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Short communication

The impact of a peer support group for children with rheumatic heart disease in Uganda

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ABSTRACT

Objective: To assess the impact of a peer-support group on knowledge, quality of life, and social support for children with rheumatic heart disease (RHD).
Methods: Children diagnosed with RHD and receiving 4-weekly injectable penicillin were invited to participate in a monthly support group for 6 months. Pre- and post-intervention assessments included a baseline RHD knowledge assessment, a measure of health related quality of life (HRQOL) (PedsQL$_{TM}$4.0), and a measure of social support (Hawthorne Friendship Scale). Groups incorporated elements of cooperative play and team building, RHD education, and emotional support.
Results: 42 participants attended ≥3 groups and were included in the analyses. Attending support groups resulted in increased total HRQOL scores (60.3 v 70.2, $p < 0.001$), as well as the following HRQOL subscores (physical functioning 55.3 v 68.6 ($p < 0.001$), social functioning 64.2 v 75.8 ($p < 0.001$) and school functioning 59.2 v 69.1 ($p = 0.001$)). Significant increases in Friendship Scale scores (15.4 v 19.7, $p < 0.001$) and RHD Knowledge scores were observed (3.6 v 6.4, $p < 0.001$).
Conclusions: Peer-support groups may be effective at normalizing decreased HRQOL scores and increasing RHD disease knowledge and social support.
Practical implications: Peer-support groups implemented in conjunction with RHD screening can minimize the negative psychosocial effects associated with early RHD detection.
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1. Introduction

Rheumatic heart disease (RHD) is a leading cause of early cardiovascular disease morbidity and mortality in low- and middle-income countries [1,2]. Echocardiographic screening for RHD has the potential to reduce cardiovascular morbidity and mortality. However, a recent study of children in Gulu, Uganda showed that being diagnosed with latent RHD was associated with reduced physical and emotional quality of life scores even when patients were clinically asymptomatic [5].

As early RHD detection efforts expand, it is critically important to diminish the negative psychological impact associated with a positive screening result. To our knowledge this is the first time a support group was studied amongst pediatric patients with RHD. Here, we examine the impact of a support group on RHD knowledge, health-related quality of life (HRQOL) and social support for children diagnosed with RHD.

2. Methods

2.1. Study site and population

A peer-support group was established in Gulu, Uganda in 2016. Children (6–15 years) diagnosed with clinical RHD or definite latent RHD (2012 WHF criteria) [6] and receiving monthly intramuscular penicillin prophylaxis were eligible to attend.

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2.2. Support group structure

The group met for two-hours every 4 weeks for 6 months. Following an aerobic warm-up, attendees rotated between support and educational programming. Educational programming provided RHD knowledge, and attempted to dispel commonly voiced fears and misconceptions heard at the RHD clinic (Table 1, Fig. 1). The support element consisted of team-building and a project-focused discussion about children's experience with RHD (Table 1).

2.3. Variables and measures

Demographic data for all participants were obtained through chart review of the Uganda National RHD Registry [7].

At the beginning and end of the program, a RHD knowledge assessment, a measure of pediatric HRQOL (PedsQL$_{TM}$4.0) [8], and a measure of pediatric social support (the Hawthorne Friendship Scale) [9] were assessed.

Transcripts of the support piece were kept for analysis. A minute evaluation was individually administered at the end of each session to capture responses to "what did you like best about today's session", "what could be improved", and "how useful was this session", with extremely useful, somewhat useful, and not useful, as the possible responses.

2.4. Ethical procedure

All children gave written informed assent and had written informed consent from at least one parent/guardian. The Institutional Review Boards of Makerere University, Kampala, Uganda, The Ugandan Council for Science and Technology, and Children's National Health System, Washington, DC approved the study.

2.5. Statistical analysis

Study data were collected and managed using the REDCap electronic data-capture system hosted at Children's National Health System [7]. Data analyses were undertaken using MedCalc for Windows version 12.2 (Ostend, Belgium). Baseline demographic, clinical, and echocardiographic data were summarized using mean and standard deviation, and median and interquartile range, where appropriate. After confirming normality of distribution, Two-tailed Student's *t*-tests were used to compare RHD knowledge score, PedsQL$_{TM}$4.0 categorical and total scaled scores, and Friendship scale scores pre- and post-support group participation. Results were expressed as a mean ± standard deviation.

