

FRAMEWORK FOR A HOLISTIC INTERVENTION IN SUPPORT OF CHILDREN WITH COLOUR VISION DEFICIENCY

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Abstract

In this article, we propose a framework for a holistic intervention in support of children with CVD, consisting of a resilience-enabling intervention for children and a parent guidance intervention for their parents. As background to the intervention we developed, we obtained baseline data on the experiences of children with CVD, specifically in terms of the challenges they face on a daily basis. We followed a mixed methods approach and implemented a collective case study design, being guided by Participatory Reflection and Action (PRA) principles. Qualitative data were generated both pre- and post-intervention through PRA-guided sessions and projective assessment measures with child-participants, semi-structured interviews with their parents, field notes and reflective journals. Quantitative data were collected both pre- and post-intervention using the Beck Youth Inventories 2nd Edition with the child-participants. Data were analysed through reflexive thematic analysis and descriptive statistics. Following the implementation of the intervention, the pre- and post-intervention datasets were compared. Our findings reveal that children with CVD face various challenges that adversely affect them on various levels of functioning yet that the holistic intervention we implemented empowered them to address some of these challenges and voice their needs to others, thereby accessing the support they are entitled to. The framework for a holistic intervention that we propose in this article offers both theoretical and practical implications for improving support initiatives with children with CVD. It can furthermore serve as a model for addressing similar needs of children who experience other special needs.

Keywords: Colour vision deficiency (CVD), intervention, parent guidance, participatory research, resilience

Introduction

Colour vision deficiency (CVD) is a common disorder of vision that affects an individual's ability to perceive and differentiate between certain colours (Kvittle, 2018; Mashige & Van Staden, 2019). CVD can be either congenital or acquired, with congenital CVD being untreatable and consistent throughout life (Valero et al., 2022). The most frequently reported occurrence of congenital CVD is approximately 8% in the male population and 0,5% in females (Kvittle, 2018). Acquired CVD may be the consequence of exposure to certain medications or neurotoxins, disease, or general and ocular pathology (Hashemi et al., 2019).

Abnormalities in colour vision can impact various levels of functioning. In the case of children, CVD can for example significantly impact their academic performance as this often rests on assessments that may include colour as differentiating indicator. In addition, children

with CVD experience higher levels of emotional, social and behavioural difficulties when compared to children with typical colour vision (Mashige & Van Staden, 2019).

As a result of a general lack of awareness and understanding of CVD amongst teachers, children with CVD may be misdiagnosed and misidentified, resulting in them being wrongly labelled as experiencing attention, behavioural or learning difficulties (Male et al., 2024). Such incorrect assumptions can in turn result in feelings of anxiety, depression, worry, shame, embarrassment, social withdrawal and frustration, leading to the development of a negative self-perception and the fear of being ridiculed and rejected by peers (Prieto et al., 2021).

Limited targeted support is currently provided for children with CVD in the school context, despite teachers being expected to practice inclusive teaching with all children with special needs. Against this background, we conducted research on the possibility of supporting children with CVD through a holistic intervention, comprising of a resilience-enabling intervention for children with CVD and a parent guidance intervention for their parents.

The framework for the holistic intervention that we propose rests on an integration of McLeroy et al.'s (1988) ecological model for health promotion, Khenti et al.'s (2016) holistic policy and intervention framework for global mental health, and Theron's (2018) theory on transactional pathways to resilience, specifically, the *connect&dream&do* mechanisms of resilience. The intervention includes both intrapersonal and interpersonal levels of influence to cultivate resilience-enhancing skills and strategies, thereby fostering positive interactions within the nested systems of children with CVD. The ultimate aim is to empower children with CVD to thrive and perform according to their potential.

Statement of the problem

Currently, the existing body of knowledge on CVD, its impact on the functioning of children and how to support them is scarce, both globally and in South Africa. Despite the fact that 1 in 12 boys and 1 in 200 girls suffer from this condition (Kvitile, 2018) and all teachers as a result probably being required to teach such a child during the course of their careers, little resources are available to guide teachers in fulfilling this task. Parents as well as children with CVD themselves are often similarly uncertain how to address the challenges they face and access the support they are entitled to (Male et al., 2024; Mashige & Van Staden, 2019).

In undertaking our research, we upheld the assumption that an understanding of the perceived implications of CVD on children's functioning could inform the development of tailored educational and support interventions to address their specific needs (Ishijima, 2022). Given the limited available research in this field, the framework that we propose for a holistic intervention does not only add to the emerging body of knowledge on CVD but can provide parents, teachers and other practitioners with a valuable tool to support these children in practice. In addition, the theory and practice on the implementation of inclusive education policy in the case of children with CVD can be strengthened.

