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An interprofessional model of care for adolescents with perinatal HIV: A qualitative study

Nicolette Comley-White | Veronica Ntsiea | Joanne Potterton

Department of Physiotherapy, University of the Witwatersrand, Johannesburg, South Africa

Correspondence
Nicolette Comley-White, 7 York Rd, Johannesburg 2193, South Africa.
Email: Nicolette.comley-white@wits.ac.za

Funding information
University of the Witwatersrand, Johannesburg; South African Society of Physiotherapy

Abstract

Background and Aims: The number of perinatally HIV-infected adolescents (PHIVA) is increasing however many health care systems are not prepared for this population and their health challenges, specifically a model of care (MoC) is lacking. Thus the objective of this study was to develop and propose a MoC for PHIVA.

Methods: Through a qualitative study design, a MoC was developed and ratified with two focus groups, consisting of PHIVA and healthcare professionals.

Results: Seven participants were included in each focus group and the following themes were developed: relatable attributes; missing components; implementation and suggestions. Changes were made to the drafts of the MoC in response to the focus group results, leading to the finalisation of a MoC for PHIVA. The MoC focused on the importance of interprofessional health care and addressed the physical sequelae that PHIVA are likely to encounter. A schematic of the MoC was created for the use in general public education.

Conclusion: It is important that healthcare facilities are equipped to handle the specific needs of PHIVA. The interprofessional MoC developed in this study helps to address the requirements of this population.

KEYWORDS
adolescence, healthcare, HIV, model of care, vertical transmission, youth

1 | INTRODUCTION

Approximately 2.8 million children live with HIV, of which 1.8 million are adolescents,[1] and 88% of the adolescents live in sub-Saharan Africa.[2] As antiretroviral therapy (ART) rollout and efficacy improves, so the population of children with perinatal HIV living into adolescence grows. These perinatally HIV-infected adolescents (PHIVA) present a novel health challenge,[3] with their entire developmental and growth period being influenced by the neurotoxic virus, as well as the effects of long-term ART usage.

There are emerging physical challenges that PHIVA face, specifically with regard to growth failure, delayed puberty, and cardiac and lung dysfunction.[4,5] Numerous studies have highlighted the detrimental effects of perinatal HIV on both birth weight and developmental milestones,[6,7] leading to persistent growth issues that extend into adolescence.[5] An analysis of data from 8737 PHIVA found that by age 10, 39% of female PHIVA and 34% of male PHIVA experienced stunted growth.[8] This childhood stunting can contribute to delayed pubertal onset,[9] placing PHIVA at a heightened risk of pubertal delay.[5,10–12] Bellavia et al. studied puberty onset in 2539 PHIVA and

adolescents born HIV-exposed but uninfected, discovering that PHIVA reached puberty approximately 6 months later on average compared to their uninfected peers, with height z-scores influencing the impact of HIV infection on sexual maturation.[13]

Githinji et al. compared the cardiopulmonary function of 515 PHIVA in South Africa with 110 age- and ethinicty-matched HIV-negative adolescents: despite ART control, the PHIVA had significantly lower lung function.[14] Potential causes for lung dysfunction include virus- or opportunistic infection-induced airway damage, chronic inflammation, and damage from HIV-related diseases.[15–18] Recent studies with perinatally infected children and adolescents have found echocardiac abnormalities in 42% of the population, with left ventricular hypertrophy and diastolic dysfunction being common[19]; and that up to 27.7% of participants exhibited early cardiac dysfunction, associated with increased systemic inflammation.[20] A model of care (MoC) serves as a structure for delivering health care tailored to a specific condition within a population, promoting cohesive collaboration among healthcare professionals and ensuring a unified approach to patient care.[21] A MoC in HIV is not "one size fits all" and differentiated care needs to be considered.[22,23] While there are MoCs available for people living with HIV, there are minimal MoCs specific to PHIVA. A review found four MoCs used in Africa for transition of adolescents to adult care but these models were not specifically for perinatal HIV, and their focus was on transition and ART adherence.[24] Important concepts specific to care for PHIVA are the disclosure of status and transitioning to adult care, but despite the growth of this unique population, many health care systems lack preparedness to deal with PHIVA and their specific challenges.[25] A situational analysis of 218 health care facilities across 23 sub-Saharan African countries found that the majority (66%) of the facilities managed adolescents within either paediatric or adult services, 26% of the facilities did not have a working definition of adolescence, 39% did not have suitable policies for nonadherence, and 49% did not have protocols for transition to adult care.[26] This highlights the need for a model that caters specifically for adolescents and thus the aim of this study was to develop and propose a MoC for PHIVA.