3. Results

Of the 52 children eligible to participate, 42 (81%) attended ≥3 sessions and were included in the subsequent analyses (Table 2).

3.1. PedsQL$_{TM}$4.0

All participants demonstrated improvements in HRQOL with an increase in the total PedsQL$_{TM}$4.0 scaled score after program participation (Fig. 2). Additionally, there were significant increases in 3 of 4 sub-scales including physical functioning, social functioning and school functioning (Fig. 2).

3.2. RHD knowledge assessment

Participants' knowledge of RHD increased significantly, with baseline knowledge scores of 36% increasing to 64% (Fig. 3A). Additionally, children repeatedly commented on the minute evaluation (109 times) that they enjoyed the educational component of the group.

3.3. The Hawthorne friendship scale

Improvement was observed in the social connectedness of participants. The group's overall mean Friendship scaled score of 15.4 (low friendship acuity) increased to 19.7 after participation (high friendship acuity) (Fig. 3B).

3.4. Minute evaluations

Over the study period, 241 unique Minute evaluations were collected. Participants described the group as "extremely useful" 96% of the time, with 100% of participants describing at least one session as "extremely useful".

Table 1
Activities conducted at each monthly support group session.

Session	RHD Knowledge		Support Component	
	Topics	Supporting material/Activity	Activity	Discussion starter
1	N/A	Baseline RHD Knowledge Quiz	QOL and Friendship Scale assessment	N/A
2	Bacteria and strep throat: How one gets RHD and how it can be prevented	Group discussion on myths and fears surrounding RHD	Obstacle course in pairs (one partner is blindfolded led by verbal cues from the other)	Trust: How did it feel to trust someone you just met? Does this relate to your diagnosis with RHD?
3	The heart: Anatomy, function and importance	Coloring activity: filling in a black and white image of the heart with red and blue crayons to represent blood flow through the heart	Hula Hoop pass: hold hands and then pass a hula hoop around the circle without unclasping partners hand	Challenges: what obstacles or "hoops" have you had to jump through because of your diagnosis with RHD?
4	The heart: How RHD affects anatomy and function. How RHD is diagnosed	1. Children listened to their own heart with stethoscope 2. Viewing of Echo images of affected Mitral and Aortic valves	Paper Plate Face Mask: create a mask that represents the strongest version of yourself	Feelings: How do you feel when others find out you have RHD? Do they treat you differently?
5	Treatment: Importance of monthly penicillin injections and routine follow ups	Group discussion on myths and fears surrounding penicillin injections	Penicillin Adherence key chains: children spelled out name in beads and then received a heart bead for being in the support group. At each penicillin clinic the children get a new bead to add to the chain	Monthly injections: How do you feel when you have to miss school for injections? Do you tell people where you are going?
6	N/A	Post-intervention RHD knowledge quiz	QOL and Friendship Scale assessment	N/A

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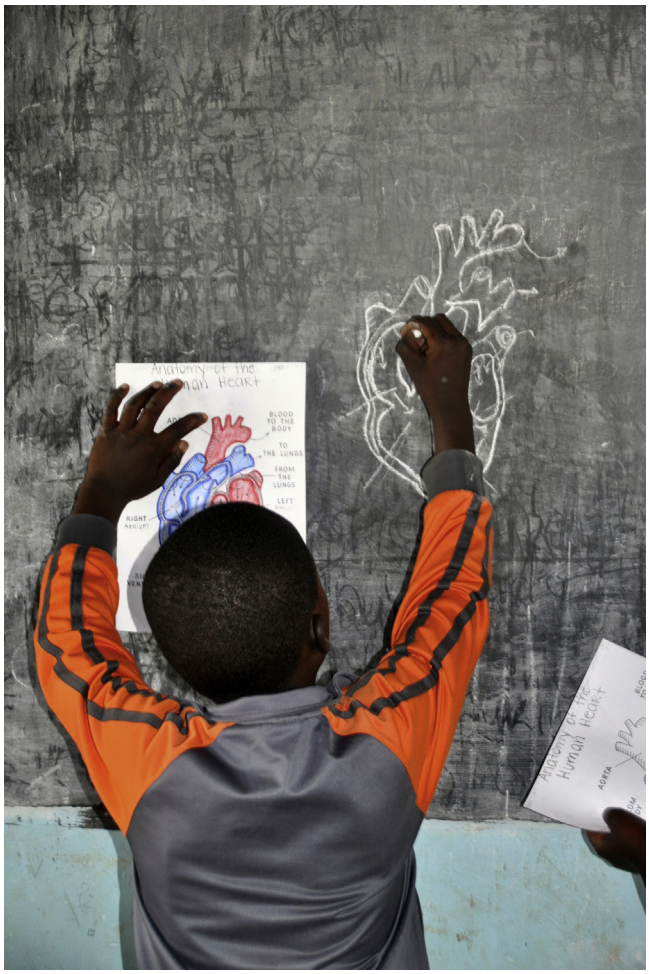

