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METHOD



The role of social support networks in a sample of older adults living with HIV: the GOLD studies

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ABSTRACT

As the epidemiological landscape of HIV/AIDS changed over the last 40 years, more people are now living with HIV/AIDS deeper into senior adulthood. People over age 50 living with HIV face myriad challenges including medical, psychological, and social comorbidities. In this analysis, we consider the social realities and social networks of older adults living with HIV and assess how relationships and communities have been affected by stigma and other challenges of aging with HIV. A total of 40 participants, ages 51–69 years, living with HIV in the Newark metropolitan area were interviewed. A thematic analysis was conducted, and four main themes were identified: (1) friends and relationships; (2) support groups; (3) stigma and discrimination; (4) family. The role of social support within this community is discussed within these key themes. This study helps us to better understand how support networks affect older adults living with HIV and how stigma and fragmented relationships can ultimately contribute to negative health outcomes.

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HIV; social support; stigma; aging; community

Introduction

More than 1.2 million people are living with HIV (PLWH) in the United States (U.S.) (Lyons et al., 2021). Due to many advances in medical technology with antiretroviral therapies (ART), PLWH are now living longer lives and thereby challenging the idea that HIV is a young person's disease (Brown et al., 2021; Emler, 2006b). According to the Centers for Disease Control and Prevention (CDC), 51% of people living with the virus in the U.S. are now at least 50 years old (Centers for Disease Control and Prevention, 2022). This community's generation-shift makes it increasingly important to understand the dynamics of social support – and lack thereof – for a group of people that often faces multiple forms of stigma related to HIV status and/or age which can diminish mental health, increase psychosocial burdens (Halkitis et al., 2017), and lead to social isolation (Emler, 2006b).

Social support through community organizations, family, friends, healthcare workers, religious groups, and support groups can greatly influence the lives of PLWH. For example, having such forms of social support can provide individuals with an outlet to connect with other people facing similar challenges and motivation to take care of themselves (Brennan-Ing et al.,

2017). In different studies, social support, along with perceived community support, has been shown to help provide a buffer for PLWH between anticipated stigma and the effects of living with HIV (Earnshaw et al., 2015; Warren-Jeanpierre et al., 2017). Additionally, many studies on social support among older population PLWH show social support decreases stress, anxiety, and depression levels within these communities (Chambers et al., 2014; Sankar et al., 2011).

Older PLWH tend to have smaller social and support networks, causing them to become more vulnerable to social isolation and co-morbidities (Sankar et al., 2011). In one study, only 43% of participants said the emotional support they receive is adequate (Shippy & Karpiak, 2005). Older adults living with HIV are more likely than young ones to live alone (Emler, 2006a). An absence of social support challenges individuals' resilience and paves the way for people to experience a plethora of physical and mental health problems – whether that's being less consistent at taking medication or facing the emotional toll of loneliness (Krause & Halkitis, 2022; Chambers et al., 2014; Sankar et al., 2011). As PLWH continue to age, there is a need to understand the landscape of their support networks. The purpose of this study is to examine the tenets of

social support within older PLWH from a geographical area that is often overlooked in many investigations (Newark, NJ) and how support affects mental, social, and physical well-being. Through analyzing extensive interviews with forty individuals in this community, we break down the avenues through which social support has impacted their lives, aging, and how they manage living with HIV. This group of people – who in many cases lost loved ones to the virus or otherwise had their networks frayed – are reaching a stage of their lives they may not have once expected to live to due to the once deadly nature of the virus. This study helps to shed light not just on the impacts of social support for people in this community but allows them to explain why in their own words.

Methods

Data collection

From April to June 2019, 40 semi-structured qualitative interviews were conducted with a diverse sample of older PLWH. Participants were recruited through community- (i.e., drag shows, pride events, meetings etc.) and venue-based (e.g., HIV service organizations, medical offices, etc.) methods. Additionally, snowball sampling was also used to reach eligible individuals associated with previous participants. In total 49 people screened for the study with 40 participants completing the full semi-structured interviews. Participants were eligible if they met the following criteria: HIV positive, reside in New Jersey, able to travel to our research office in Newark, NJ for the interview, and at least 50 years of age. After arriving at our research office, participants first provided confirmation of HIV status and informed consent. Upon completion, were

compensated \$40 for their time. The interview contained questions on personal experiences with HIV, sexual orientation, social networks, aging, substance use, mental health, and resilience. Each interview took approximately 45–90 min to complete. All study activities were approved by the Rutgers University Institutional Review Board.