2 | METHODS

2.1 | Study design

This study used a qualitative design with focus groups to propose a MoC for PHIVA as the final phase of a larger, mixed-methods study. Details of the methodology of the larger study have been published elsewhere[27] as well as the results of the different phases of the overall study, which included a cross-sectional analysis of the physical sequelae in PHIVA,[28,29] a qualitative analysis of their perceived physical challenges[30] and a scoping review of the literature pertaining to physical sequelae in PHIVA.[31,32] The Standards for Reporting Qualitative Research were used as a guide for reporting this study.[33]

2.2 | Participant selection and study site

Based on the outcomes of the preceding studies, a MoC was drafted and proposed to two focus groups: one group of PHIVA and one interprofessional group (IPG) of health care providers working in the paediatric and adolescent HIV field. The data collection period with the focus groups ran from August 2021 to January 2022.

Files and the booking diary of a large, urban HIV clinic in Johannesburg, South Africa were screened for potential participants who had perinatally acquired HIV and were aged 10–16 years. Using convenience sampling following the screening procedure, potential participants were telephonically invited to participate in the study. The focus group was held face to face in a private room of the clinic. All COVID-19 precautions were adhered to.

For the IPG, purposive snowball sampling was used to identify a variety of healthcare professionals that work with adolescents with HIV across multiple clinical sites. This was done to ensure that there was a sufficient variety of input and clinical experience available for the focus group. Healthcare professionals that work in HIV adolescent care in South Africa include the medical doctors, nurses, counsellors (working across the disciplines of lay counsellors, social workers, and community health workers), physiotherapists and occupational therapists (both of whom address physical well-being to minimise impairments and maximise quality of life). The focus group was done online through video conferencing software to allow participants to attend from across South Africa.

2.3 | Procedure

2.3.1 | Development of the MoC

The MoC was developed following the study objectives laid out by Chetty and Hanass-Hancock during their development of a MoC for rehabilitation of people living with HIV in South Africa.[34] These steps entail a review of the literature (i.e., the prior scoping review[31,32]); exploring the perceptions of the stakeholders (i.e., the qualitative interviews done previously with PHIVA[30]); identifying criteria to be included in the model (i.e., data from the preceding cross-sectional and qualitative studies[28–30]); and development and appraisal of the model (i.e., the focus groups of this study).[34] This procedure is similar to other steps described in literature, which involves a review of the literature; qualitative gathering of information from involved parties; and populating the model.[21,35]

The International Classification of Functioning, Disability and Health (ICF) is a common tool used to discuss disability[36] and it was used as a conceptual framework for the basis of the MoC. Figure 1 presents the initial draft of the MoC based on the physical impairments established in the preceding studies.

