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Original Article

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.[1] 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.[2] 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.[3] 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.[2,4-7] 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.[8] 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).[9] 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.[10] 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

with the context of the conversation during the in-depth interview. Following that, the transcription underwent a translation process into English. A translator from a medical background who was fluent and skillful in writing completed the translation in English and local dialects. The translation was done line by line to preserve the transcription accuracy during the translation. The respondent was then sent a soft copy again to confirm that what had been translated was accurate and according to the context of the conversation. No repeat interview was conducted. The audio recordings were captured using an Apple iPad Mini, whereas Microsoft Word 365 was used for all transcription and translation. After that, the translated verbatim was uploaded into Atlas ti version 22 software for qualitative data analysis. Memoing was performed throughout the analysis to capture the explanation behind every qualitative data analysis process.[11]

Following the grounded theory approach that requires the researcher to collect, code, and analyze the available data before further data collection was undertaken, the transcripts underwent a free coding process from the first to the last respondent according to their turns for an in-depth interview.[12] The coding was undertaken line by line and focused on the respondent's lines. As more transcripts were subjected to the free coding process, the researcher would gain a better understanding of the transcripts. After all free codings were created, new and different codings were discovered as long as they were coded differently, like in various spellings or the same code described differently. Upon merging all the free codings, they were further grouped into initial codings, also known as the subthemes.[11] Thereafter, intermediate coding was built on the initial coding phase, whereby initial coding would be a basic data structuring activity. Intermediate coding would then transform basic data into more abstract concepts, allowing the theory to emerge from the data. A core category would become evident as categories were established. Hence, relationships were identified between the categories and the analysis was refined. In other words, intermediate coding would be the phase for theme construction.

Based on the analysis using the grounded theory approach and information gleaned from the respondents, the major domains of what could have caused RHD were identified. These major domains were the theories or the theme categories that would result in a sensible storyline when linked. Two researchers conducted all three coding levels independently, and the findings were compared upon completing the coding and analyses. While overlapping results were accepted, discrepancies and differences were discussed in the presence of a third party. When all three researchers were satisfied with the findings, the finalized version was prepared to be presented. Respondents were labeled before coding according to their sequence number, gender, and age group. Sequence numbers (R) were paired with their number, gender was labeled with male (M) or female (F), and age groups were either adult (A) or teenager (T).

Unique components of qualitative research concerning qualitative rigor were safeguarded throughout the process, including credibility, dependability, confirmability, and transferability for the study to be trustworthy.[13,14] Credibility was assessed to ensure that the findings from the respondents' perspectives were true, credible, and believable. Meanwhile, dependability ensured the findings were repeatable when the inquiry occurred within the same cohort of participants, coders, and context.[15] Credibility was assured by training the research team to perform their roles through adequate knowledge, research skills, prolonged engagement, and debriefings conducted with the respondents throughout the studies. Meanwhile, dependability was ensured with detailed study drafts throughout the study and establishing an audit trail of detailed track records of the data collection process. Confirmability aimed to extend the confidence that the results would be confirmed or corroborated by other researchers, and this was achieved through reflexivity and triangulation.[14,15] Reflexivity was performed by memo writing and team discussion throughout the study, while triangulation was undertaken by comparing the findings during the data analysis. Lastly, transferability was ensured via the application of purposive sampling in recruiting respondents and point of saturation in data analysis.[15]

This study obtained ethical clearance from the Faculty of Medicine and Health Sciences Research Ethical Committee, Universiti Malaysia Sarawak. Informed consent was obtained before participation,

while the confidentiality of the personal details was declared.

Results

Ten respondents agreed to participate and completed the qualitative data collection process, while others were either unreachable or refused to take part in the study. Two face-to-face interviews and eight phone calls lasted about 10 to 20 minutes as long as the respondents had something to say. Respondents were stopped when they had nothing more to add about the questions asked. One-fifth of the respondents were males, while the remaining four-fifths were females. Regarding the relationship with RHD patients, two respondents were the patients themselves, whereas the other eight were family members. Likewise, two respondents were fathers among the family members, and the eight were mothers. Furthermore, nine respondents were adults, and one was a teenager. Lastly, seven respondents were from the Dayak race, and the remaining three were from other ethnicities (**Table 1**).

