Post-surgical experiences of women living with rheumatic heart disease in Namibia

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Background. Rheumatic heart disease (RHD) remains a public health problem predominantly among women of reproductive age in low- to middle-income settings. Women living with RHD have various experiences pertaining to physical, psychological and reproductive health, before and after surgery.

Objectives. To explore and describe the post-surgical experiences of women living with RHD in Namibia.

Method. The study used a qualitative approach, using an explorative descriptive study to collect data from women living with RHD with in-depth interviews, followed by thematic analysis of the data. The final sample size was five participants.

Results. Key themes that emerged were related to positive experiences in terms of surgical outcome; stigma, family and social relationships, and reproductive health. The findings indicated that the women had a broad range of experiences both at home and at work, and in their reproductive relationships.

Conclusion. It is recommended that community RHD education programmes be enhanced to raise awareness and educate the communities in order to curb stigma and discrimination against women living with RHD. Programmes to support women with family planning and good maternal and child health are also recommended. The study findings have potential significance with regard to clinical practices involved in caring for women living with RHD, and efforts to improve their life experiences.

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Rheumatic heart disease (RHD) is a chronic condition resulting from acute rheumatic fever (RF), which is an autoimmune response to antigenic mimicry of certain group A streptococcus (GAS) antigenic protein during a GAS bacterial infection of the pharynx.[1] RF causes inflammation of the heart valves, causing progressive fibrotic changes due to avascularised valvular tissues, which lead to chronic RHD. The disease presentation ranges from mild to severe clinical disease, with severe outcomes including heart failure, atrial fibrillation, poor maternal outcomes, progressive morbidity/disability with reduced quality of life, and premature mortality.[2] Sometimes called 'a disease of poverty', RHD is commonest in socioeconomically disadvantaged settings, and is partially attributed to social determinants of health such as overcrowding, poor sanitation and inequitable access to healthcare, in addition to a genetic predisposition.[3]

Globally in 2018, RHD was estimated to affect ~40.5 million people and to cause >300 000 deaths annually, mostly in low- and middle-income countries.[4] The disease is most prevalent among people aged <30 years, mainly children and women of reproductive age. RHD is estimated to affect ~1% of the Namibian population, mostly children and young adults, with women of reproductive age most affected.[5-7] It is most common in the northern part of the country, which is mainly rural. Patients are managed at the only public cardiac clinic in the capital city, Windhoek, at the public tertiary hospital, Windhoek Central Hospital, where they receive chronic treatment and surgical interventions.[7] RHD is preventable by multimodal interventions focusing on reducing risk factors through improved living conditions, equitable access to healthcare, and benzathine penicillin to prevent recurrence of RF.[4] Surgical interventions are needed to repair or replace the damaged heart valves in severe disease. Patients with RHD need to take lifelong chronic medicine to manage their symptoms. Anticoagulants, mainly warfarin, are added to the treatment plan after surgery for patients with mechanical prostheses, to reduce the risk of stroke and thromboembolic events.[7]

Women of reproductive age are most affected by RHD, which places them at an increased risk of complications during pregnancy and childbirth.[8,9] Lifelong anticoagulation treatment after surgery is another contributor to adverse maternal, fetal and neonatal outcomes.[8] In addition to the risks posed by their heart disease, these women are also vulnerable to negative experiences and social challenges such as stigma and difficult future reproductive decisions, and discrimination due to compromised function in activities of daily living.[10] These life experiences and challenges often lead to emotional and psychological problems.[11] However, there is a paucity of knowledge regarding the experiences of women living with RHD in many of the endemic countries, including Namibia.

This study aimed to explore the post-surgical experiences of women living with RHD in Namibia. This information has potential significance in terms of their clinical and social care, and efforts to improve their living experiences.

Methods

We used a qualitative, exploratory approach to collect data relating to the post-surgical experiences of women living with RHD in Namibia. Purposeful sampling was used to recruit participants from women waiting in the queue at the cardiac clinic at Windhoek Central Hospital during their routine medical follow-up in June 2022. We included women aged ≥18 years who could provide consent to participate in the study, and were able to understand and speak English. Individual in-depth interviews were conducted by the researcher (SKK) using a semi-structured interview guide, in a private room at the clinic. Interviews were recorded with an audio tape recorder with the permission of the participants. Before data collection, the interview guide was pre-tested on three women living with RHD and revised based on their comments. Data saturation was achieved with five participants when no new themes emerged about the patients' experiences.

Data analysis was done using thematic analysis.[12,13] Transcription of the audio recordings, coding and analyses were done (by SKK) in Microsoft Word 2019 (Microsoft, USA). The researcher (SKK) familiarised himself with the data by rereading the transcripts before coding, and subsequently developing subthemes and themes. The transcripts were reviewed (by PPS) in a series of steps to confirm the classification of codes and theoretical saturation.

Ethical approval was provided by the Bioethics and Research Management Ethics Committee of the Namibian Ministry of Health and Social Services (ref. no. SKK2022). The hospital superintendent's office approved collection of data. Informed consent was obtained from each participant before the interview. After explaining the aims and significance of the study, participants were given an opportunity to ask questions. When they were satisfied with the answers given, they proceeded to sign the written informed consent. Audio tape recorders, field notes and transcription notes were stored in a lockable cabinet accessible to the research team only.