Purpose of the study

The purpose of our research was threefold. Firstly, we explored children's experiences of living with CVD and the challenges they face, in order to understand the extent to which their functioning on various levels are impacted. Secondly, we relied on this data to conceptualise, develop and implement a holistic intervention with children with CVD and their parents, in support of the children coping with the challenges they faced. Thirdly, we explored the outcome and potential value of the holistic intervention. In undertaking the research, we upheld the

assumption that a holistic intervention involving children with CVD as well as their parents can support and enhance the academic, emotional and social functioning of these children.

Research questions

The following research questions were posed for the research:

- How does CVD affect the holistic functioning of children with CVD?
- Which challenges do children with CVD typically experience as a result of the deficiency?
- What does a holistic intervention for children with CVD entail?

Methods and materials

We conducted a concurrent mixed methods study employing a collective case study design (Creswell & Creswell, 2023), being guided by Participatory Reflection and Action (PRA) principles (Chambers, 2015). We relied on both convenience and purposeful sampling (Babbie, 2021) to select four children with CVD, ages ranging from 11 to 16 years who would be available to participate in the research project for the duration of a year. In addition to the child-participants, six parents were purposefully selected as a second group of participants.

Our research entailed four phases and involved three postgraduate studies, under the supervision of one supervisor, all forming part of a broader research project. During the pre-intervention phase (Phase 1), data were generated/collected on the lived experiences of the child-participants, focusing on the challenges they faced and the impact of CVD on their various levels of functioning. Qualitative data were generated during PRA-guided sessions with the child-participants through the use of various qualitative activities, including PRA-matrices, the Rotter Incomplete Sentences Blank, Draw a Person and Kinetic Family Drawing techniques, field notes and reflective journals. For quantitative data on the emotional and social functioning of the child-participants, the Beck Youth Inventories 2nd Edition (BYI-II) was administered. In a parallel process, semi-structured interviews were conducted with the child-participants' parents to explore their perceptions of the challenges their children with CVD were facing, as well as their suggestions on suitable content to be included in a holistic intervention.

During Phase 2, the intervention phase, a holistic intervention was conceptualised, developed and implemented. The intervention consisted of a resilience-enabling intervention for the child-participants and a parent guidance intervention for their parents. The resilience-enabling intervention was implemented over 11 months through PRA-guided sessions with the child-participants, facilitated individually and primarily *via* online platforms due to COVID-19 and the associated social contact restrictions at the time of our field work. The parent guidance intervention was implemented over a 14-week period *via* a WhatsApp group.

For the post-intervention phase (Phase 3), we focused on determining the value of the intervention, by exploring the functioning of the child-participants at the time as well as the participants' perceptions on the intervention. Data were generated/collected in the same way than pre-intervention, implementing the same measures and instruments. During Phase 4, we compared the pre- and post-intervention datasets, in order to establish the value of the intervention in accordance with the overarching goal of our research.

We analysed the qualitative data by following the steps of reflexive thematic analysis as suggested by Braun and Clarke (2022). For quantitative data analysis we relied on descriptive

statistics to organise and compare the numerical data obtained on the BYI-II by representing the data graphically and numerically (Leavy, 2023).

Throughout, we followed the necessary principles of ethical research. We obtained permission to conduct the research from the higher education where the project resides (ethical clearance number EDU194/20) as well as informed assent and consent from the participants. In addition, we respected the ethical principles of voluntary participation, protection from harm, anonymity, confidentiality, trust, and respect for privacy (Babbie, 2021). We also strived to meet the necessary criteria of validity and trustworthiness.

Results of the study

We primarily report on the results obtained during the pre-intervention phase of our research, as we relied on this dataset to conceptualise the holistic intervention proposed in this article.

Limited understanding and even an unawareness of CVD by various role-players

All four of the child-participants indicated either a lack of or a limited understanding of their visual condition, resulting in them finding it hard to share knowledge of their condition with others or indicate their needs for support. In this regard, one of the participants said that, *Some of them [friends] ask how does it work, but I can't really tell them ... because I don't really know. So, I just tell them I can't see certain colours.* Contributions such as these emphasise the importance of children with CVD being informed about their condition, in order for them to be able to inform others and access the support they require. The parent-participants similarly demonstrated an insufficient understanding of CVD and its effect on their children's functioning, saying that, *We parents lack understanding of exactly what it is and how it occurs.* Parents reportedly only realised the extent of CVD after a diagnosis by a professional.

