

‘Listen to my heart’: Qualitative researchers and people living with rheumatic heart disease collaborate to direct future RHD research

C Read,¹ PhD; A Mitchell,² PhD; TD Johnson,¹ BIntlDev MCHMED; ME Engel,³ MPH PhD; O Matshabane,³ PhD; I Ssinabulya,⁴ MD; A Scheel,⁵ MD; T Erio,⁶ MPH; J Lawrenson,^{7,8} MB ChB MMed; S Perkins,³ MX; J de Vries,^{3,9} DPhil Oxon; L Zühlke,^{3,8,10} MB ChB PhD

¹ Telethon Kids Institute, University of Western Australia, Perth, Australia

² Charles Darwin University, Darwin, Australia

³ Department of Medicine, Faculty of Health Sciences, University of Cape Town, South Africa

⁴ Uganda Heart Institute, Kampala, Uganda

⁵ Children's National Health System, Washington DC, USA

⁶ Mwanza Intervention Trials Unit, National Institute for Medical Research, Mwanza, Tanzania

⁷ Department of Paediatrics, Faculty of Medicine and Health Sciences, Stellenbosch University, Tygerberg, Cape Town, South Africa

⁸ Division of Paediatric Cardiology, Department of Paediatrics, Red Cross War Memorial Children's Hospital, Faculty of Health Sciences, University of Cape Town, South Africa

⁹ NeuroScience Institute, University of Cape Town, South Africa

¹⁰ South African Medical Research Council, Tygerberg, Cape Town, South Africa

Corresponding author: L Zühlke (liesl.zuhlke@mrc.ac.za)

Background. Rheumatic heart disease (RHD) is a preventable chronic cardiac condition that causes over 350 000 deaths annually, largely in low and middle-income countries, as a direct result of structural inequalities and inadequate access to comprehensive healthcare. People living with and affected by this disease are a key stakeholder group and need to be directing research priorities.

Objective. To improve care and provide direction for future research, a group of qualitative researchers and people living with RHD from six countries convened in Cape Town in 2016.

Methods. People with RHD shared their lived experiences while RHD researchers, clinicians and advocates presented a spectrum of qualitative research methods to explore these experiences. The Continuum of Care® (CoC, developed by the Medtronic Foundation) was used as a framework to guide participant discussions. Thematic summaries of the discussions were undertaken in an iterative process throughout the workshop.

Results. Three themes emerged in the summaries: there is no ‘typical’ patient journey; a biomedical focus on RHD does not reflect people’s lived experiences; and a diversity of research methods is required to investigate experiences of people living with RHD.

Practice implications. Qualitative research methods are invaluable for allowing patient ‘voices’ to be heard. To this end, qualitative approaches should be incorporated in all RHD research to ensure maximum benefit for patients.

Conclusion. Greater understanding of the patient journey was gained for strengthening and expanding the global RHD research agenda. Future research should reflect on and incorporate the realities of patients’ lived experiences, and these experiences should be integrated into healthcare models for chronic conditions.

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In recent years, there has been considerable focus in RHD research on epidemiology and burden of disease, laboratory-based studies into human genetic susceptibility, and immunology.^[1-7] Although the importance of the ‘patient voice’ has been progressively acknowledged,^[7,8] relatively few studies include a focus on people with the disease and their lived experiences.^[9] Qualitative research – such as ethnographic studies, participatory action research and lived experience studies – examines social issues and seeks explanations into the ‘how and why’ of people’s behaviour and their understanding of their medical conditions.^[10] The inclusion of qualitative methods better informs all research on RHD and has potential to inform improved care practices and care models.^[11]

The critical need to integrate a broader perspective in RHD research prompted this first workshop of researchers proficient in qualitative methods and people living with RHD in Cape Town,

South Africa on 12 September 2016.^[12] With a strong focus on hearing patients’ narratives, the workshop provided a networking opportunity and a forum to share experiences of living with RHD, and of RHD research. The workshop facilitated the formation of a group of mixed-methods researchers who are committed to ongoing qualitative research to strengthen global knowledge and insight around living with RHD and thereby improve care.

Objective

To improve care by learning from patients about their experiences of living with RHD; to inform an agenda for future research through discussion on the contribution and significance of qualitative research in building global knowledge around RHD; and to consider methods to enhance qualitative research on RHD. This paper reports on the main outcomes of the collaborative workshop between researchers and patients.