The analysis was conducted according to the grounded theory approach, whereby the identification of free coding was started in each transcript, followed by merging processes into the initial coding and generating subthemes.[16] Coding processes were performed until a saturation point was reached. As soon as subthemes were established, intermediate coding was performed by grouping all subthemes into themes. Subsequently, an advanced coding process was carried out by categorizing all themes according to a sensible and appropriate storyline.[12] Based on the analysis using the grounded theory approach and information gathered from the respondents, two major domains of what could have caused RHD were identified. A brief description would diagnose a child with RHD due to internal and external causes. The findings from the qualitative data analysis are summarised in the following thematic map (**Table 2**).

Table 1. Characteristics of the respondents for the in-depth interview (N=10)

Respondent	Gender	Relationship with patient	Age group	Ethnicity
1	Male	Family (father)	Adult	Dayak
2	Female	Own self	Teenager	Dayak
3	Female	Family (mother)	Adult	Others*
4	Male	Family (father)	Adult	Dayak
5	Female	Family (mother)	Adult	Dayak
6	Female	Own self	Adult	Others*
7	Female	Family (mother)	Adult	Others*
8	Female	Family (mother)	Adult	Dayak
9	Female	Family (mother)	Adult	Dayak
10	Female	Family (mother)	Adult	Dayak

*Others include Malays and Melanau

Table 2. Thematic map of qualitative analysis (N-=10)

Theme categories	Themes	Sub-theme	N
Internal causes	Individual factors	Hygiene practice	5
		Spirituality	1
		Immunity	1
	Socioeconomic situation	Income	6
	Knowledge application	Crowding	8
		Lack of knowledge	10
External causes	Environment	Other unexplained cause	5
		Unfavorable environment	8
	Healthcare	Healthcare accessibility	8

Internal causes were considered factors that could be managed or manipulated to improve an individual's capacity or family.[17] When internal causes were left unaddressed, individual factors, socioeconomic situations, and knowledge application would decline towards the damaging or harmful direction, making someone susceptible to diseases and infirmity.[5]

The individual and their family could not able to do something to improve themselves in any or every aspect of individual factors to prevent themselves from being at risk of getting ARF or worsening into RHD. Individual factors, socioeconomic situation, and knowledge application generated themes from the internal causes. Therefore, all the initial codes would reflect that these situations would be unique among respondents as an individual. Individual factors could be among health determinants as different people would have their practices, beliefs, and immunity levels.

Subtheme: Immunity

A child with low immunity would be prone to diseases likewise.

Maybe his immunity is low, but maybe, can give him vitamins and eat more vegetables. If his immunity is strong, maybe he can avoid getting the illness (R3, F, A).

Subtheme: Hygiene practice

When there is a lack of hygiene practice, this situation might make someone prone to infection and vice versa.

… But maybe because he hangs out with his friends near the house within the housing area. When I saw there were boys and his friends, they didn't seem to take care of personal hygiene as well. I am afraid they're carrying dirty germs as well (R3, F, A).

… That's the problem with it. This toilet was a toilet that went straight to the river. It was a bit dirty back then (R1, M, A).

So, the villagers are more dependent on the river. So, the water from the river would be channeled through the village pipes. So that water is used for cooking and washing (R10, F, A).

Subtheme: Spirituality

The same goes for spirituality, as individual religious beliefs and practices would differ. When someone prays more, their hope for betterment will affect their lifestyle towards matters that would be beneficial for health.

…. for me, doctor, there is no other way for me to just pray. That's the key for my child (R4, M, A).

Theme: Socioeconomic situation

When a person comes from a low socioeconomic situation, they would usually be at a higher risk for poor health and diseases like RHD. Low income and home crowding were the proxy measures of the socioeconomic situation. Nevertheless, low income might be related to home crowding because the family could not find and get a space of their own. That being the case, the socioeconomic situation would determine the child's health status.