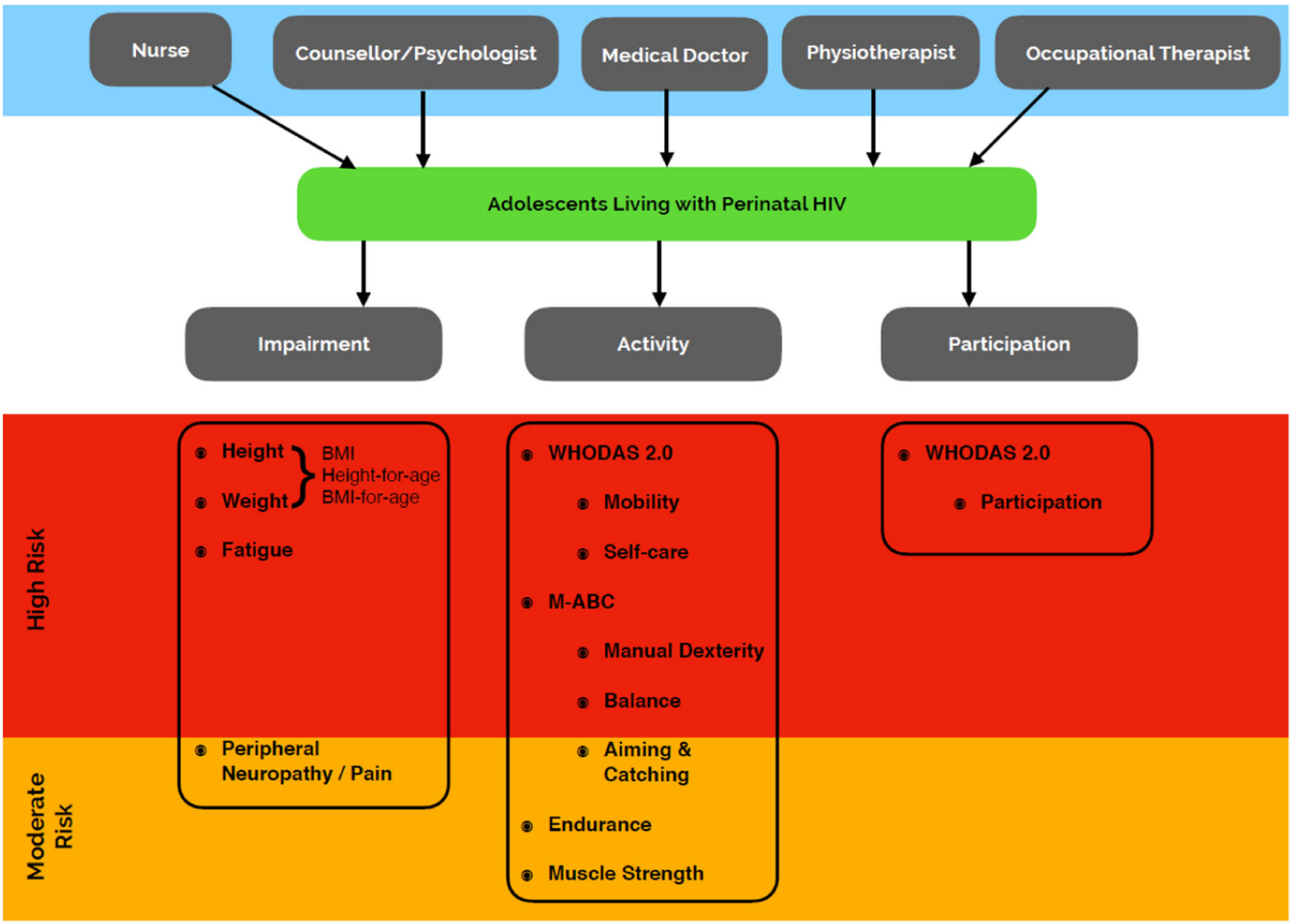

FIGURE 1 First draft of the interprofessional model of care for PHIVA. PHIVA, perinatally HIV-infected adolescents.

2.3.2 | Focus groups

For both focus groups, following an icebreaker activity, the principal investigator (PI) presented a brief overview of the development of the MoC and then shared the MoC with the participants. The participants were given time to reflect upon the MoC and then shared their opinions on what they felt were positive attributes of the MoC and what they believed was missing from it. The PI asked probing questions and facilitated the free-flow of discussion and idea-sharing. For the PHIVA group a clinic counsellor was present for recruitment and data collection, and she was an important asset in the study because she was familiar with the adolescents, their caregivers and the logistics of the clinic.

2.4 | Data analysis

The focus groups were audio-recorded and transcribed verbatim. Identifiers were removed from the transcriptions and the PI cross-checked them for accuracy. Field notes captured by the PI summarised the focus group's input and were an added component of data collection.[37] The transcriptions were analysed thematically and from these themes, adjustments to the proposed MoC were made, resulting in a final tool.

3 | RESULTS

3.1 | Demographic and clinical information

Seven adolescents participated in the PHIVA group and seven healthcare professionals participated in the IPG. Details on the PHIVA group and IPG are presented in Table 1 and Table 2, respectively. Data saturation was reached within the focus groups with the stakeholders and thus further focus groups were not indicated.

3.2 | MoC

Following the presentation of the draft of the MoC (Figure 1) and discussion around it the resulting themes were developed:

TABLE 1 Description of the adolescent focus group ($n = 7$).