Methods

Participants

The researcher and patient workshop had global participation, with attendees from South Africa, Uganda, Tanzania and Australia, as well as representatives from the World Heart Federation, Switzerland and Children’s HeartLink, USA. A range of disciplinary backgrounds was incorporated in the workshop. Attendants included five academics/clinicians; one epidemiologist/microbiologist; three social scientists; four PhD students in the social sciences; one nurse/healthcare worker; and seven representatives of RHD advocacy organisations. One advocate had grown up with congenital heart disease and meaningfully contributed in terms of the shared experience of being a patient with heart disease. Most importantly, the workshop included five people living with RHD from rural and urban areas of South Africa and Uganda, one of whom is also a nurse. These participants had travelled to Cape Town for an annual event for people living with RHD named ‘Listen to my Heart’; co-organised by RHD Action and the University of Cape Town to strengthen patient empowerment and advocacy by including, recognising and celebrating the RHD patient community.^[13] After the patient event, the attendees participated in the researcher and patient workshop. A total of 26 people took part in the workshop.

Framework for workshop discussions

The CoC is a patient-centred framework developed by the Medtronic Foundation. It has been utilised for a range of medical conditions, including RHD, to track ‘the movement of a hypothetical patient at risk of or affected by RHD through the health system.’^[14] The workshop commenced with dialogues on the ‘typical’ patient pathway

for RHD using a hand-drawn linear version of the CoC adapted especially for use in the workshop (Fig. 1).^[14,15] The CoC stimulated discussions on the various points at which a person may enter the healthcare system, barriers that might prevent people from accessing care, and opportunities that exist to address gaps in the healthcare system for people to regain stable health.

Data collection

Five people living with RHD shared their experiences and personal health narratives in response to the CoC pathway in an interactive process within the group. Clinicians reported their experiences of caring for people living with RHD, particularly in relation to the CoC pathway, while one clinician also shared personal experiences of needing cardiac care. Researchers presented their experiences of conducting qualitative research on RHD topics. A broad range of methodologies was shared: from traditional qualitative methods using focus groups and in-depth interviews, through ethnographic research, case studies, use of media and participatory action research. As the meeting evolved, emerging insights were frequently summarised, presented and discussed to gain consensus with the entire group in an iterative process.

Detailed notes were taken throughout the meeting. Together, the summaries and notes were used to develop the contents of this meeting report.

Ethical considerations

This is a meeting report and as such no ethics approval was secured. Where the perspectives of patients are presented in the paper, we have ensured that they are not identifiable in any way. Where names

