

The RHD Endgame Strategy: Evidence Brief #6

Peer support for people living with RHD

Being diagnosed with RHD can be a frightening and overwhelming experience, particularly if people are experiencing debilitating symptoms or complications. Many people with RHD are unsure about the cause of disease and its consequences.¹

There is strong evidence that peer-support activities can be beneficial for young people living with chronic conditions.² Supporting people living with RHD to understand the nature of the disease, its treatment and prevention, is an important way to help people manage their condition.³ Internationally, RHD peer-support programs have shown improved overall health-related quality-of-life scores and helped participants “*feel less scared about the future*”.⁴ Although there has been limited formal evaluation of peer-support programs for young people with RHD in Aboriginal and Torres Strait Islander communities, they appear to be well-regarded and likely to incur similar benefits.

There are a number of self-reported benefits in improved peer-support capacity, including quality of life, and confidence in self-management. Improving access to information and connection with other people living with chronic disease for remote Aboriginal and Torres Strait Islander young people is likely to be equity enhancing, and pilot programs have demonstrated acceptability among participants. Peer-support programs which increase health literacy and self-management capacity may plausibly improve uptake of secondary prophylaxis or clinical outcomes, however it is yet to be demonstrated in RHD peer-support programs. Establishing peer-support programs appears to be feasible with some months of planning and a small amount of funding, but maintaining momentum may be challenging, particularly for small programs relying on committed individuals. Further larger-scale activities, including those which connect people between remote communities, require transport and potentially staffing costs that must be factored into planning.

There are several acknowledged risks implicit in peer-support programs, including participants making unfavourable assessments of themselves relative to the group, and sharing of behaviours which are counterproductive.² Additionally, programs which are not culturally appropriate or poorly facilitated can be harmful if incorrect or stigmatising information is shared. Participation in a peer-support program also implies that people are comfortable disclosing their history of ARF and RHD. Community and cultural leadership with strong technical support could mitigate these risks.

A small number of programs have been piloted to explore different kinds of peer support for RHD in Australia:

Champions4Change

Champions4Change involves people living with ARF or RHD assisting others to navigate the health system, alongside education and disease management.⁵ Anecdotal evidence suggests that the program assists significantly with the uptake and maintenance of secondary prophylaxis protocols, acting as peers within their communities, and a mechanism of support for other young people.

Ngukurr needle crew

The *Needle Crew* involved twelve Ngukurr youths in the remote NT community providing peer support during their spare time to those overdue for secondary prophylaxis.⁶ Clinic staff facilitated young people with RHD to provide ‘mental and emotional support’ to each other while receiving their injections.⁶ With permission from

families, the crew members aged between 9-15 years brought students who were scheduled to take their needles to their appointment.⁶ Peer support has enabled those with ARF and RHD to improve their understanding of the importance of injections while being able to relate to members of the crew who demonstrate leadership and initiative.⁶

Happy Healthy Heart Kids

An all-female RHD peer support group, self-titled the 'Happy Healthy Heart Kids' (3HKids), was trialled at Menzies School of Health Research in November 2017, involving six people with RHD and their family members (personal correspondence, Dr. Alice Mitchell, 2018). While coming from different communities in Yirrkala and not having met previously, attendees were all members of the same language group. During the 60-minute session, attendees had the opportunity to ask questions of the workshop facilitator who spoke their language, took part in craft activities and group discussions, and shared snacks and drinks. Support group attendees expressed their appreciation for the program and were interested in attending subsequent events. The event organiser considered several reasons for the success of the session, including the location (away from a clinic setting), the opportunity for family members to attend, and the facilitation provided by non-clinic staff.

Danila Dilba Peer Support initiative

A peer-support initiative facilitated by Danila Dilba Health Service aimed to address the needs of young people living with RHD and evaluate the potential for a peer-support program within the Darwin region.⁷ Five young people participated in the pilot program which took place over three sessions in 2018 between October and November. These involved discussions about RHD, support activities such as cooking, games, and opportunities for the young people to connect and discuss their experiences.⁷ While the sample size was small, the project demonstrated a need for an ongoing program in the Darwin region to assist young people living with RHD.

South Australian RHD Camp

Children aged 9-15 and living with RHD in South Australia were invited to a two-day camp hosted by SA Health in 2018.⁸ During this period, children participated in educational activities focusing on treatment and general health and hygiene, while partaking in sporting and outdoor pursuits.⁸ The camp provided young people with an opportunity to connect with those with a shared experience, while collectively learning more about RHD.⁸

Recommendations

- There is reasonable evidence that peer-support programs can improve the lived experience for Aboriginal and Torres Strait Islander young people affected by ARF and RHD.
- Resourcing to support peer-support programs and encourage connections and self-management should be provided, and a range of peer-support models iterated by people living with ARF/RHD and communities.
- Clinical information relevant to peer-support programs should be provided to help share high-quality and relevant information.

About the END RHD CRE

In 2014, The End Rheumatic Heart Disease Centre of Research Excellence (END RHD CRE) was established to address the urgent need for a comprehensive, evidence-based plan to eliminate rheumatic heart disease across Australia.

Bringing together leading experts from 16 institutions across Australia and backed by a grant from the National Health and Medical Research Council (NHMRC), the CRE has synthesised the collective experience of communities, clinicians, Aboriginal Community Controlled Health Organisations, and government and non-government organisations – as well as more than 25 years of research – to tackle this need head on.

The result is *The RHD Endgame Strategy: The blueprint to eliminate rheumatic heart disease in Australia by 2031*. Outlining the best existing evidence-based strategies to prevent new cases of RHD in Australia and improve the lives of those already living with the disease, The RHD Endgame Strategy was launched in October 2020 and can be viewed at telethonkids.org.au/rhd-endgame.

Acknowledgements

The RHD Endgame Strategy is a product of collaboration between researchers, Aboriginal and Torres Strait Islander leaders, communities and people with lived experience.

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