Fig. 1. A support group participant demonstrating his knowledge of heart anatomy during the educational session.

Table 2
Demographics, disease classification and penicillin adherence for group participants.

Age (mean, IQR)	10.81 (9–12)
Gender (% female)	61%
Clinical RHD	17%
Disease Category	
Severe	14%
Moderate	7%
Mild	79%
Penicillin Adherence (mean)	94%
Time linked to care (mean, years)	1.6

4. Discussion and conclusion

4.1. Discussion

Here we report the impact of a peer support group on children living with RHD. The results were overwhelmingly positive, with children demonstrating a nearly 50% increase in RHD knowledge, significant gains in overall HRQOL, and improved social connectedness. Additionally, participating children identified the group as extremely useful, which was exemplified by high attendance to the group. Our data suggest that a multidisciplinary approach to screening, inclusive of a peer support program, may be effective at reducing the negative impact associated with positive results.

This aligns with findings from a pediatric asthma-screening program consisting of disease education, extracurricular activities, and meetings with a psychologist. At the end of the 3-year study child reported HRQOL scores increased significantly [10]. Similarly, HIV positive adolescents attending a 2 year peer support group reported increased emotional well-being, decreased preoccupations about illness and a less negative view about treatment [11].

It is important to note that we have limited understanding of normal HRQOL scores in Uganda, and that the PedsQL$_{TM}$4.0, though validated in over 80 languages, has not been formally studied in Dholuo. Although the PedsQL$_{TM}$4.0 itself does not provide cut- off values for normal vs. abnormal results, it has been suggested that a clinically important cut-off for abnormal HRQOL be set at 1 SD below the population mean [8]. The baseline HRQOL scores from previous work in this region suggest that HRQOL in Uganda may be lower than high income countries like the United States, with a mean of only 71.1 reported in 139 healthy schoolchildren [5,12]. Although a larger study is needed to determine proper mean and standard deviation in this population, we believe the increases seen with support group participation are statistically and clinically significant.

Improved social support is consistently associated with higher medication adherence [13], an issue of critical importance for patients with RHD. Adherence to monthly injections is challenging, and recent cohorts of RHD patients have reported only slightly more than half receiving an adequate number to confer protection [14,15]. By improving social connectedness, support groups could play a critical role in improving adherence. Further work is needed to study this effect directly, as our cohort had uniquely high baseline adherence (94%).

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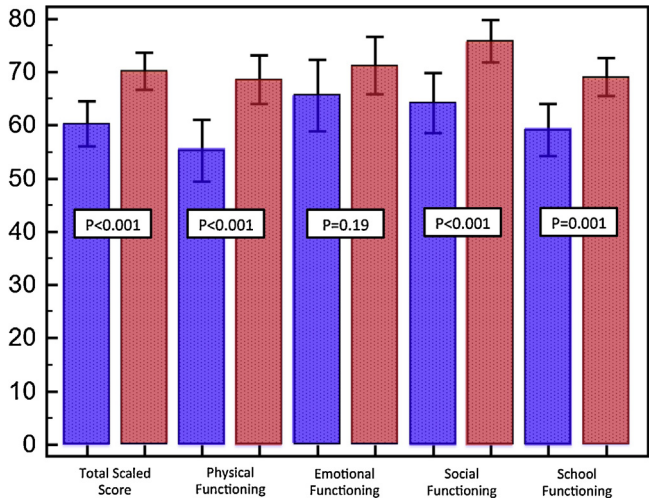

Fig. 2. Total and subcategory PedsQL$_{TM}$4.0 scaled scores pre-intervention (blue) and post- intervention (red).

