

Original Research Article

Rising Above Stigma: Exploring the Coping Strategies of Adolescents with Albinism in Tanzania Through a Group Coping Intervention

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ABSTRACT

Aim: Adolescents with albinism in Tanzania regularly experience stigmatisation, yet little is known about their coping strategies or related interventions. This qualitative brief report aims to explore the stigma-coping strategies employed by adolescents with albinism, and to gain insight into the influence of peer support on those strategies through a group coping intervention.

Methods: Data were collected from ten Tanzanian adolescent girls with albinism who participated in four sessions of a group coping intervention, followed by individual interviews. One universal and one stigma-specific coping framework were used in the analysis.

Results: Data suggest that adolescents with albinism employed, prior to the intervention, mostly strategies related to disconfirming stereotypes, such as becoming educated. Through participation in the intervention, the participants mostly learned about coping strategies linked to primary and secondary control engagement, such as building self-acceptance and help-seeking, indicating some form of empowerment. All but one participant expressed a desire to continue meeting with the peers in their intervention group to discuss stigma and coping.

Conclusion and Implications: Adolescents with albinism in Tanzania possess a diverse range of strategies to cope with stigma. Group coping interventions can be beneficial for the development of complementary and potentially healthier stigma-coping strategies. Peer support could be a positive factor. More research into the careful implementation and interpretation of a group coping intervention for stigmatised youth is warranted.

Keywords: group coping intervention, stigma-reduction intervention, qualitative, peer support, albinism, stigma, coping

Guest Editor: Heather Aldersey

Article History:

Received: December 08, 2024 Accepted: October 10, 2025 Published: December 20, 2025

Citation: Charlotte Moore, Tjitske de Groot, Kim Hartog. RisingAbove Stigma: Exploring the Coping Strategies of Adolescents with Albinism in Tanzania Through a Group Coping Intervention. DCIDJ. 2025, 36:Special Issue. doi.org/10.20372/dcidj.833

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INTRODUCTION

Oculocutaneous albinism is a genetic mutation causing hypopigmentation of the skin, eyes, and hair (Lund, 2005). In Tanzania, the prevalence of albinism is relatively high (UNICEF Tanzania, 2021). Around one in every 2,000 children is recorded born with albinism, which is about six times higher than the average of one in 13,000 in European

countries (Kromberg et al., 2023). In reality, the prevalence of people with albinism in Tanzania is estimated to be higher, as families can be hesitant to report the birth of a child with albinism due to fear of discrimination from community members (Lund & Roberts, 2018).

Prevailing myths about albinism cause an unsafe situation for people with the condition (de Groot, 2020). For instance, the birth of a child with albinism is seen as a curse (de Groot et al., 2023), body parts of a person with albinism are thought to bring good fortune when sold to a witchdoctor (Brocco, 2016), and having sexual intercourse with a person with albinism is believed to cure HIV (Nkrumah, 2020). As a result of these and other beliefs (Reimer-Kirkham et al., 2019), many people with albinism live in fear of abduction, rape, decapitation of body parts, and murder (Nkrumah, 2020). Up to 2024, there have been 208 reported attacks on people with albinism in Tanzania, of which 78 have been fatal (Under The Same Sun, 2024).

Stigma

Stigma refers to the stereotypes, prejudices, and discrimination expressed towards people who have a socially undesirable characteristic, causing a devalued perception of that person (Goffman, 1963). In Tanzania people with albinism experience stigmatisation on a day-to-day basis (Possi & Milinga, 2018; Nkrumah, 2020). A distinction can, among others, be made between public stigma, self-stigma and structural stigma (Corrigan et al., 2005; Herek, 2007). Public stigma refers to the expression of negative prejudices, stereotypes and actions against a population, while self-stigma is the internalisation of such views (Corrigan et al., 2005; Link & Phelan, 2001). Structural stigma acts at the societal level, where institutional practices work to the disadvantage of the stigmatised group (Link & Phelan, 2001). Stigma creates a threat to identity (Major & O'Brien, 2005), and adolescents may be more vulnerable to stigma's negative effects, since they are in a critical period for identity formation (Albarello et al., 2017). Experiencing stigmatisation can, among others, impact psychosocial wellbeing negatively and be a risk factor for suicidal ideation (Tambala-Kaliati et al., 2021).