Variable	$n = 7$
Male	2 (28.6%)
Female	5 (71.4%)
Mean age	12 year 4 month (SD ± 1 year 2 month)
Mean age at HIV diagnosis	3 year 7 month (SD ± 2 year 2 month)
Mean age of ART initiation	3 year 7 month (SD ± 3 year 3 month)
Mean CD4 percentage	34.8 (SD ± 6)
Viral load < 500 copies/mL	7 (100%)

Abbreviations: ART, antiretroviral therapy; HIV, human immunodeficiency virus; SD, standard deviation.

TABLE 2 Description of the interprofessional focus group ($n = 7$).

Variable	$n = 7$
Male	1 (14.3%)
Female	6 (85.7%)
Mean age, years	43 (SD ± 13)
Clinical profession	
Physiotherapist	2
Medical doctor	1
Nurse	1
Occupational therapist	1
Counsellor	1
Clinical psychologist	1
Mean years of experience with adolescents	13 (SD ± 6)

Abbreviation: SD, standard deviation.

relatable attributes; missing components; implementation and suggestions. The two focus groups viewed the MoC from different perspectives (patient vs. health care professional) and there were many areas of agreement. Table 3 presents the codes and themes from the focus group sessions.

3.2.1 | Adolescent focus group

The strongest code to come out from the PHIVA group was mental health. The participants spoke about challenges with mental health, especially in regard to depression, anxiety and coping with peer pressure, and this was seen as a missing component on the MoC draft.

> "What's missing here is two things that almost every teenager goes through: it is anxiety and depression…. And peer pressure." –female, age 14

Another missing component was the role of the social worker within the healthcare professional input. Many of the participants discussed seeing a social worker during their clinic visits and felt that it should be reflected in this MoC. They also had not attended support groups which could be a component of implementation. When the PHIVA were asked what they could relate to on the MoC, they discussed having dissatisfaction with being underweight ("I struggle with the weight… too little"), and one participant said that he was struggling with aiming when playing sport. Pain was discussed but in broad terms (relating to menstrual pain), highlighting the necessity of clarifying types of pain in PHIVA on the MoC.

3.2.2 | Interprofessional focus group

Following the PHIVA focus group, the MoC draft was updated with comments on the missing information about social workers, mental health and pain presentation. The updated MoC (Figure 2) was used for the interprofessional focus group.

The first point of discussion from the IPG was about what was seen as relatable items that is, what they experienced within their clinical work. Mental health challenges in PHIVA was the primary code, with all seven participants verbalising their experiences of it within this population. The discussion expanded upon how mental health in PHIVA impacts on treatment adherence, risky behaviour and substance abuse. Additionally, it is affected by one's acceptance within a community and the influence of peer pressure and depression. Lastly, the role of mental health and school achievement was discussed, and how when PHIVA are not performing academically and are held back at school it impacts on their mental health and well-being.

> "I really do see so many mental health problems… the impact of that on treatment adherence, never mind risk behaviour, is enormous."—Psychologist

Additional relatable items on the MoC pertained to activity limitations. A physiotherapist discussed how in her work she encounters impairments specifically with self-care and mobility in PHIVA, as well as problems with fine motor control. These challenges were reiterated by the medical doctor in the group who discussed how PHIVA in the clinic often present with lower levels of functioning causing problems with self-care, such as not managing their appointment dates, medication schedules, sexual health etcetera.

Following the discussion around relatable items on the MoC, the focus group discussed what could be missing from it. Mental health had already been discussed in detail as a crucial part of the

TABLE 3 Codes and themes derived from the adolescent and interprofessional focus groups.

Themes	Interprofessional group	Adolescent group
Relatable attributes	• Mental health challenges frequently encountered • Similar activity limitations on the MoC observed clinically	• Weight challenges • Impairments with aiming
Missing components	• Mental health • Social worker • Dietician • Cognitive and school performance	• Mental health • Social worker
Implementation and suggestions	• Screening as an interprofessional team • Use of support groups (age appropriate) • Bidirectional referral • Continuity of care	• Clarify presentation of pain specific to PHIVA • Use of groups

Abbreviation: PHIVA, perinatally HIV-infected adolescents.