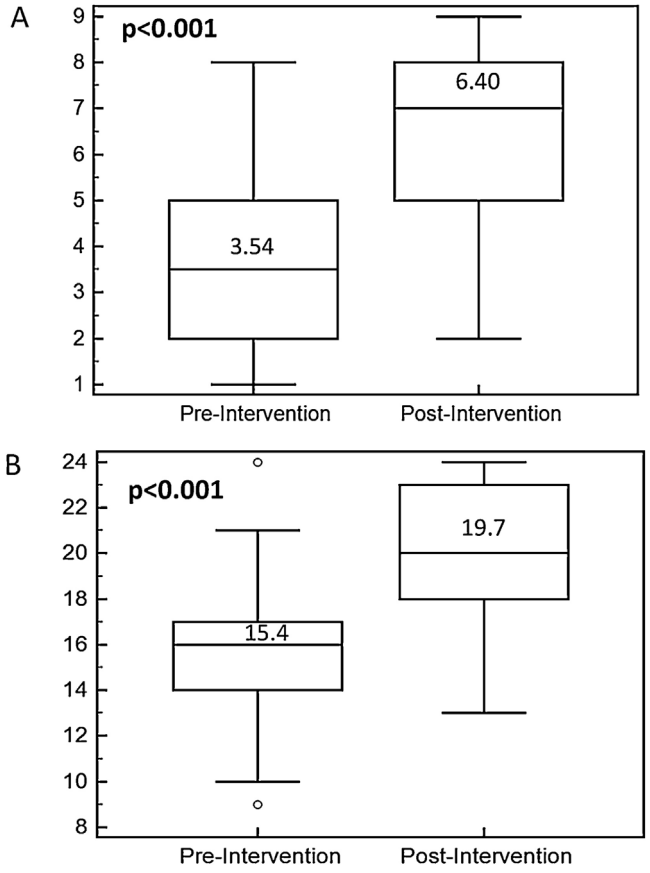

Fig. 3. A. A comparison of mean RHD knowledge scores at baseline and after 6 months of support group. B. A comparison of mean Friendship scale scores at baseline and after 6 months of support group.

RHD knowledge scores increased through support group participation. A study of children with cancer showed that health education, as a single intervention does not improve HRQOL [16]. Similarly, the level of disease related knowledge in patients with irritable bowel disease did not impact HRQOL scores [17]. However, understanding of the etiology of RHD and the rationale behind chronic, sometimes life-long prophylaxis is critical to dispel community misperceptions about RHD and justify the need for ongoing care and prophylaxis, particularly in asymptomatic children.

This study has several limitations. No peer control group was studied. However, previous data suggest that only linkage to care is not significantly beneficial to HRQOL in this population [5]. Additionally, there was no significant difference in baseline HRQOL scores between participants linked to care for >1.5 years vs. those who had been in care for a shorter time. Due to our small sample

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size, we were unable to account for factors that could potentially influence HRQOL and social support such as changes in medical management and both school and home environments. Children with poor participation were excluded from analysis, and may not have been receiving as much benefit from attendance. As the majority of children were included in analysis (81%) we believe this effect to be small. All participants were linked to care, had definite RHD, and were highly compliant with monthly penicillin prophylaxis at baseline. This population is not representative of all children diagnosed with RHD, and further study is needed to determine the impact of a RHD support group on children with poor adherence to follow-up and secondary prophylaxis. Lastly, we did not include children with borderline RHD, though early data suggest that a diagnosis of borderline RHD through screening may decrease HRQOL [5].

4.2. Conclusion

Our findings suggest that peer support groups for children with RHD are effective at normalizing decreased HRQOL scores and increasing RHD disease knowledge and social connectedness. Additionally, support group sessions were well-received and well-liked by participants.

4.3. Practice implications

Peer support groups implemented in conjunction with RHD screening and clinical programs could minimize the negative psychosocial effects associated with early RHD detection and additionally improve the experience of children by increasing disease understanding and reducing feelings of social isolation.

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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Conflict of interest

Authors have no conflicts of interest to disclose.

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