Subtheme: Income

Therefore, by not living in a better home environment, this situation might be a condition that does not promote health but causes disease instead.

… Because there is no place left to stay. Indeed, that place is our people's home. Not mine but my father's for a long time. So, I got a job in the plantation, the oil palm plantation also within the stream of Sungai Adong (R1, M, A).

... My wife is a housewife. I work with the company, building the road—just a driver (R4, M, A).

… That's not there, nothing. Therefore, used a generator (R1, M, A).

Subtheme: Crowding

Most respondents mentioned that many home occupants were living under one roof. So, when someone gets sick or unwell in a crowded home, that would harm the rest in that same house. Likewise, when different individuals get exposed and sick from outside, they might endanger the other home occupants.

… Yes. This too, I can comment a little on this. If the house is too crowded and there are many families in the house. That too can cause this problem. Because we don't know what they're dealing with. Sometimes, they have a fever or flu (R10, F, A).

… During the school days, they mostly stay in dormitories. Maybe it's crowded in their dormitory because she was in a dormitory from primary school to secondary school (R4, M, A).

Theme: Knowledge application

When there was an absence of or inadequate knowledge, the respondent could not tell the cause of RHD. However, when the appropriate knowledge about RHD was applied, the respondent could identify and be away from the cause of ARF and RHD. Therefore, when there was a lack of knowledge, respondents could not practice preventive measures against the disease. Also, this would allow the disease to be in "stealth" mode, as humans do not know of its existence.

Subtheme: Lack of knowledge

Respondents could shunt away wrong concepts about RHD when the proper knowledge was applied during the interview and throughout their lifetime.

… So, I'm not sure if the home environment plays a role or not. We might not have any problem with the area within the house (R3, F, A).

I don't know. How? I have no idea either. What does the doctor think? (R9, F, A).

I don't know how to avoid it because I also don't know what is the cause. So, it's hard to avoid it (R5, F, A).

Honestly, Doc, I'm not sure (R8, F, A).

Knowledge application is also challenging due to respondents having different concepts of understanding. For example, all causes were mentioned because the child had experienced the condition. However, even though respondents expressed these thoughts, they still said they were unsure.

… Maybe she was too fat since childhood (R7, F, A).

… Maybe because it was too strong, maybe the kick was strong. Maybe, it's possible (R6, F, A).

… It already existed before birth. His heart was disabled (R1, M, A).

Theme category 2: External causes

External causes are considered factors that cannot be managed or manipulated to improve an individual's capacity or family. Therefore, these factors were considered beyond their control. These external causes would require something or a group of powers, such as the authority or the collaborative effort within the community, to manage or take control.[17] Health could be preserved or obtained with some influence from the authorities or through good collaborative effort and the other way around.[18,19] When the environment is unhealthy, human health is also negatively affected.[20,21] Their health in general would also be affected by the community surrounding them and the condition of their surroundings. Thus, the external causes are categorized into environment and healthcare accessibility.

Theme: Environment

The environment would include all areas outside the home wall, within the house compound, and beyond the house compound within the residential area or village. Apart from being exposed in their home's immediate area, exposure could also happen elsewhere. Some next-door neighbors maintained their surroundings, making the respondent's home in better condition.

Subtheme: Unfavourable environment

Given that personal spaces within the home compound were favorable for health, this does not guarantee the surrounding area or the residential areas will be as good since it would be due to other individuals' practices. Therefore, the respondents' environment should be from the pooled results of everyone in a residential area or anyone who ever existed in that same area.

Yes. Since I was young, there have been people who have smoked cigarettes near our place (R2, F, T).

… But maybe the environment outside the house, because I don't even know how far he went playing with his friends (R3, F, A).

… Usually on the football field with his friends (R4, M, A).

Because we here are living in a house located by the roadside. It's indeed dusty. Most likely, that was the cause too. We can't deny it (R9, F, A).

One factor considering the area of our house is sometimes, among the residents they will throw garbage everywhere, or throw it by the river. There is a drought, so the trash will be stopped without drifting away (R10, F, A).