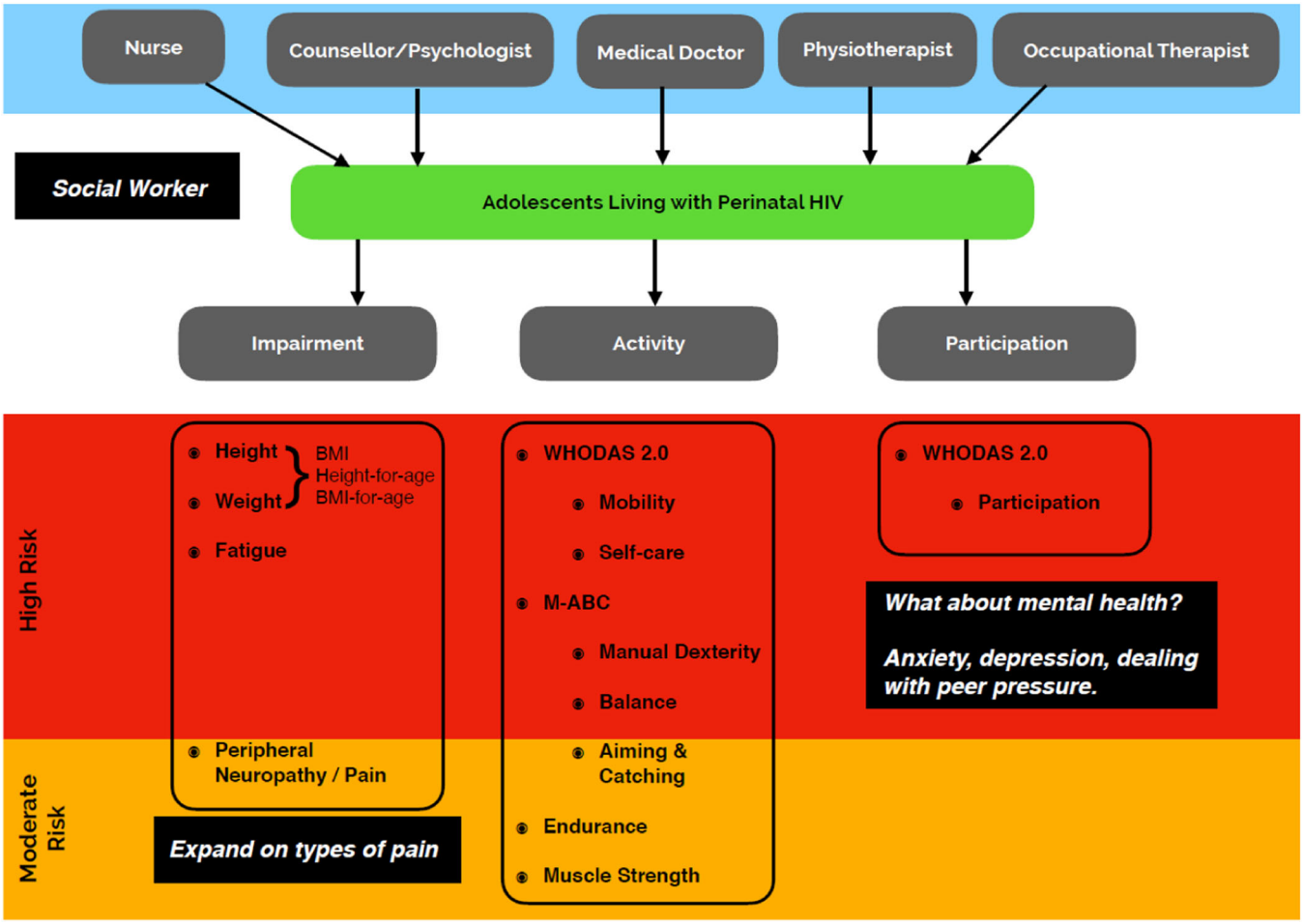

FIGURE 2 Second draft of the interprofessional model of care for PHIVA. PHIVA, perinatally HIV-infected adolescents.

MoC, and additional suggestions were made to include a dietician and social worker to the team. The participants reported social workers working with groups of PHIVA in their clinics, and with regard to the dietician, input was given on the need to refer PHIVA with poor eating habits (interlinked with mental health impairments) and poor nutritional statuses to a dietician. Lastly, cognitive and school performance were highlighted as an important component to consider in the MoC.