Both the parent- and child-participants furthermore indicated concern that teachers as well as peers typically also lack the necessary awareness and understanding of CVD, with this effecting the academic performance of children with CVD within the school context. One of the parents mentioned an example of a teacher not realising that her son's atypical colour use was caused by CVD, saying that, *I don't really think they [teachers] know a lot about colour blindness.* In some cases, teachers would reportedly misinterpret the difficulties experienced by these children as indicating a lack of knowledge or even a below average intelligence, or in some cases as attention deficit disorder or behavioural problems. Based on these experiences, both the child- and parent-participants emphasised the need of greater awareness and education about CVD among individuals with CVD themselves and their parents but also among teachers, in order to prevent misunderstandings and ensure appropriate accommodations of these children in school. A parent for example noted that, *Teachers need to be educated ... because then they think the child doesn't know colours and he is just being naughty*".

Negative effect of CVD on the daily living of children

All four of the child-participants indicated that they experienced difficulty during daily living activities due to them finding it hard to differentiate colours, for example when selecting clothes. When incorrectly identifying colours in clothes or other objects such as stationery, they experienced frustration and emotional distress. In addition, these children experienced challenges to distinguish road signs and traffic light colours, implying future challenges for them when they would be old enough to drive. In this regard, a participant stated the following: *I'm a bit worried about like different colours of signs and things that I might not be able to see.*

Further challenges that were often experienced by these children relate to distinguishing objects in daily routines, such as identifying currency or personal items such as toothbrushes and bath sponges. The parent-participants explained how this challenge would often lead to confusion and even result in conflict amongst family members. The inability to function like others and see things as others with typical colour vision do, seemingly also had a negative effect on the children with CVD's experience of life, evoking negative emotional experiences. In the words of one of the child-participants, *I can't really see things that other people see. So, they see something and then I can't see it. Sometimes you feel like left out ... It just feels like, I wish I could see what they see.*

Negative effect of CVD on the academic functioning of children

The child-participants experienced several challenges within the academic environment as a result of not being able to differentiate colours. In this regard, a child-participant stated that, *For school I don't think it is nearly as easy as a normal kid's life because it doesn't make it really easy. My life and someone else's problems at school is very different, because my friends tease me sometimes about it. And the teachers get angry with me because I can't see colours when they don't know I can't see colours.* Several other child- as well as parent-participants confirmed the challenge of being teased by peers and experiencing frustration from teachers who are unaware of the condition, potentially resulting in emotional distress.

According to the participants, children with CVD are at a disadvantage with regard to the possibility of performing well academically. A child-participant for example explained that he, *In elementary school we always had to say what colours of the rainbow that we had to colour it in, but I never got full marks for my rainbow, so it's annoying.* During later grades, these children would potentially experience difficulty in a variety of subjects, including Mathematics (graphs), Geography (map work), Arts and Science (chemistry practical). In addition, the child-participants indicated the negative of CVD on their participation in sports, explaining that they would typically struggle to locate a red cricket ball on green grass or distinguish between team uniforms when colour is used as indicator. These challenges hindered the ability of these children to fully enjoy sports activities, often resulting in them steering away from participation in extracurricular activities at school such as team sports.

Negative effect of CVD on the psycho-social functioning of children

The qualitative data of our study indicate that the child-participants experienced several psycho-social challenges as a result of their CVD, such as difficulty with their self-concept and self-confidence as well as feelings of isolation. For example, a child-participant expressed conflicting emotions about his self-identity, stating, *... sometimes I think I'm unique with it and sometimes when I struggle because of it I think it's a disability.* Another child-participant emphasised his emotional frustration by remarking that, *... emotionally just get annoyed.*

Teasing and bullying by especially peers emerged as specific sources of emotional distress. The child-participants for example referred to being repeatedly asked questions about colours, which left them feeling irritated and frustrated. For instance, one of the child-participants stated that, *... it makes me feel angry about it ... sometimes it's irritating because my friends ask me the whole-time what colour it is,* while another admitted feeling upset when others tease him about not seeing colours. This frustration extended to career concerns as well, with the participants expressing frustration over the career limitations imposed by CVD.

Feelings of sadness, rejection, and insecurity were prevalent among the child-participants. A child-participant explained this by saying that, *Sometimes it's just like I kind of get annoyed*

and I can't see this and like I wish I could see this. Another child-participant shared a fear of rejection, worrying that people might not accept him because of his condition. The participants also felt insecure when others doubted the legitimacy of their CVD, with these challenges being exacerbated by the lack of recognition and support from peers and teachers, leaving participants to feel invalidated and challenged to ask for help when needed.