Coping

According to Major and O'Brien (2005), coping with stigma and stress can reduce the impact on self-esteem, academic achievements and health. Coping, as defined by Compas et al. (2001, p. 89) is the "conscious, volitional efforts to regulate emotion, cognition, behaviour, physiology, and the environment in response to stressful events or circumstances". The Responses to Stress model (Connor-Smith et al., 2000) proposes that coping strategies can be distinguished into three universal categories: primary control engagement coping, secondary control engagement coping, and disengagement coping (Table 1). Primary and secondary control engagement coping are generally associated with positive psychological outcomes, whereas disengagement coping is generally associated with negative psychological outcomes (Connor-Smith et al., 2000). For coping with stigma especially, Moses (2015) identified two additional categories: confrontational and aggressive coping, and disconfirming stereotypes (Table 1). While both of these strategies can generate positive outcomes when used to some extent, excessive use may lead to backlash and increased stigmatisation (Moses, 2015).

Table 1: Categorisation of Coping Strategies

	Primary Control Engagement Coping	Secondary Control Engagement Coping	Disengagement Coping
Universal coping strategies (Connor-Smith et al., 2000)	Controlling or changing a stressful situation by altering objective condi- tions, such as the stressor itself or one's emotional response to the stressor.	Adapting to a stressor by means of cognitive restructuring.	Avoiding or denying a stressor and its effects.
	Confrontational and	Disconfirming	
Stigma-specific	Aggressive Coping	Stereotypes	
coping strate-	Reacting verbally or	Behaving contrary to	
gies (Moses,	physically to people	the stereotype of one's	
2015)	enacting stigmatisation.	stigma.	

Interventions to address self-stigma

Reviews looking into stigma reduction interventions beyond a specific stigmatised label, such as having a mental health condition or being a refugee, have shown that adults are targeted more than children, and that only a minority of interventions address self-stigmatisation and coping (Majeed et al., 2024; Hartog et al., 2020). Self-stigma reduction interventions include (individual and group) counselling and peer support groups, among others (Hartog et al., 2020). In a trusting environment of people who have all experienced stigma, a peer support group is defined by mutual support and information exchange among participants, sharing life experiences, exchanging problem-solving advice, and taking collective action (Hartog et al., 2020). Multiple studies have shown the positive influence of peer support interventions on the quality of life of stigmatised populations, such as the reduction of social isolation and feelings of shame, an increase in feelings of empowerment, a greater sense of own wellbeing, and the creation of social ties which increases social and emotional support (Bunning et al., 2020; He et al., 2024; Paudel & Baral, 2015). Furthermore, peer support groups have demonstrated their capacity to aid the development of positive self-concepts and identity, and increase action for change and social integration (Bunning et al., 2020; Dale et al., 2016; Heijnders & Van der Meij, 2007).

Peer support groups may also benefit participants' coping abilities through the sharing of coping strategies, though in most studies this is a secondary focus (e.g. Bunning et al., 2020; He et al., 2024; Paudel & Baral, 2015). Few studies explore peer support groups primarily focusing on the development and strengthening of coping strategies (i.e., group coping intervention). Fuster-Ruize de Apodaca et al. (2016) demonstrated the benefits of a group coping intervention for people living with HIV. The intervention reduced perceived stigma, increased participants' self-efficacy to cope with stigma, increased their usage of coping strategies, and improved their self-esteem and quality of life. Gaebel et al. (2019) and Luoma et al. (2023) found varying results, yet both studies highlighted the importance of further research on group coping interventions for stigmatised populations.

The Current Research

The potential benefits that group coping interventions offer for stigmatised populations may also extend to adolescents with albinism in Tanzania. However, to our knowledge, no studies have yet addressed this. Therefore, this exploratory research aimed to gain preliminary insights into which coping strategies adolescents are using, and in what way a group coping intervention influences the development of such strategies.

METHODS

Participants

To explore the stigma-coping strategies and the related workings of a group coping intervention for adolescents with albinism in Tanzania, the current brief report describes participants' engagement in a group coping intervention, followed by conducting individual interviews. In total, 10 adolescents between 14 and 17 years old with albinism were purposefully approached and they all participated in the current research. All participants were recruited from an all-girls secondary boarding school in Tanzania's Lake Region, as the prevalence of albinism is relatively high in that region (Nkrumah, 2020). To increase the intervention's sustainability, it was desirable to conduct the research at a location where adolescents with albinism met naturally. The boarding school, a common way of schooling in Tanzania, in question was purposefully selected, since the relatively large number of adolescents with albinism living at that school could easily continue seeking each other's support after the intervention ended.