> "…it also adds to their [PHIVA] mental health and anxiety when they start failing various grades at school. There is a lot of peer pressure and the adolescents in our clinic do very badly when they have to be kept back a year."— Medical doctor

The last aspect of the focus group was a discussion on suggestions and implementation ideas for the MoC. A frequent code was the need for screening of PHIVA when they come to the clinic. It was noted that many PHIVA with additional impairments or activity limitations are only referred to other interprofessional team members very late in their presentation or when there is an obvious disability. The occupational therapist stated that "the referral is based on when the patient mentions it, and how urgent and affecting it is to them." Suggestions were made for regular screening within the clinics, especially if there are adolescent groups, and that the screening can be done by any of the interprofessional team member if they have had sufficient training.

> "Ideally it would be nice to have the whole multi-disciplinary team but if not, I think just having a good understanding of what the roles are of the whole team so that you can develop really good referral structures"—Physiotherapist

> "In a very busy clinic, quick screening tools which can be done by counsellors or nurses or even self-completed by the patients would help identify children who may be presenting with the need for an increased level of intervention."—Medical doctor

Referral structures and the necessity of referral was also a strong code within implementation. The psychologist discussed the role of referrals between the clinic and community organisations, working in both directions and not just a down-referral to community structures: "… the importance of bidirectional referrals. So that one can access the services that are being offered by community-based organisations within the community. So that between visits the young person has the support that they need." One of the challenges raised with regard to screening and referrals is that often the clinics have a high staff-turnover, resulting in a lack of commitment in addressing additional problems, and this continuity of care was echoed by the physiotherapist who expressed "it really comes down to having a multidisciplinary team that is passionate about it [screening PHIVA], and doing screening days, and really building good referral structures across everyone."

Lastly, the role of support groups was discussed. Most of the clinical settings from the focus group participants used groups for their PHIVA management and the suggestions were given with regard to screening PHIVA and the importance of the peer support that the groups offered. It is important that groups are age-band specific and not all adolescents (aged 10–24 years) are convened together.

> "Our doctor…has put them [PHIVA] into a club setting, and within that club setting they get training as well as social connection and support group with other adolescents, which has worked really well. … It definitely has to have one person spearheading it, otherwise it kind of gets lost."—Occupational therapist

3.2.3 | Finalisation of the MoC

Final additions and changes were made to the MoC, based on the results of the focus group data analysis. The need to expand on the potential types of pain experienced by PHIVA was addressed through examples of pain found in the preceding studies.[29,30,32] Figure 3 presents the final MoC that can be used to guide clinicians in screening, referrals and interaction within the interprofessional team. Finally, a simplified schematic of the MoC was developed and is depicted in Figure 4.

4 | DISCUSSION

This study sought to develop a MoC for PHIVA, the initial draft of which was based on results from preceding studies. The MoC drafts were presented to two focus groups (PHIVA and healthcare professionals) and adjustments were made, resulting in a final interprofessional MoC for PHIVA.

4.1 | Changes to the initial MoC

Based on the focus group input, the following changes were made to the MoC draft: dietician and social worker were added as part of the interprofessional team; mental health and cognitive functioning were additional impairments; and a list of pain examples was given.

Mental health challenges and cognitive health dysfunction are important sequelae of perinatal HIV and have significant effects on adolescents.[16,38] Some of the most common areas of neurocognitive dysfunction in PHIVA are cognitive and achievement scores, visual recognition memory, intelligence and executive dysfunction, with scores significantly lower than in HIV-negative adolescents.[3,39–42] Mental health challenges that PHIVA frequently face are depression, suicidal tendency, anxiety, anger, and attention deficit hyperactivity disorder.[43–45] In drafting the MoC, the initial decision was made not to include mental health and neurocognitive dysfunction because it lay outside the scope of *physical* sequelae for PHIVA. While these two items are not necessarily physical outcomes in themselves, they are still strongly linked to physical sequelae and thus they were included in the final MoC, following the focus group feedback that highlighted their importance.