Data analysis

The interviews were audio-recorded and stored on a secure database. Trained research staff transcribed and cross-checked all 40 interviews for accuracy. Participant names and identifying information were deleted during the process to ensure anonymity. The research team utilized a multi-step approach to identify and analyze prominent themes from the transcripts. This included open coding, application of codes to transcripts, and thorough review of transcripts and codes to identify themes and patterns. Upon completion of coding, quotations were extracted and organized by codes and sub-codes into larger themes, based on patterns revealed throughout analysis. All analyses were reviewed closely by the first two authors, to address occasional differences in interpretation and to understand relationships among established codes. Qualitative data were coded and organized using Microsoft Excel and Word.

Results

Sociodemographic characteristics

The sample of older PLWH ($n = 40$) was diverse in terms of sexual identity, age, and gender (Table 1). The average age was about 57 years old ($M = 57.85$, $SD = 4.01$) and ranged from 51 to 69 years old. The gender identity divide was split, with 55% ($n = 22$) identifying as male and 45% ($n = 18$) identifying as female. The study overwhelmingly recruited Black individuals ($n = 37$, 93%) with the remaining participants identifying as White ($n = 2$, 5%) or other ($n = 1$, 3%).

Summary of qualitative results

Four main themes emerged from the qualitative data regarding social support for older individuals living with HIV. (1) Friends and Relationships, (2) Support Groups, (3) Stigma and Discrimination (4) Family. Many statements within each of these themes included support by other PLWH, friends, family or chosen family, relationships, support groups, medical providers, and religious organizations in addition to the social experiences of stigma and discrimination,

Table 1. Demographic information of GOLD IV participants ($n = 40$).

		<i>n</i> (%)
Race	Black	37 (92.5)
	White	2 (5.0)
	Other	1 (2.5)
Gender	Male	22 (55.0)
	Female	18 (45.0)
Age	50–55	12 (30.0)
	56–60	19 (47.5)
	61–65	7 (17.5)
	66–70	2 (5.0)
Sexual Orientation	Heterosexual	17 (42.5)
	Homosexual	9 (23.0)
	Bisexual	4 (10.0)
	Did Not Specify	10 (25.0)

Table 2. Themes and example quotes illustrating social support among older PLWH in Newark, NJ.