Group coping intervention

The group coping intervention was inspired by recent work (Hartog et al., 2023). Table 2 illustrates the flow of the research alongside the implementation of the intervention: four group intervention sessions, followed by individual interviews. By the completion of the intervention, four goals were intended to be reached: (a) recognition of existing coping strategies; (b) the participants' development of their own stigma-coping strategies, (c) the participants' empowerment and the reduction of experienced (self) stigma, (d) the enablement of social support and learning between participants.

After the first collective session, participants were divided into two groups. Groups were based on participants' ages, in case this would influence their understanding of stigma, and to create a non-hierarchical environment. All intervention sessions were held in Swahili, facilitated and guided by the researcher with the assistance of an English translator. The intervention sessions lasted one hour and 10 minutes, one hour and 20 minutes, one hour, and 35 minutes, respectively. There were six, three, and four days between the intervention sessions, respectively.

Table 2: Flow of the research alongside the implementation of the intervention

Group Coping Intervention

Data collection

Session 1: Identity reflection. Participants shared identities. Other participants reacted in one of two ways expressively: agreement (if identity applied to them too) or appreciation (if identity did not apply to them). Followed by a group reflection on identity.

Duration: 1h10min

Pax: 9

Session 2: Board game. Participants developed a narrative of a main character with albinism, who encounters stigma. They identified ways for the main character to cope with stigma, inspired by included coping strategies in the intervention material. Followed by participants writing a personal development goal, and with which coping strategies they intend to reach this resolution.

Duration: 1h20 min.

Pax: 5 + 5

iv. Session 3: Reflection. Participants wrote their personal goals (session 2) on a personal worksheet. They wrote which strategies they had tried and were

- i. Unstructured observations
- ii. Recorded and transcribed conversations
- iii. Intervention material

planning on trying, and how. Tracing symbols on the worksheet (i.e. a star) helped the participants to track how far they had come with their personal goal.

- v. Duration: 1hvi. Pax: 5 + 4
- vii. Session 4: Maladaptive strategies. Participants worked on an additional worksheet. Each participant studied and presented one maladaptive coping strategy on the sheet. Participants evaluated whether it was a good or a bad strategy by marking a 1-10 scale. Followed by reflection.
- viii. Duration: 35 min.
- ix. Pax: 5 + 5
- x. Interviews: Individual interviews were conducted with each participant
- xi. Duration: 20 min.

xii. Recorded and transcribed interviews (20-30min) with the participants

Data collection methods

A qualitative approach was chosen for the current research, to explore whether and how discussions between participants would influence their opinions or usage of particular coping strategies. Data were collected through i) observations from each intervention session; ii) structured notes of visual observations; iii) intervention materials such as worksheets; and iv) 20 to 30 minute individual semi-structured interviews. In the interviews, participants were asked how they experienced the intervention, and whether it had influenced their usage of coping strategies. In an attempt to ensure validity, questions were based on the Responses to Stress Questionnaire (Connor-Smith et al., 2000), as well as on existing literature on stigma-coping strategies in other African contexts (Folayan et al., 2016; Moses, 2015; Mutumba et al., 2015). All data were recorded and transcribed.

Procedure

Ethical clearance was provided by Utrecht University. All participants provided informed consent, with additional mandatory parental consent for participants under 16 years. Parental consent was provided orally via phone call, since all participants lived at the boarding school. The matron of the school signed the consent form on the parents' behalf.

Data analysis

Data were coded using NVivo software and analysed using both deductive and inductive analysis. Deductive codes consisted of all intervention-provided coping strategies. Additionally, inductive codes were developed, related to additional coping strategies participants mentioned. Both deductive and inductive codes were grouped together thematically, according to the categorisation in Table 1. In each category, the reasoning for participants to use or not use a strategy was coded and compared to the reasoning mentioned for strategies in other categories. Furthermore, a comparison was made between strategies participants said to be performing before the intervention and those after. Lastly, the observations served to evaluate the intervention's execution.