The relationship of physical outcomes with mental health and neurocognitive dysfunction is multifactorial. Cognitive impairment is strongly correlated with functional impairment, such as interpersonal

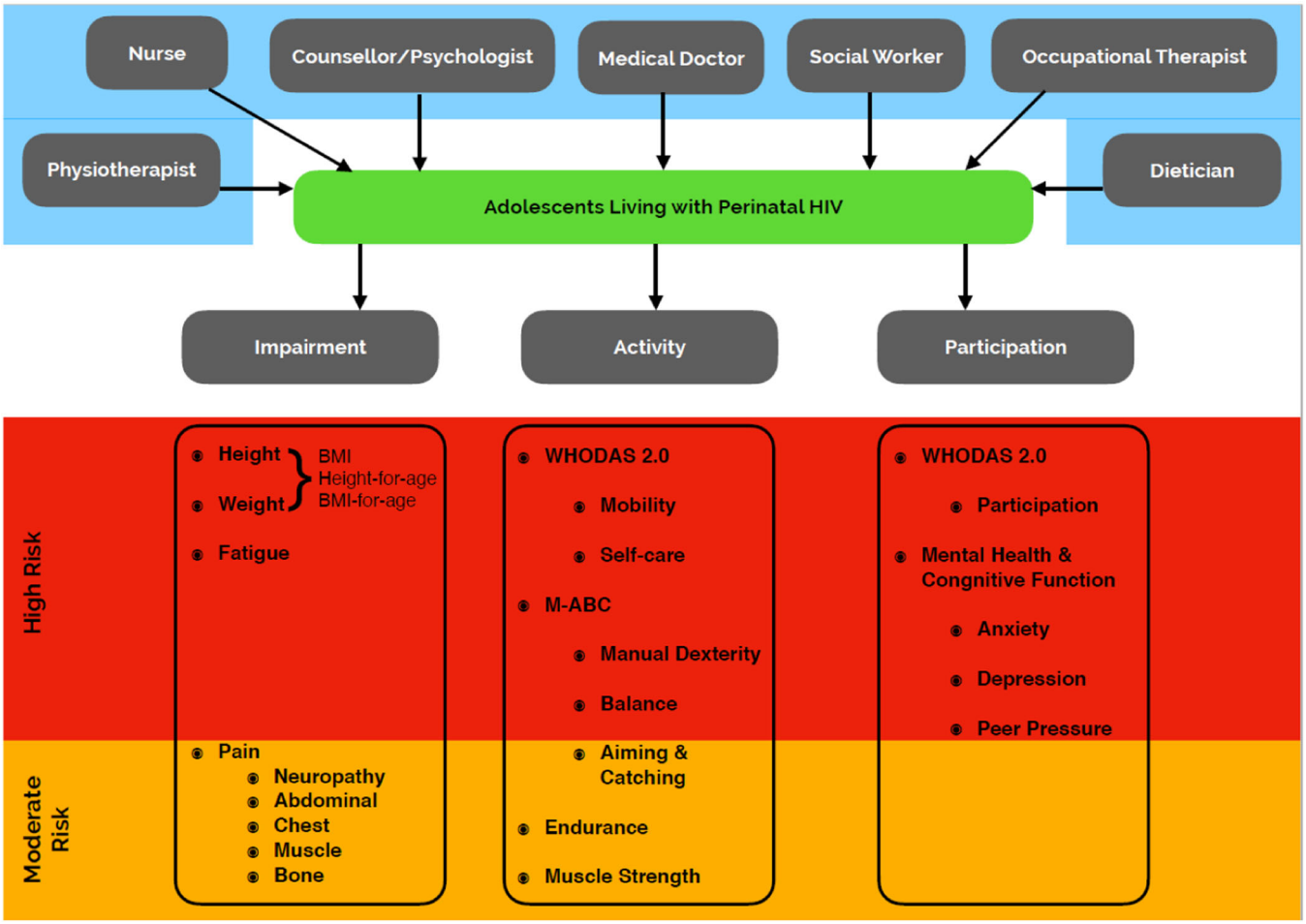

FIGURE 3 Final version of the interprofessional model of care for PHIVA. PHIVA, perinatally HIV-infected adolescents.

relationships,[46] and a study of multisystem impairments in PHIVA found that of those who had neurocognitive impairment, nearly 60% had additional system impairments (e.g., renal and cardiac).[47] Furthermore, mental health challenges impact negatively on quality of life and ART adherence, which in turn impacts on physical well-being.

A recent scoping review of physical sequelae in PHIVA found pain to be a component, specifically chest pain.[32] Qualitatively, PHIVA also have complained of chest pain, as well as abdominal pain,[30] and muscle aches have also been reported in PHIVA.[48] A point prevalence of pain in adults with HIV ranged from 54% to 83%, with multifactorial causes[49] but there is little literature available on the prevalence of other pain in PHIVA. Other studies in children with perinatal HIV have shown reports of generalised pain, abdominal pain, neuropathic pain and bone pain,[50,51] highlighting the necessity for pain screening to be an important component of the MoC.