The quantitative results obtained pre-intervention on the BYI-II confirm these experiences, with regard to the child-participants' emotional and social functioning. Figure 1 provides the pre-intervention BYI-II quantitative results for all four participants.

Figure 1

Pre-intervention BYI-II scores for the four child-participants

| BYI-II INDEX SCORES PRE-INTERVENTION | | | | | |
|--------------------------------------|----------------------------------|--------------------------|----------------------------------|----------------------------------|----------------------------------|
| Participant | Self-Concept Index | Anxiety Index | Depression Index | Anger Index | Disruptive Behaviour Index |
| 1 | 61.6% Average | 67.7% Average | 18.2% Much lower than average | 21.2% Much lower than average | 23.7% Much lower than average |
| 2 | 35% Much lower than average | 80% Mildly elevated | 85% Mildly elevated | 39% Lower than average | 21% Much lower than average |
| 3 | 13.1% Much lower than average | 75.4% Mildly elevated | 83.9% Mildly elevated | 97% Extremely elevated | 89.9% Mildly elevated |
| 4 | 77.3% Mildly elevated | 82.3% Mildly elevated | 68.7% Average | 46.5% Average | 4.5% Much lower than average |

Overall, these results indicate varying levels of emotional and behavioural challenges experienced by the child-participants, with certain concerns in areas of a poor self-concept and high levels of anxiety, depression and anger.

Emotional and social functioning post-intervention

Both the qualitative and quantitative data obtained post-intervention indicate increased levels of self-confidence, self-perception and self-worth amongst all four the child-participants. The BYI-II results reflect a 33.3% increase on the self-concept scale for child-participant 1, a 25% increase for child-participant, a 21.2% increase for child-participant 3 and a 19.7% increase for child-participant 4. These improvements are corroborated by the qualitative results that highlight all four of the child-participants' enhanced self-esteem, self-confidence and self-image following their participation in the resilience-enabling intervention.

As the participants developed a better understanding of their condition and became aware of their strengths and available resources, they also reported feelings of emotional upliftment, hopefulness and optimism. This positive change is reflected in the post-intervention BYI-II scores, with the anxiety scale decreasing by 15.7% for child-participant 1, decreasing by 3.7% in addition to a significant 15.2% decrease on the depression scale for child-participant 2, and

child-participant 4's depression score decreasing by 13.1%. These reductions in scores on the anxiety and depression scales align with the qualitative results that suggest a decrease in feelings of emotional distress, as well as the child-participants' enhanced ability to manage their emotions effectively. Although some of the participants showed a slight increase in their anger and disruptive behaviour scores, these remained within Average or Much lower than the average range, reflecting overall stability in behaviour.

Discussion

In our study, we found that children with CVD face a variety of challenges across multiple levels of functioning. At the physical level, they struggle with everyday tasks that require accurate colour discrimination, which impacts their independence in daily activities. On an emotional and social level, they may experience anxiety, frustration, feelings of being different, isolation, as well as difficulties in maintaining a positive self-concept and peer relationships. At the academic level, CVD impacts tasks involving colour-based learning, which can hinder academic performance and classroom participation. These findings of our research align with existing literature (Kvitte, 2018; Mashige & Van Staden, 2019), which highlights the multifaceted challenges faced by these children across the various domains of functioning.

Based on the pre-intervention results we obtained, we conceptualised and developed a holistic intervention to address the challenges faced by the child-participants across the various levels of functioning. In recognising that children operate within a broader system (McLeroy et al., 1988), we incorporated both a resilience-enabling intervention for the child-participants and a parent guidance intervention for their parents.