FINDINGS

Coping Strategies

Table 3 displays all coping strategies participants mentioned. These are further elaborated on below, categorised as per Table 1.

Primary control engagement coping

When asked how participants cope by controlling or changing a stigmatising situation, the majority responded that they make efforts to reduce the stigmatising behaviours of others. For instance, six participants explained they stand up for themselves by educating others on the biological aspects of albinism, hoping to demonstrate the irrelevance of the differences between people with and without albinism:

I will sometimes need to explain to them and educate them about my situation. Because sometimes they might call me zeru zeru, which is not a good name to be called as a person with albinism. So, I will just go and tell them "You are not supposed to call me zeru zeru because I am just a normal person, and my skin and my situation made me like this".

Participants also mentioned more self-focused coping strategies. For instance, six participants explained that when they experience stigmatisation, conducting stress-release activities helped them to divert their anger and regain their calm. As one participant recounted: "Sometimes you might bump into a group of people that say bad words to you. And then you get so mad, and then you think 'Okay now let me just go do some exercise or just go and sing', so I release my stress".

Table 3: Number of Participants Mentioning a Particular Coping Strategy

Coping strategy	Rejection	Appreciation	Usage	Total appreciation/ usage	
Primary control engagement coping					
Educating others*	1	5	5	6	
Conducting stress-release activities*	-	6	3	6	
Asking for help	-	4	-	4	
Seeking social-emotional support*	-	2	3	3	
Seeking religious support*	-	3	2	3	
Reporting to a teacher	-	2	1	3	
Seeking psychological assistance*	-	1	-	1	
Being kind	4	-	-	-	
Secondary control engagement coping					
Building self-acceptance*	-	6	5	9	
Learning from others*	-	3	3	4	
Accepting the situation*	-	-	3	3	
Feeling useful*	-	2	2	2	
Using humour*	-	-	1	1	
Disengagement coping					
Avoiding situations*	-	10	5	10	
Ignoring* ⁿ	3	5	3	5	
Finding distraction*	4	-	1	1	
Confrontational and aggressive coping					
Standing up for oneself*	-	2	4	4	
Using verbal∮ physical aggression*	7	3	1	4	
Disconfirming stereotypes					
Becoming educated*	-	7	6	7	
Managing the condition*	-	5	3	5	
Joining a group*	1	4	4	5	
Disconfirmirtg stereotypes*	9	1	-	1	

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strategies participants criticised. Appreciation refers to strategies participants praised and/or intended to try in the future. Usage refers to strategies participants mentioned they had carried out.

Due to overlap between participants that appreciated and used particular strategies, *total appreciation/usage* is not necessarily the sum of those two categories.

Note 2: The strategies with a *-symbol are strategies featured in the intervention. Strategies without a *-symbol were brought up by participants without them being a structured part of the intervention.

Secondary control engagement coping

During the intervention, participants also discussed ways to cognitively adapt to stigmatisation, for example in the form of building self-acceptance. Participants used terms such as "feeling useful", "feeling important", "believing in myself", "knowing I am valuable" and "knowing I can do many things". During the interviews, five out of nine participants who said they intended to work on this strategy, mentioned they had in fact felt more self-acceptance over the past few days. As one participant expressed: "I started to feel important and to accept myself".

Disengagement coping

All participants were positive towards avoiding situations that might lead to stigmatisation. As one participant explained: "I will need to avoid any situation and people that will lead me to feel stigmatised". Contrary to this unanimity, there was more disagreement in participants' opinions on ignoring acute expressions of stigmatisation. Three participants rejected the coping strategy of ignoring, yet five participants appreciated it.

Confrontational and aggressive coping

When discussing confrontational responses to stigmatisation, four participants mentioned they would stand up or have stood up for themselves when people stigmatise them, for example by telling them off: "I will always tell them not to repeat [the bad words] again". There was some disagreement in the group whether using verbal and physical aggression when doing so was a good strategy or not. Seven participants rejected using verbal or physical aggression, whereas four participants appreciated the strategy, and two more were even dismissive towards being kind in general. Two participants contradicted themselves by appreciating verbal/ physical aggression during the intervention, yet rejecting it during the interviews.

