

## Determinants of rheumatic heart disease: findings from qualitative research approach

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### Abstract

**Background** Rheumatic heart disease (RHD) is an autoimmune heart disease following unresolved or untreated acute rheumatic fever (ARF), which results in irreversible valve damage and heart failure. Strategies for managing RHD could be planned to understand the disease determinants in local settings.

**Objective** To explore the determinants of RHD among the family with an RHD case.

**Methods** The study was a qualitative design using a grounded theory approach after in-depth interviews with respondents from families with RHD patients. Analysis was conducted after the scripts were finalized. Initial, intermediate, and advanced codings were performed. Ten respondents agreed to participate and completed the qualitative data collection process.

**Results** The analysis yielded two theme categories of what could have led to RHD among respondents due to internal and external causes. Internal causes were considered factors that could be managed or manipulated to improve an individual and family's capacity. In contrast, external causes were considered factors that could not be managed or manipulated to improve an individual's capacity or family. Therefore, these factors were considered beyond their control.

**Conclusion** This study explored RHD determinants according to the patients' and their families' perspectives. A holistic approach can be applied to managing RHD by considering these factors. [*Paediatr Indones.* 2023;63:483-91; DOI: <https://doi.org/10.14238/pi63.6.2023.483-91> ].

**Keywords:** *rheumatic heart disease; acute rheumatic fever; causes; determinants; children*

Rheumatic heart disease (RHD) is a chronic heart disease caused by an abnormal immune response to a Group A streptococcal infection in susceptible individuals.<sup>1</sup> Acute rheumatic fever (ARF) precedes RHD and can affect multiple organs, especially the heart, resulting in irreversible valve damage and heart failure. Untreated RHD could lead to heart failure or death. More than 33 million cases of RHD were estimated to have occurred in countries where the disease is endemic, and more than 200,000 cases were reported in countries with a non-endemic pattern.<sup>2</sup> In Malaysia, the burden of RHD was reportedly lessened, characterized by a decreasing trend of mortalities due to RHD, but heart valve surgeries due to complications of RHD have been increasing.<sup>3</sup> This event was due to the silent nature of RHD in which individuals presented to health facilities only when symptoms persisted, reflecting they were already at a stage requiring further treatment and care.

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In several previous studies, ARF and RHD have been linked to socio-economic and environmental factors.<sup>2,4-7</sup> This evidence was contributed mainly by the studies and reports from the low and middle-income countries in Africa, Oceania, South Asia, and some interior regions of developed nations in Australasia. Although these studies and reports were essential for advancing ARF and RHD management for Malaysia, the concept of “one size fits all” might not be applicable to RHD management in local settings as different nations would have their issues and challenges.<sup>8</sup> Therefore, a study on RHD among children in the local setting would be warranted, which might assist commentaries regarding the suitable approach for RHD study in the local context.

A clear explanation of non-medical components of disease prevention would be a compelling reason for health agencies and others to collaborate with those involved in economic development and sustainability, the environment, and human capital development. When major stakeholders like the government have a clearer understanding of the current RHD situation, future commitment could be established to manage the disease. Moreover, according to the local settings, this study would explain the modifiable socio-environmental factors in RHD's primordial and primary prevention. Many comprehensive strategies could be planned for managing RHD in a population by elucidating the disease determinants in the local settings. Therefore, this study aimed to explore the determinants of RHD among families with an RHD case.

## Methods

The study was reported according to the *COnsolidated criteria for REporting Qualitative research (COREQ)*.<sup>9</sup> The study was a qualitative design using a grounded theory approach, focusing on creating conceptual frameworks or theories by building inductive analysis from the data.<sup>10</sup> This qualitative method prioritizes analysis over description, new categories over preconceived ideas and existing theories, and systematically focused sequential data collection over large initial samples. Therefore, this study was conducted to develop theories explaining the determinants contributing to RHD.

An echocardiographic survey among school-

going children in the divisions of Kuching, Samarahan, and Miri, Malaysia, was conducted previously and managed to detect 14 respondents with RHD. Thus, this study targeted the same population and was designed to include the children (or their parent or guardian) of the primary and secondary school-going age groups ranging from five to 25 years old diagnosed with RHD during the survey.

The in-depth interviews were primarily facilitated by one author (RNA), a medical officer with ten years of experience in medical practice. Medical officers (MSD and MFG) with nine years of medical practice experience worked with the primary facilitator. All three facilitators were male doctors, and at least one of the facilitators lived and worked in each division where interviews were conducted and were fluent in the local language. Study participants had met at least one research team member during the previous echocardiographic survey.

The respondents were recruited using purposive sampling and contacted over the phone since they had been identified from the echocardiographic survey. No issue was experienced in building a rapport before the interview, given that a good relationship had been established during the echocardiographic survey. The respondents could either be the RHD cases themselves or their parents. Once the respondent agreed, the interview time, date, and mode were confirmed. Before the recording, respondents were informed about the confidentiality of the information gathered and advised to be comfortable and away from any disturbance. The interview had two facilitators, whereby one person served as the interviewer and performed the notetaking while another played the role of an observer as well as notetaking. The interview was conducted in the local dialect according to the respondent's preference in addressing the question of the RHD causes aligning with the interview plan.

After each interview session, the audio recordings were transcribed into written form. The transcriber performed the transcription manually, listened to the recordings a few times, and began typing them line by line. Before completing each transcription, the transcriber conducted another round of checking by listening to the same recording and reconfirming the transcription. Upon executing the transcription, a soft copy was sent to each respondent to countercheck that what had been written was correct and aligned