Theme	Descriptions	Example quotations
Friends and Relationships	Significant relationships with other PLWH	<p>Interviewer (I): So, have you disclosed your status to your family and or friends?</p> <p>Participant (P): Friends yes – well other HIV positive people, but not my family. It was easy because they were also positive. The ones I disclosed to were also positive. I haven't disclosed to my non positive friends. (Black, Male, 64)</p> <p>Some of the friends that I do associate with, they have the same thing. So that kind of like makes me feel little, little better because now I'm associating with people that have the same thing I have, so when I look at them, they look at me, we can say you know [we're] proud that this is what we have and you know. We're all accepting it, we're dealing with it. Everyday of our life we're dealing with it, and ... we're not in denial anymore. (Black, Female, 56)</p> <p>I: In addition to seeing a psychiatrist and also your support groups, what other strategies do you utilize to cope with your mental health?</p> <p>P: Hanging out with the right people, it's a big thing. A lot of the people I hang out with are positive – maybe half ... so we have that common bond ... But as far as besides support groups and my therapist it would be hanging around like minded people. A lot of gay people [and] a lot of positive people (Black, Male, 60)</p>
	Loss of social networks	<p>Well my partner, we were together, but he died in '99. We had each other for support during that time when he was alive. It wasn't that hard for me I think. I wasn't alone. We went to doctors appointments together, we got blood work together, we did everything together regarding our health. (Black, Male, 60)</p> <p>Some days I wish I had gotten married. Some days I regret being gay because I haven't found happiness in the gay life. And I have some crazy thoughts sometimes I say that's because God don't want gay in me even though I believe God love everybody ... I wish I got married had a family somebody to share my life with 'cause I don't have nobody to share my life with. I've been single for basically all my life, and it gets real lonely. (Black, Male, 58)</p> <p>Oh um, well I think if I would've told other people I probably would have been treated different ... But because I kept it a secret, to myself, um it kind of like helped me a little bit. It also kind of scared me from wanting to have relationships with men now, because of that too ... I'm afraid of telling them because I don't know how they will react to it. (Black, Male, 58)</p>
Support Groups	Overall impact	<p>There, I feel more comfortable because there are other people who have the same problems I have. (Black, Female, 58)</p> <p>I: So you'd rather just kinda keep it to yourself?</p> <p>P: Well I go to groups deal with it</p> <p>I: Do you still attend the groups?</p> <p>P: Oh. It's all I do. Just stay from the streets you know cause ain't nothing in the streets. Ain't nothing but trouble you know and uh brothers been doing different things and I ain't got time for that type of life ... it's just life is too short. You know dealing with disease I try to stay home you know deal with my own problems ... Take my medicine religiously ...</p> <p>P: They changed my life. (Black, Male, 55)</p>
	Life improvement	<p>I just – actually a support group got me to that point though. Because I went and talked about it in group one day. And they just was like [name] you gotta take your medicine. And my health, I started getting really sick; I was sick all the time then and they thought, [name] you gotta take your medicine. And I guess I cared enough for them in the group and they were sincere enough that I said I'm'a try it. So I started taking my medicine. And my health like improved drastically. (Black, Male, 58)</p> <p>And I'm 56 years old and I came a long way. From where I was at, it was like, I was sleeping in abandoned apartment with no water, no lights, with dogs ... I was living a rough life. Me and my kids, I had them sleeping in abandoned houses with me. Yeah and I just I said "no this not me, I can't". And then I went and got help and stuff ... By me going back to the support group – they helped me get me an apartment and everything. Now I'm more humble and stuff. And now they help me with most of my rent, I pay my portion. And they pay they portion. Yea ... I've been there for five years and I love it. (Black, Female, 56)</p>
	Challenges finding support groups	<p>P: Back in the day there was no support groups like that (I: okay). You know, you only got a few support groups now for men and women ...</p> <p>I: Are you able to tell me what your, from your own opinion, why support groups for-of that type are dwindling or decreasing?</p> <p>P: It's decreasing because nobody wants to step up (I: okay). Nobody want to be the one, to start the support group. Nobody wants to take over that commitment, you know. It's just like being in a place where you got a group of people, you got friends, you know five friends that are positive and y'all meet at my house once a week. And now ... being that we got five friends and we meet at my house every day, that next person knows somebody now there's seven of us. That person knows somebody and brings them to my house now there's ten of us (I: yeah). Now we can't do it at my house no more, now we have to find a place to do it at so what do we do? ... It [the support group] was for, straight and gay men (I: okay) and we all used to come together, buy food, and we sit there and we have that conversation for an hour and a half, whatever topic we had ... But now it's not like that anymore. Everything is fading away ... Who's going to help that person? ... I'm going to advocate for this person, navigate for this person until I get him where he needs to be. (I: yeah) I'm going to make sure he get a support group – we have support groups at our offices (I: okay) – I'm going to make sure he get a support group and make sure he get connected. If he's homeless, I'm going to make sure he gets housing. (Black, Male, 62)</p>

(Continued)

Table 2. Continued.