Disconfirming stereotypes

Throughout the research, it became apparent that the vast majority of participants coped with stigmatisation through compensating for stereotypes related to their situation. For instance, seven participants spoke about becoming educated as a coping strategy. They reasoned that becoming educated is a way of securing community members' respect instead of their disdain. As one participant explained: "having the identity [albinism], ... we need to study very hard so we can be respected".

Moreover, five participants spoke about how joining in structured groups can help them to blend in with peers without albinism. They hoped to show that they are just as 'normal' as anybody else, as the following quote illustrates:

I think it [to join a group] is a good strategy because it will get me to involve myself with normal persons. So, it is going to get easier for me to interact with others, because they are now getting used to me and seeing that I am normal.

Participants stressed the need for the normalisation of people with albinism in the community on multiple occasions throughout the research. On the one hand, participants expressed their desire for others to treat them as equals, and on the other hand to feel 'normal' themselves. However, while not wearing their sunhat would strengthen 'blending in' with peers, all but one participant indicated they would not leave off their sunhat.

Participants' Experiences with the Group Coping Intervention

During the interviews, participants were asked which strategies they were already performing before the intervention, and which they had learnt as a result of the intervention. An overview can be found in Table 4. Overall, while previously-known coping mechanisms included more disconfirming stereotypes, the group intervention triggered participant learning about primary and secondary control engagement, including self-acceptance. The following quote illustrates this process: "When I read my (personal development) goals, I saw myself as an ordinary person, like the others".

Table 4: Coping Strategies Participants Learnt About Through Intervention Versus Used Before Intervention

Learnt About Through Intervention	Used Before Intervention		
Building self-acceptance (5)*s	Becoming educated (4)* DS		
Asking for help (3) P	Joining a group (3)* DS		
Accepting the situation (2) ^s	Managing the condition (3) DS		
Conducting stress release activities (2) $^{\rm P}$	Learning from others (2) ⁵		
Becoming educated (1)* DS	Building self-acceptance (1)*5		
Joining a group (1)* DS	Avoiding situations (1) DC		
Educating others (1)* P	Educating others (1)* P		
Ignoring (1) DC	Seeking social-emotional support (1) P		
	Seeking religious support (1) P		

Note: The strategies with a * symbol are present in both columns. P=Primary control engagement; S=Secondary control engagement; DC=Disengagement; DS=Disconfirming stereotypes

Reflecting about coping mechanisms in a peer group was key to this intervention, to facilitate learning from and inspiration by peers. Implementation observation showed that participants seemed hesitant to speak up, although some participants, during the interviews, mentioned that they enjoyed the group discussions, with one participant indicating she had gained confidence from seeing her peers speak: "I was always looking who was so brave and confident in answering questions... They inspire me to have the confidence to answer questions". Concurrently, participants voiced their desire to join groups of peers without albinism, since this would benefit the process of their normalisation. Nevertheless, multiple participants voiced their enthusiasm for the intervention and all but one participant wanted to continue to seek contact with the girls in their intervention group for discussing various issues.

DISCUSSION

The current qualitative brief report explored the stigma-coping strategies of adolescent girls with albinism in Tanzania, and the influence of a group coping intervention on the development of such strategies. Ten adolescents with albinism participated in four sessions of a group coping intervention, followed by individual interviews. The small set-up of the research necessitates one to read the findings and conclusions with caution. The following section explores patterns of coping strategies, and reflects on the group coping intervention based on the identified research goals. We propose future research to explore group coping interventions for stigmatised populations based on below interpretations.

The intervention firstly aimed to support adolescents with albinism to recognise existing coping strategies. Participants seemed to conduct mostly coping strategies categorised under disconfirming stereotypes. The notion that adolescents actively adopt strategies to gain respect despite their condition may be interpreted to mean that it is challenging to gain respect in harmony with their condition. Instead of embracing the identity of having albinism, adolescents sought to compensate for it. In the situation where one is constantly aware of how others evaluate their identity so they can actively endure compensating behaviours, a social identity threat is ever-present (Major & Schmader, 2018). This identity threat is then not only imposed by others, but also by the self. In other words, the efforts adolescents in the current research make to reduce public stigma, might actually increase self-stigma. Compensating for one's identity in an attempt to reduce stigma is common with various stigmatised populations (Shih, 2004). Nevertheless, it is found that it leads to lower levels of self-esteem, higher levels of anxiety, and is viewed as a draining process that ultimately hurts individuals (Ilic et al., 2011; Miller & Myers, 1998; Shih, 2004). The constant demonstration of disconfirming stereotypes connects to one of the basic sources of stigmatisation, namely the enforcement of social norms (Phelan, Link and Dovidio, 2008). By educating others and joining in groups with peers without albinism, adolescents reasoned others would see how 'normal' they are, thereby reducing the source of stigmatisation. Furthermore, adolescents sought acceptance and respect from the community, for example by becoming educated, which would prove their status in society. Bradbury-Jones et al. (2018), Huang et al. (2020), Varkaneh et al. (2022) and Wan (2003) described similar findings for coping of people with albinism, who display themselves as activists, advocators, hard workers and role models, all in the effort for normality and blending in. Condition management as a strategy, by keeping on their sunhats, overruled the desire to blend in.