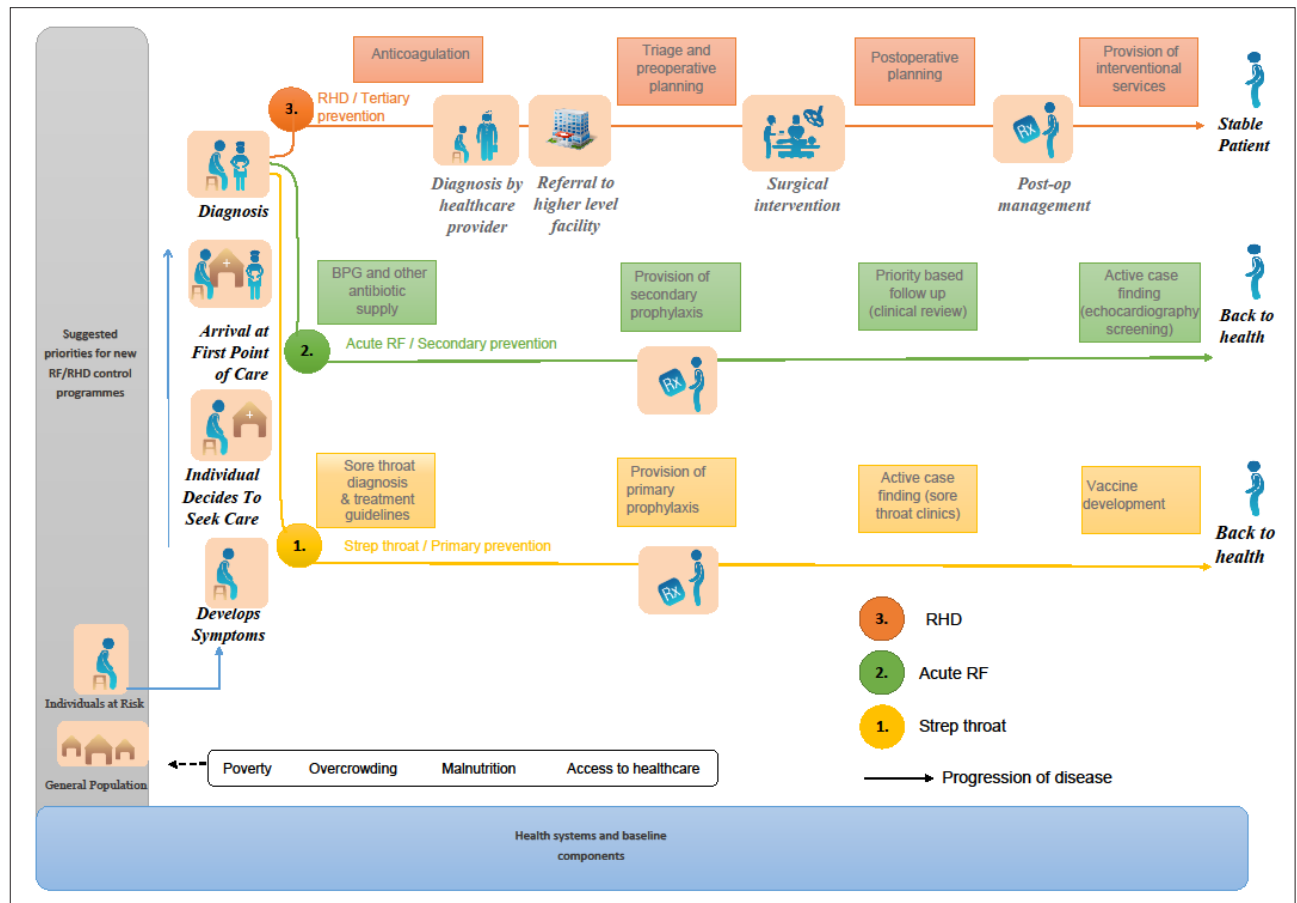


Fig. 1. Adaptation of Continuum of Care© (Medtronic Foundation) patient journey for use in the workshop – originally hand drawn.

Table 1: Diversity of experiences of people living with RHD

Fifi, Uganda A cardiac nurse whose RHD was diagnosed shortly after the birth of her child. She described the fear she felt upon her diagnosis and recounted the trauma of having to secure funding for expensive cardiac surgery while caring for her newborn baby. She also emphasised that she had to live with the stigma of a chronic disease that is associated with HIV/AIDS by many people in Uganda. This was due to the need to take daily medications, a well-known requirement of those with HIV. Nevertheless, Fifi expressed the support and comfort she had received from her husband and through her faith.

Allison, Western Cape, South Africa described the deep anxiety and distress she experienced following her heart operation. She was thankful that her doctor had provided clear information for her post-operative management, listened to her and referred her to a social worker from whom she received effective support for anxiety.

Banathi, Western Cape, South Africa similarly praised the information given by medical staff, and said he appreciated the solidarity with other RHD patients when visiting the hospital for regular blood tests. Meeting with other patients with the same health problems was a source of insightful information stemming from their shared experiences of heart surgery and the need to take long-term medications.

Tumelo and Camagwini, Limpopo, South Africa Two young women who raised the issue of late or misdiagnosis. Tumelo was initially diagnosed with and treated for asthma before seeking diagnosis in a private hospital. Camagwini saw a traditional healer and many health workers in district and provincial hospitals before finally being diagnosed by a paediatrician with training in cardiology many years after first becoming ill.

Table 2: Juxtaposition of a biomedical focus against patient experiences

Biomedical focus	Aspects of patients' experiences in their context
Diagnosis	<ul style="list-style-type: none"> Getting to a correct diagnosis can take years and sometimes requires extensive financial resources, such as private healthcare Women may be diagnosed during or immediately after pregnancy, leading to the need to juggle conflicting emotions during a vulnerable time
RHD and reproductive health	<ul style="list-style-type: none"> Centrality of childbearing in the human experience, which may be compromised in RHD, raises multiple questions for the person with RHD: <ol style="list-style-type: none"> Does a woman endanger her health to become a parent? How does this affect the lives of young women? What is the interplay of gendered blame in this story? How can patients deal with the anxiety experienced by their children? Finding the right contraceptive, particularly when hormonal treatment may not be suitable, and women may not (for cultural reasons) have the power to enforce use of condoms or other forms of contraception Worry about heritability of RHD, and passing the condition to children and grandchildren
Adherence to secondary prophylaxis	<ul style="list-style-type: none"> Pain and the practical, financial and logistical challenges of receiving regular prophylactic injections Stigma due to perceived association of regular medication with the treatment of chronic HIV/AIDS, syphilis and gonorrhoea
Access to tertiary care (heart surgery)	<ul style="list-style-type: none"> Lack of fairness and justice due to the healthcare system and economic limitations Ethical/emotional burden for healthcare workers who see patients die when they could have been saved in a better-resourced healthcare system
Post-operative management	<ul style="list-style-type: none"> INR testing: practical, logistical and financial aspects of going for regular tests Continuation of secondary prophylaxis after surgery: adherence and understanding
Cardiac conditions	<ul style="list-style-type: none"> Symbolic importance of heart problems Anxiety pre- and post-operatively Shock when telling others about your RHD diagnosis