4.2 | Implementation of a MoC

Suggestions made for the implementation of the MoC focussed predominantly around the importance of screening and referrals within the interprofessional team. The interprofessional team is a key player in the management of PHIVA, and although a paediatrician is adequately trained for adolescent health, an integrated interprofessional team is the ideal situation, and should include social workers, nurses, mental health professionals and counsellors.[5,52] The results of this study show that the interprofessional team can be expanded beyond these disciplines listed in the literature, to include occupational therapists, physiotherapists and dieticians.

A prevalence study of children with HIV at a clinic in South Africa found that of the children presenting with disability, only 46% had been referred to the relevant interprofessional team member.[53] Despite the study being based at a busy urban research and services clinic, many children with disabilities were not accessing the services that they required and this is a cause for concern, especially when one considers children and adolescents receiving HIV care in less structured settings. One of the barriers to care in children with HIV is poor multi-disciplinary team functioning, with recommendations made for ongoing training of healthcare workers.[54]

Additional recommendations for PHIVA care include screening for chronic complications of perinatal HIV, peer-led support

FIGURE 4 Schematic of the interprofessional model of care for PHIVA. PHIVA, perinatally HIV-infected adolescents.

groups, strategies to manage stigma and sufficient screening and management of mental health.[4] These components have been factored into the MoC developed in this study, with the idea that clinics and interprofessional team members working with PHIVA will be able to use the MoC as a guideline tool for sufficient screening and bidirectional referral.

Ensuring that HIV clinics provide services that are adolescent-friendly is crucial,[55] as such services have been demonstrated to facilitate HIV care for South African adolescents.[56] While the jargon of the MoC is appropriate for medical professionals, it is not PHIVA-friendly and thus the schematic (Figure 4) was developed. This diagram can be displayed on clinic walls, incorporated into healthcare materials, and used for public education to raise awareness about the challenges faced by PHIVA.

4.3 | Limitations and recommendations

A limitation of this study was that, due to study logistics, the PHIVA group was comprised of participants from one study site and thus are not fully representative of this population. The authors attempted to mitigate the homogeneity of the participants by ensuring that the IPG covered a wider background. Future recommendations for research would be to investigate the types of pain in PHIVA to create a more specific screening tool.

5 | CONCLUSION AND IMPLICATIONS FOR PRACTICE

This study aimed to establish an interprofessional MoC for PHIVA that is a reflection of the physical challenges that they face in terms of impairments, activity limitations and participation restrictions. Through two focus groups a final tool was developed that highlights the necessity of interprofessional screening and referral, with a focus on the physical sequelae of perinatal HIV, as well as their mental health. The MoC was also presented in a user-friendly schematic which can be utilised in public education and healthcare materials.

With the growing population of PHIVA, who present with unique healthcare challenges, it is imperative that medical facilities are adequately equipped to cater for this population. The physical sequelae of perinatal HIV require regular screening and early intervention, for which all team members are responsible. This MoC is relevant on a global level, however, with the majority of adolescents with HIV living in sub-Saharan Africa, it is imperative that the region gains access to a MoC designed specifically for this vulnerable population. The development of this MoC has provided an opportunity for further research in the implementation and evaluation of it, especially within the South African (and greater sub-Saharan African) context.

AUTHOR CONTRIBUTIONS

Nicolette Comley-White: Conceptualisation; data curation; formal analysis; funding acquisition; investigation; methodology; project administration; writing—original draft. **Veronica Ntsiea**: Conceptualisation; funding acquisition; methodology; supervision; writing—review and editing. **Joanne Potterton**: Conceptualisation; funding acquisition; methodology; supervision; writing—review and editing.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

Approval was obtained from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (M180226). The procedures used in this study adhere to the tenets of the Declaration

of Helsinki. All participants and the caregivers signed informed assent and assent, respectively.

TRANSPARENCY STATEMENT

The lead author Nicolette Comley-White affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

ORCID

Nicolette Comley-White http://orcid.org/0000-0002-6834-4104
Veronica Ntsiea http://orcid.org/0000-0003-4208-5498
Joanne Potterton http://orcid.org/0000-0002-8020-274X

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