Secondly, the intervention aimed to let participants reflect about coping strategies currently unfamiliar to them. Participants seemed to have learnt most about strategies related to primary and secondary control engagement, such as building self-acceptance, asking for help and conducting stress-release activities. This could indicate that participation in this group coping intervention has triggered a shift from the psychologically taxing efforts to conform with local norms and obtain external validation (Major & O'Brien, 2005) to more internally focused adaptation and coping (Connor-Smith et al., 2000). Regarding building self-acceptance, findings of group-based interventions for other stigmatised populations have also indicated that people with HIV (Dale et al., 2016; Makoae et al., 2008; Paudel & Baral, 2015) as well as caregivers of children with disabilities (Bunning et al., 2020; He et al., 2024) reported more acceptance post-intervention. The current intervention's positive influence on the recognition of self-acceptance as a coping strategy can potentially be explained by findings of Bunning et al. (2020) and Makoae et al.'s (2008), which suggest that self-acceptance is fostered through peer support of others who face the same stigma. We can carefully assume that our participants found a level of social support in the group as they indicated enthusiasm to stay connected after the intervention.

Thirdly, the intervention aimed to contribute to participant empowerment and reduction of self-stigma. It can be argued that the recognition and appreciation of self-acceptance stimulates the reduction of self-stigma, since accepting oneself can help to counter feelings of shame and self-devaluation related to their stigma (Moses, 2015). Additionally, help-seeking, impeded by stigmatisation (Reimer-Kirkham et al., 2022) including self-stigmatisation (Cheng et al., 2018) seemed to be a newly recognised strategy emerging from the reflections, potentially linked to more self-acceptance or decreased self-stigma (Nickerson et al., 2020).

Lastly, the intervention aimed to create a supportive environment of learning between peers (Hartog et al., 2020). While indications were provided that engaging with peers with albinism was helpful, a desire for integration in groups with peers without albinism was omni-present. This could be explained by their need to fit in and 'be normal' (Phelan, Link and Dovidio, 2008), while on the other hand could be triggered by increased sense of self-acceptance, where they already see themselves fitting in, 'despite' their albinism.

Limitations

The researchers' positionality as Dutch researchers led to limitations. Firstly, the researchers may have interpreted findings from a Western perspective (Rhodes, 1994). Secondly, the usage of a translator might have influenced the results. The researchers attempted to manage both limitations by closely collaborating with the local NGO NELICO and the translator. Socially desirable answers due to social hierarchies in Tanzanian culture were minimised by emphasising there were no right or wrong answers throughout all stages of the research, however this still might have been at play. Thirdly, data were limited due to the sample size and the length of the interviews , therefore findings cannot be generalised. Data analysis was done by one researcher, though feedback was provided by co-authors. Additionally, the participants were not monitored in potential implementation of the newly acquired coping strategies. Still, the current research shows interesting findings, however conclusions should be drawn carefully.

CONCLUSION

Adolescents with albinism in Tanzania experience stigmatisation. In an all-girl secondary boarding school, a short group coping intervention expanded the coping strategies previously available to the participants, beyond the main use of disconfirming stereotypes strategies into primary and secondary control engagement coping, such as building self-acceptance and help-seeking. A group intervention with peers with albinism was appreciated, but the desire remained to belong to groups with peers without albinism. We urge other researchers to further study group coping interventions more rigorously.

ACKNOWLEDGEMENTS

The authors are grateful to the New Light Children Centre Organisation for assisting with the recruitment of participants and providing transport and a translator throughout the research.

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