are used, these are pseudonyms. All attendees gave permission for the paper.

Results

Thematic summary of the workshop

Three themes emerged in the discussions at the meeting: there is no 'typical' patient journey; a biomedical focus does not reflect people's real-life experiences of their condition; and diverse research methods are required to investigate the experiences of people living with RHD.

There is no 'typical' patient journey

The biological disease pathway for RHD is universally recognised. After group A streptococcal infection, a susceptible person may develop rheumatic fever, which may go on to cause permanent damage to the heart, termed rheumatic heart disease. Cardiac

valve repair or replacement surgery may then be required for survival. However, each participant living with RHD at the workshop experienced a different path to diagnosis, treatment and ongoing management. Table 1 outlines the experiences of people from Uganda and South Africa living with RHD.

A biomedical focus does not reflect people's real-life experiences

A key outcome was agreement among participants on the need to expand the CoC model to better reflect the reality of patients' lives. This should include consideration of social, psychological and emotional factors, such as stigma and similar experiences that are not currently captured in the CoC model. People living with RHD emphasised the importance of various aspects of their lives. The group outlined the following aspects that should be considered: the impact of RHD on the chances of finding a partner; on the ability

Table 3: Summary of research approaches used to investigate experiences of people living with RHD

Research topic	Representation	Methods employed	Summary of presentation and discussion
The role of children's advisory and support groups	Uganda: Dr Isaac Ssinabulya and Amy Scheel from Uganda Heart Institute	Thematic analysis of support groups, and doctor-patient communication	The capacity of adult and paediatric support groups to improve patient adherence, and the success of a doctor-patient WhatsApp group in allowing patients to easily ask their doctor questions about RHD. The initiative was described as an 'extension of medical school', and the experience 'makes me feel part of a complete contribution to someone's life.'
Young Aboriginal people's experiences of ARF and RHD care	Australia: Alice Mitchell, Menzies School of Health Research, Charles Darwin University	Focused ethnography and subsequent community-based participatory action research	The need for communication in a patient's first language and better connection between patients and healthcare workers was highlighted in a summary of research underway in the Northern Territory of Australia. The study used participant observations and serial interviews, mostly with adolescent boys living with rheumatic fever and RHD. While blame was often placed on Aboriginal patients for not adhering to regular penicillin injections, conversely patients felt that doctors should take more responsibility in helping them access health services. A new participatory action research study emerged from this ethnography.
Understanding RHD	Tanzania: Tusajigwe Erio, Mwanza Intervention Trials Unit	In-depth interviews and focus groups	A small qualitative study in Sengerema, Tanzania, highlighted language as a barrier to improving awareness and health-seeking behaviours in communities as there is no word for RHD or rheumatic fever in Kiswahili. Additionally, in locations of very low awareness among the general population, researchers need to be prepared to provide information due to their interviews stimulating questions from participants about their condition.
Surgery in children and young adolescents	South Africa: Prof. John Lawrenson, Stellenbosch University	Ethnographic case study of 10 children	The possibilities of engaging patients using social media in relation to a study in which researchers interviewed children and young adolescents who were about to undergo heart surgery.
Stigma in genomics	South Africa: Prof. Jantina de Vries, Marlyn Faure and Olivia Matshabane, University of Cape Town	Visual methods, in-depth interviews and focus groups	The effect of genetic attribution on stigma relating to RHD, and the potential of visual methods to improve the relationship between researchers and study participants.

of female patients to have children; on patients' ability to find and maintain employment; the burdens imposed by regular clinic visits; and fear associated with heart surgery in the case of South African patients. These aspects were identified as central in patients' journeys. While each patient's interaction with the healthcare system is an individual experience, it was collectively agreed that an integrated approach to RHD management and care is needed. This involves ensuring a strong social support network; providing psychological and counselling support; creating patient support groups and other coping strategies; and recognising religious beliefs as a source of comfort and strength. A non-biomedical perspective recognises the impact of these factors on RHD health outcomes. Inequality, poverty, disempowerment, crowded housing and poor hygiene are influential in all components of the CoC model. These socioeconomic factors impact on the entire CoC model and affect health outcomes and should be integrated into the design of RHD prevention strategies within healthcare systems.