Theme	Descriptions	Example quotations
Stigma and Discrimination	Impact on relationships	<i>You know stigma is big ... I have learned to accept, that stigma comes from being uneducated ... But, umm, it hurts, that people judge you, and you have to deal with that, everybody looking back around and people thinking if I sneeze I'mma get it. So, that stigma still carries me through, like I was offered to speak with the governor on what we need for HIV and AIDS, and I refused to. Because I don't know where it's going to go, because I ain't comfortable to let the whole world know where I'm at today ... my comfort zone is not in Newark because of the stigma. (Black, Female, 58)</i>
	Stigma against support groups	<i>These days now you still have people that've been HIV-positive for a long time but still haven't accepted their status, and the reason why, the stigma. People judging you, and they think that this is something that you ask for. So, you got all this going on in your head, and you don't wanna think about it. People don't wanna go to support groups. Because somebody might tell your business. They're gonna say well, you – this is a closed group, they go the same thing you got, so in order to know your stuff and they have to be there with they stuff. (Black, Female, 58)</i>
	Stigma preventing formation of relationships	<i>It well I most of my relationships were with other HIV [positive] people. I did start dating someone, this was years and years back, who we didn't really do anything but [they] freaked out when I told him I was HIV positive ... that affected me a little bit so then after that I would just try to date people who were pos. (White, 62, Male)</i>
Family	Need to educate about HIV	<i>I have a young lady that I told and she was oh my gosh ... I adopted her as my mother and she's 100% supportive. I educated her because she was very um naïve about it, she was given false information about the virus. So, I educated her ... I could talk about anything with her (Black, Female, 58)</i>
	Providing assistance and support	<i>It was my oldest brother, his children, one of my sisters, and two of my nieces. Everybody they took turns, anything that I needed, taking me to the doctors, making sure that I had food, washing me bathing me because I couldn't do anything. I was down to maybe like uhm almost like 86 pounds. (Black, Male, 59)</i> <i>My grandkids, is my support, part of my support group cause they keep me busy. I have ten grandkids! 6 boys and 4 girls. And they keep me active, they keep me moving about you know. They play a big part in my recovery. And they give me much respect. They always call and say "Ma you good? You alright? You take the medicine?" Very supportive. Which I thought it would never be like this! (Black, Female, 58)</i>
	Finding purpose through new generations	<i>I: Good, so you're taking care of yourself!</i> <i>P: Mhmm, I got too much to live for! I got my daughter and my grandson back in my life since I stopped using drugs and stuff, you know. I got my people back in my life. (Black, Female, 58)</i>
	Loneliness	<i>After the-after the diagnosis ... I lost my mother and that was my only support, when that was the only person I could talk to ... Plus I was with the wrong people ... They just steered me the wrong direction. And since she wasn't there then I had the virus, I was like oh I just might as well kill myself. That's the way I felt ... I know what lead to it ... Me not having nobody when I once I got diagnosed with the HIV and my mother was the only one. (Black, Female, 58)</i> <i>Um [pause 1 s] right now [pause 1 s] it's like I'm a little lone-lonely right now cause I lost a lot of loved ones. And I know they not coming back, so I know that I had to live on and keep living on. I can't let, keep dwelling and dwelling. And get myself sick and stuff cause I know they not coming back. (Black, Female, 68)</i>

independence, and mistrust. These quotes are all outlined in Table 2.

Theme 1: friends and relationships

Many of the participants shared that having close friends and relationships helped in maintaining their physical and mental health while living with HIV. Those who didn't have these networks described challenges they faced, including social isolation. Close relationships, having friends with similar backgrounds and experiences, loss of relationships, and loneliness due to aging were also themes that were widely discussed.

One of the most prominent aspects of support in the older HIV community was having a common bond. Most participants expressed having significant relationships with those who were also HIV positive and relied

heavily on the support and friendship of other PLWH due to similar life experiences. As a result, many participants found support groups specifically for PLWH to be helpful places to discuss their issues with those who shared the same status. One participant explained that it is difficult to disclose their status to others who were not living with HIV. Similarly, another participant discussed how associating themselves with people who have HIV has helped them work through problems because they can brainstorm solutions together. Because many participants had lost support networks due to death and illness, being around people who have the same diagnosis is crucial to long-term survival and positive health outcomes.

While many participants talked about the importance of friendships in their journey, a common theme among the others who did not have as strong of a social support network was a sense of loneliness

and loss of support networks through death. Many elaborated about their loss of partners and friends in their communities. Additionally, participants mentioned aspects of loneliness and not having a stable friend group or long-term partner to support them.

Most participants who struggled with relationships also mentioned they had few people to confide in. With so much mistrust, discrimination, and stigma in relationships, participants found themselves apprehensive to talk to others.

Theme 2: support groups

Support groups for people living with HIV were a point discussed in nearly every interview. Almost every participant had been to a support group for HIV at some point in their lives, and many still attended weekly. Participants reported how support groups have drastically helped them navigate through their HIV status, age, substance abuse, housing challenges or job issues. They also helped to create trusting friendships. Overall, examples from this study strongly suggest that having a support group is a necessity to ensure positive health and wellbeing for the aging population with HIV.