Subtheme: Healthcare accessibility

Healthcare accessibility will always be a problem due to geographical challenges, especially in Sarawak. Given the limited access to healthcare, the children's health would be less advantaged apart from the lack of infrastructure and basic facilities. Moreover, since RHD is usually asymptomatic, parents would ordinarily assume everything was fine. This would

reduce the opportunity for the respondents to improve their health. Besides, no early screening could be provided when healthcare access is problematic.

This village has many factors that the residents need to care for, especially these children. The reason is that these children when they are in the village, they are not aware that the village environment is not clean anymore (R10, F, A).

So, there was no health check whatsoever. We all won't know (R5, F, A).

Maybe have them got checked earlier. But during their younger age, they never miss any nurse or doctor's appointment. Maybe during that time, the doctor should scan their heart. I guess (R8, F, A).

Maybe from a young age, she lived in a village far from the hospital (R5, F, A).

Discussion

Internal and external causes are some of the issues that could not be handled and vice versa, which led to adverse health consequences and the occurrence of RHD. This storyline is similar to past publications,[17,22] whereby internal and external factors determined the likelihood of engaging in a particular behavior that either encourages or discourages health-relevant behaviors. Although the internal and external factors were described differently than internal and external causes, similar conclusions were implied as internal factors would still be manageable by individuals or families. Furthermore, external factors would also go beyond an individual's or family's control and may require enormous extra efforts or authority to manage.

To complement the storyline grounded on the qualitative analysis, the internal and external causes could also be viewed as the *Strength, Weakness, Opportunity, and Threat* (SWOT) analysis. The strengths and weaknesses of SWOT analysis could be considered an internal aspect of a situation, whereas opportunities and threats could be regarded as external aspects.[23,24] Therefore, in internal causes theory, a person's strength could be used to better their health or life situation while an individual's weakness could be remedied accordingly with the same aim to improve health or life situation. Likewise, when the strength of a person was not leveraged as an advantage, and the weakness was not appropriately addressed, that person's health or life situation would remain status quo or continue to deteriorate.[19,20,25] In external causes theory, the opportunities could be the positive factors favorable for health or life situation improvement, and the threats could be otherwise. How much an individual or family tries to intervene in their health or life situation, these opportunities and threats would still be unaffected unless intervention came from a higher power or authority. The internal and external causes storyline would make more sense for these reasons.Moreover, the findings of thematic analysis had been in line with the social determinants of health, whereby the non-clinical variables that affect health outcomes could be viewed as factors that could and could not be managed or controlled by individuals and families.[19,21]

Building a relationship between the researcher and the respondent is integral to all types of qualitative studies.[26] There were minimal difficulties in building a rapport with the respondents before in-depth interviews for qualitative data collection, given that the same people had been screened during the echocardiographic survey. Therefore, the strength of this study lies in the data collection, considering the respondents were expected to respond without hesitancy during the interview. Since the target population in data collection was only limited to children with RHD, the findings can be generalized to a lesser extent unless respondents from the group without RHD were included. Opinions and inputs from healthy individuals or families without RHD would contribute to the value of the findings from the qualitative analysis.

Research implications suggest that the findings may be necessary for policy, practice, theory, and subsequent research improvements and implementations. Given that RHD predominantly affects lower and middle-income people, the screening program could target the lower socioeconomic status population. By addressing the problem from the perspective of the local community, a holistic approach could be strategized, and effective implementation could be done. These significant stakeholders could tailor their approach by promoting and encouraging self-improvement in socioeconomics and the home environment. Since these aspects of life depend on individuals and families, the government does not need to be entirely responsible for personal matters

that could and should be managed by themselves.

In conclusion, this study explores the determinants of RHD according to the family with RHD diagnosis and their perspectives are seen as internal and external causes. A holistic approach can be applied to manage RHD after considering these factors. Moreover, this study can also be used as important evidence to attract the attention of non-health stakeholders so that a collaboration that would make a difference could be turned into a reality.

Conflict of interest

None declared.

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