A range of research methods is required to investigate the experiences of people living with RHD

The workshop group recognised the need to draw on and integrate the broad diversity of methods that can assist in the investigation of experiences of people living with RHD. During the workshop,

examples across a broad range of RHD qualitative research methods were presented. These are summarised in Table 3.

Discussion

Research in recent decades has had an increased focus on care models for chronic disease management due to the escalation in chronic conditions globally and the resultant increasing demand on healthcare systems.^[16-19] Additionally, there has been a desire to improve practices by using alternative care models including integrating and leveraging off care models for other chronic conditions, such as tuberculosis, HIV and RHD.^[20] There has been a corresponding emphasis on and acceptance of the need for patient-centredness in healthcare.^[21] While care models are useful for providing an overall framework for practice and for planning and resourcing healthcare systems, they can be greatly enhanced if they are informed by patients' multifaceted experiences as 'expert witnesses' on health conditions.^[22,23] The results reported here highlight that conducting collaborative qualitative research with people living with the chronic condition of interest, is critical for gaining insight into and enhancing chronic care models, and therefore patient care. This sentiment is expressed in the statement encapsulating the Listen to My Heart events in South Africa, 'Nothing about me without me.'^[13]

The CoC framework aptly presents a stylised patient journey on the topic of RHD to inform healthcare system design for a global audience.^[15] However, patients' narratives, presented in our workshop data, build an informed understanding of patient journeys and have potential to improve care by ensuring that the experiences of people with the conditions are known; for instance, while a patient is depicted in the model as having symptoms that lead to care-seeking and then to diagnosis, patient experience is that it may take years and much effort to receive a correct diagnosis, or a diagnosis may be missed and only revealed traumatically during pregnancy or childbirth. We argue that qualitative research methods should be prioritised for building global knowledge around patients' lived experiences of RHD.

A range of qualitative research methods can be used to explore multiple components on the patient journey of people living with RHD as depicted in the CoC model. However, more importantly, these methods have the capacity, and provide an opportunity, to modify the predilection to a purely biomedical approach in healthcare systems on the part of clinicians and researchers. Through revealing the deeper human experiences of both clinicians and researchers on the one hand, and people living with the condition in question on the other, development of an integrated approach to RHD care is made possible.

Setting a research agenda for RHD involves a commitment to ensuring people living with RHD are fully involved in project design and implementation, and have an opportunity to share their experiences. We recommend:

- People living with RHD be included on committees setting RHD research agendas;^[22]
- All RHD research proposals, including biomedical and screening studies, have a component devoted to engaging people living with RHD, and social research investigating their experiences. We proffer that even laboratory-based projects, due to their nature, are not necessarily excluded from the possibility of incorporating qualitative components;
- Monitoring and evaluation mechanisms be included in all RHD studies;
- Research results are disseminated (first) to patients, patient advocacy groups and the broader research community; but also to policymakers and those setting healthcare system priorities and redesign;
- A repository of global research that utilises qualitative methods or qualitative components, including unpublished writings on RHD patient experiences, be collated.

Practice implications

Sociological studies describing the experiences of people living with RHD are scarce, leading to unrecognised limitations in widely adopted care models such as the CoC, as well as limitations in clinicians' knowledge and understanding of patients' experiences. As a priority, nuanced understandings of the non-biomedical patient journey are needed to complement biomedical understandings. This includes, where possible, incorporating qualitative research methods into biomedical studies, thus providing an opportunity to improve healthcare models through revealing deep human experiences so that deeper knowledge can be gained and people living with RHD receive maximum benefit.

Conclusion

The platform for in-depth discussion on RHD care provided in this workshop resulted in valuable information to inform and strengthen supportive healthcare models. Publication of the themes generated in

this workshop details our collective commitment to ensuring that the patient voice is at the core of how we tackle RHD globally and for this understanding to complement and inform all research with an RHD focus more broadly.

Declaration.

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Conflicts of interest. None.

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