Participants expressed the importance of having support groups with others who also have HIV. A common theme discussed was a sense of comfort and safety in support groups. Most participants discussed how groups had changed their lives for the better. Many said they only opened up about their challenges and HIV status to people within the group setting. One participant said he doesn't disclose his status to anyone, but groups have been a significant part of his life.

There was a strong sense that support groups influenced individuals to take better care of themselves. Many instances included improving their mental health, repairing relationships, ceasing drug use, taking their medications, or going back to school. Another participant mentioned how support groups had shaped her life for the better and helped improve her housing situation.

On the contrary, a lack of HIV support groups was pointed out by some participants. One challenging aspect of support groups is maintaining them overtime. One of the male participants explained that groups were fading away due to challenges of organizing them and a dearth of people stepping up to bring them together.

Theme 3: stigma and discrimination

The effects of HIV-based stigma and discrimination have been widely documented throughout the last 40 years of the epidemic. However, the long-term effects

of stigma/discrimination in relationships are often overlooked in the older adult populations living with HIV. Participants discussed the causes of stigma and discrimination and how it directly impacts their relationships. They attribute stigma to general misinformation and lack of HIV-related education.

As noted before while some thought support groups were very helpful, others don't attend groups due to various forms of stigma, some of which caused apprehension to disclose their status and other personal information. Other participants noted that they were not in romantic relationships due to past experiences with stigma. In particular, one participant noted that a partner "freaked out" when they disclosed their HIV status so that he only dated other PLWH after that point in time.

In contrast, many participants noted that stigma has gotten much better over the years as more people learn about the virus and the scientific progress around managing it. But, even as public knowledge of HIV has improved, there remain widespread misconceptions that still lead to challenges for PLWH in developing romantic and other relationships.

Theme 4: family

Finally, most participants mentioned family as one of their main support systems. Although some had poor relationships with their family, creating negative health outcomes, most participants expressed the need for these relationships and how much they helped them both physically and mentally. For participants who did not have family as a support system, they described the challenges that absence can invoke for day-to-day life. Many discussed the importance of educating their family members who may have an inaccurate idea of what HIV/AIDS is and how it is transmitted.

Several participants explained that close family members worked to ensure that participants could take care of themselves. Of those who had supportive families, many discussed how their family members made sure they were taking the right steps toward recovery and a healthy lifestyle. This was particularly true for those who had more physical limitations.

Other participants discussed how their lives had more purpose when their grandchildren were born. Previously, participants were struggling with mental health, abuse, and keeping up with their medications. However, once grandchildren entered their lives, they felt like they had something to live for. Similarly, participants expressed how their grandchildren kept them moving and always looked out for their wellbeing.

Conversely, some participants had lost their closest family members. Of the participants who did not have their family in their lives, many discussed how death took a toll on their support networks, especially if close family members were the primary person they could confide in. Others highlighted the specific impact of loneliness after a family member passes on.

Discussion

This study provides an understanding of how social support affects older adults living with HIV and the life events they have experienced with age. Our results show that there is a need for older PLWH to have steady and strong networks of support. Without these support networks, participants experienced a multitude of challenges – including increases in substance use, depression, anxiety, homelessness, and other negative health outcomes.

Support is crucial to aging and recovery in those living with HIV as described by nearly all participants in the study. This aligns with previous studies that discuss how friends and support groups dominate their support systems, while isolation also plagues this population (Brennan-Ing et al., 2014; Brennan-Ing et al., 2017). Similarly, adequate social relationships and networks in other geographies and populations have been shown to be critical for strengthening access to HIV/AIDS resources as well as emotional wellbeing (Fauk et al., 2019). The support of families and communities, however, can be influenced by external factors such as moral judgement, religious thoughts, and social perceptions (Fauk et al., 2021). Our findings add to the existing body of research as aspects of stigma and discrimination within these support networks, and the effects it has on this population were highlighted with more depth.

