusations from partners. Gursahaney *et al*, [26] allude that due to the patriarchal nature of many relationships, women's choices on condom usage are often ignored which exacerbates the need to empower women living with HIV to be able to negotiate consistent condom usage with their consensual partners.[26] Studies have found fear of rejection by sexual partners, recent enacted stigma experience, non-disclosure of HIV status and the dominant nature of male partners as reasons for engaging in condomless sex.[8,18,23,24] In the Uganda study, female participants expressed concerns about being perceived as promiscuous when seen carrying condoms, while they noted that men are often viewed positively for doing so.[24] In contrast, male participants reported never facing challenges when introducing condoms in relationships.[24] This perception may explain why condom use was reported to be higher among males than females during the last sexual encounter in the South African survey.[25]

Additionally, among individuals aged 15-24 condom use was found to be significantly higher for males (67.7%) compared to 49.8% of females.[25] Participants from this study also indicated they had never encountered challenges with condom availability and access from healthcare facilities.

Limitations of the study

The study draws new findings pertaining to adolescents and young people living with vertically acquired HIV, however, was limited to three healthcare facilities across three districts of a single province. The methodology applied relied on self-reported behaviours, which introduce potential inaccuracies in the data due to subjective reporting. Additionally, the retrospective design of the study may raise concerns regarding recall bias, as participants may have found it difficult to recall past behaviours and experiences. The generalisability of the findings to other districts and provinces may be limited as the sample was drawn exclusively from three metropolitan districts within one province. This highlights the need for further research in diverse districts and provinces to deepen our understanding of these issues.

Conclusion

Despite regular interactions with healthcare providers for routine HIV care, adolescents and young people living with vertically acquired HIV continue to face unmet SRH communication needs both at home and in clinical settings. This gap can lead to long term negative impacts on their SRH outcomes. Our findings align with previous studies that highlight the limitations and barriers to sexual communication in both domestic and clinical environments. There’s a pressing need for service integration that includes comprehensive sexual education, family planning, HIV disclosure, and condom negotiation skills during routine care visits to enhance SRH outcomes. To achieve this, we recommend healthcare provider training, the establishment of youth friendly clinics and integration of SRH to HIV management. The insight gained from this study contributes to the existing body of evidence advocating for open sexual education and the creation of non-judgemental, safe spaces for adolescents and young people living with vertically acquired HIV.

Authors contributions

Authors 1 and 2 conceptualised the study and designed the methodological framework. Both authors investigated the SRH needs of adolescents and young people living with vertically acquired HIV. Author 1 performed data analysis, while Authors 2 and 3 provided oversight and supervision of the research findings. Author 1 drafted the initial manuscript with contributions from Authors 2 and 3 in the interpretation of the findings, as well as in the review and editing of the final manuscript. All authors discussed, contributed and approved the final manuscript.

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