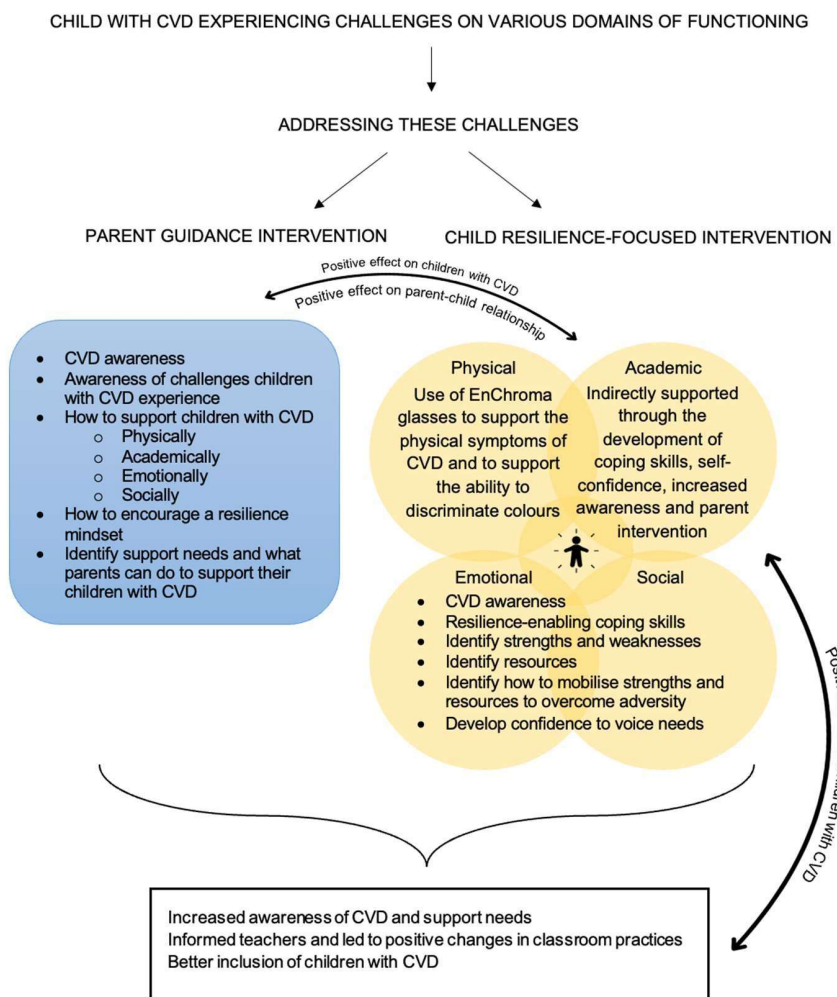
In support of the child-participants' functioning on the physical level, they were provided with EnChroma glasses as part of the resilience-enabling intervention, with the aim of assisting them to overcome some of the challenges they experienced with colour discrimination. On the emotional and social levels, the intervention sessions focused on the fostering of resilience-enabling skills, in support of the child-participants' self-concept, self-confidence and the skill of managing their feelings of isolation and frustration associated with CVD. To address their limited understanding of CVD, we included an educational component that informed the children about their condition, empowering them to seek support from others by voicing their needs, which led to positive changes in their social and academic environments. By addressing these areas, we aimed to empower the child-participants to advocate for adjustments and accommodations in support of their learning and performance.

Parallel to the focus on empowering children with CVD, their parents were empowered through the parent guidance intervention, which provided them with knowledge of CVD and on how to support their children emotionally and socially. Equipped with this understanding, parents were able to share insights with teachers, which improved communication and support in the academic setting.

In summary, the integrated results of the qualitative and quantitative components illustrate the effectiveness of the resilience-enabling intervention for the child-participants in fostering a healthy self-concept, reducing emotional distress and enhancing emotional regulation abilities, with these leading to an overall positive effect on their psycho-social functioning. They accordingly showed improved levels of self-confidence, self-worth, emotional stability, self-image and emotional resilience as well as reduced levels of anxiety and depression following their participation in the intervention. These results confirm the potential value of the holistic intervention when wanting to support children with CVD to navigate the challenges they face with greater self-assurance. Based on the findings of our research, we propose framework for

such support provision to children with CVD, or for that matter, with any learning disability. The framework we propose is captured in Figure 1.

Figure 1: Framework for a holistic intervention for children with CVD



Conclusions

The findings of our study reveal that children with CVD face challenges that impact various domains of their functioning. If these challenges are not adequately addressed, they can hinder and adversely influence the children's ability to thrive. A general limited understanding of CVD among people suffering from the condition as well as those interacting with them within their nested systems contribute to the challenges faced by these individuals.

By proposing a framework for a holistic intervention that can be implemented to provide comprehensive support to children with CVD, by addressing the multi-level challenges they face, we aim to address the need for ways of offering targeted support to children with CVD. By implementing this research-based framework, parents, teachers and other practitioners in the

helping professions may facilitate positive change in the lives of children with CVD, enabling them to function according to their potential. While the framework was specifically conceptualised for children with CVD, its principles are also applicable to children with other special needs. In following a proactive approach with such children, an environment can be created where they can manage their unique challenges and thrive academically, emotionally and socially.

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