Support groups are clearly critical, and their absence is deeply felt. Even though support groups were discussed by almost all participants, several expressed frustrations due to the lack of them in their communities. Newark, NJ is geographically proximal to New York City, a metropolitan area known to have many resources for older PLWH compared to other locales in the U.S., but it has markedly less opportunities for support groups. HIV-service and other community-based organizations work tirelessly to provide services and support for PLWH; however, many do not have enough financial resources to provide and manage different types of support programs. It has been documented that financing for HIV-specific programming has been diverted to other non-HIV programs (Kiplagat et al., 2022; Lyu et al., 2023; Yu et al., 2008). In the U.S., many PLWH rely on public funding and safety nets

via the Affordable Care Act, Medicare, Medicaid, or the Ryan White HIV/AIDS Program, however that support is usually only for direct medical care (Kiplagat et al., 2022; Lyu et al., 2023). Likewise, in even more under-resourced areas, older individuals living with HIV express a lack in both healthcare and social services funding (Kuteesa et al., 2012). In order to provide holistic care for older PLWH that spans beyond physical and/or mental health and into psychosocial and emotional health, it is imperative that the organizations leading these efforts are adequately funded.

Additionally, it is important to note that these interviews were conducted during Spring 2019 and thus, before the onset of the COVID-19 pandemic when many support networks and groups were not as easily accessible due to the implementation of social and physical distancing measures (Szkody et al., 2021). Even in the general population, many relationships were lost and people experienced things such as social isolation, increased anxiety and depression, and loneliness (Banerjee & Rai, 2020). Older PLWH are at a heightened risk for these problems (Algarin et al., 2020; Brown & Weissman, 2020). In-person support groups were mostly paused or curtailed due to the pandemic – which had been one of the main networks utilized by older individuals living with HIV, and which presented a multitude of problems for the community when these connections were lost. As such, it is critical to resume activities and support groups for older PLWH and to re-evaluate the needs of this population moving forward.

Lastly, participants showed that the more social support they receive through relationships, groups, and community, the more resilient they will be. Support systems have greatly lowered the amount of depression and anxiety in those living with HIV, while increasing their positive thinking and resilience (Fang et al., 2015). Our participants mirrored these results, and tended to express more resilience to stigma when they had an adequate support system to fall back on. Another study conducted with older adults living with HIV in the deep South demonstrated that as oppressive systems increased, resilience decreased (Brown et al., 2021). However, when social support increased, the ability for individuals to bounce back also increased significantly (Brown et al., 2021). Incorporating resilience and strengths-based perspectives into training for providers and community-based organizations will offer an important perspective of approaches to holistic care, especially for aging PLWH. With proper support and decreased stigma in their closest relationships, older PLWH can live long, fulfilling, and happy lives.

Limitations

This study explores the effects of social support on the lives of PLWH by highlighting themes that members of the community discussed as being impactful, letting their words from extensive in-person interviews explain what it means for their lives. Limitations of such an analysis include that the lack of binary-response questions makes it effectively impossible to break down the ratios of which participants viewed each subject as important or to quantify the responses, instead relying on the themes that emerged as the participants spoke freely across the semi-structured interviews.

Additional constraints for this study include geographic limitations, as participants were all from the Newark, New Jersey area. For example, this concentration within a specific area could mean that individuals from different geographies may have varied relationships with community-based social supports like groups. Alternatively, not many studies have been done in Newark, New Jersey or other urban areas, and we did not have many studies to reference while analyzing the data. Additionally, given that this data was collected prior to the COVID-19 pandemic, the spread of that disease and the resulting safety measures could have eroded many of the networks that participants relied on, making follow-up interviews in order to assess the current state of the support systems a potential starting point for future research.

Conclusions

Social support is crucial to PLWH, especially within the older adult population. This study helps us to better understand how support networks affect older adults living with HIV and how stigma and fragmented relationships can ultimately make way for negative health outcomes. Without adequate social networks, participants are vulnerable to myriad biopsychosocial health issues as they age. Furthermore, these findings identify a need to increase funding, social programming, and research for and within this population as research and programs tend to cater toward those who have recently seroconverted and/or younger PLWH.

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Study conception and design: KDK & PNH; analysis and interpretation of the data: KDK, SGC; the drafting of the paper: SGC; revising it critically for intellectual content: KDK & PNH; final approval of the version to be published: SCG, KDK, & PNH. All authors agree to be accountable for all aspects of the work.

Disclosure statement

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Data availability statement

The data that support the findings of this study are available from the corresponding author, KDK, upon reasonable request.

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