Results

A total of five women living with RHD participated in the study (Table 1). The mean age was 32 years, and only two participants had had children after their heart surgery.

Thematic domains

Key themes generated in the interviews were grouped into four domains (Table 2): (*i*) positive experiences related to surgical outcome; (*ii*) stigma; (*iii*) family and social relationships; and (*iv*) reproductive health.

The findings indicated that the women had a broad range of experiences, both at home and at work, and in their reproductive relationships.

Discussion

The findings of the present study illustrate the living experiences that women with RHD go through in their daily lives. A positive theme in the findings was personal life experiences related to successful surgical outcome. Women with RHD are often reported to have a positive attitude to their lives after surgical intervention and positive outcomes of care.[10] Comparing their lives before surgery and at the time of the study, the participants indicated that the surgery had helped improve their quality of life, which had been adversely affected by their heart condition, as they could not perform heavy duties, carry heavy objects or walk long distances. Participants also reported positive experiences in that they were now able to perform all tasks relating to their personal and self-care.

Experiences with regard to family and social relationships varied between participants, but were consistent in terms of positive and negative experiences. On the positive side, the participants reported receiving support from family and friends, at home and in social places. On the negative side, they revealed that they were treated differently by relatives and friends because of their RHD. Participants sometimes felt that they were being treated differently even though they could manage their daily tasks. In most cases, family, relatives and friends treated them as someone with a delicate condition that prevented them from living a normal life and undertaking routine activities in their homes such as cleaning, cooking and doing laundry – they were considered fragile. Even socialising outdoors was seen as a risky activity, and in most cases friends were known to be reluctant to take them for outdoor activities, fearing a relapse. The participants felt that this was all related to people being sceptical about and fearful of the condition. The findings within the theme of family and social relationships in this study are similar to those of previous studies exploring the experiences of people living with RHD. A study in Uganda by Chang *et al.*[10] found that women with RHD often received good support from family and friends, but other relatives stigmatised the women in terms of their ability to perform daily chores. Tye *et al.*[11] reported similar findings to the present study, with people living with RHD being treated with special care by their families and within their social circles, even though they could manage their daily tasks with no difficulty.

With regard to stigma, our findings are similar to those of previous studies in which women with RHD reported experiencing stigma in various forms, both in the community and in the workplace.[10,11,14] This stigma was largely related to the physical limitations due to the illness being viewed as potentially causing difficulties at work. Participants in the present study reported challenges of being stigmatised in the community and in the workplace. Because of their condition, some of the participants were barred from performing certain tasks even though they were fit enough, and some had even found themselves losing out on work opportunities upon disclosure of their health status. Apart from unintended discrimination or stigmatisation, some participants also identified a change of attitude towards them upon disclosure of their health status to their colleagues or management. On a positive note, changes of attitude were not always negative, as some people admired them for living with their condition yet being able to perform their duties like everyone else. Overall, however, participants felt that the stigma around RHD was often sufficient to make those living with the condition completely give up any chance of getting a job. With regard to performing job-related tasks, one participant stated that she was able to do her job as efficiently as other people who were not living with RHD. She could spend the whole day standing at work and was still able to do the household chores when she got home, as well as anyone else.

The present study found women to have negative experiences regarding their reproductive health, which is similar to reports in the existing literature. Women are likely to have negative pregnancy outcomes, which can subject them to poor treatment by their relatives and partners.[8,15] Voleti *et al.*[16] reported that women with a diagnosis of RHD were victimised by their husbands and their husbands' relatives,

Table 1. Sociodemographic characteristics of the study participants (*N*=5)

	Participant				
Variable	**1**	**2**	**3**	**4**	**5**
Age (years)	29	27	30	33	39
Marital status	Single	Engaged	Engaged	Divorced	Single
Highest qualification	Certificate	Certificate	Degree	Certificate	Matric
Employment	Unemployed	Unemployed	Employed	Employed	Employed
Children post surgery	0	0	2	2	0
RHD diagnosis year	2019	2001	1997	1997	1990
Surgery year	2021	2004	2011	2010	2008

RHD = rheumatic heart disease.

Table 2. In-depth interview themes and exemplar quotes

Theme	Exemplar quotes
Positive experiences related to surgical outcomes	'I am now fine compared to the way l was before operation and I can do any other work that other people who are not diagnosed can do.' (P3)
Stigma	'… they understand the condition of RHD though they see me as patients even after operation.' (P1) 'It is disturbing for most if not all RHD patients especially relation-wise since some of the boyfriends or husbands end up separating from us because of RHD. It is something I am going through.' (P4)
Family and social relationships	'They're fine and they don't discriminate. They involve me, but I don't like going out as I hate noise.' (P5) 'He understands because we met before my operation, and he saw me suffering before.' (P1)
Reproductive health	'They do. For example, if I want to have a baby, you should talk to a doctor before you can have a baby.' (P1) 'He takes it as it is as he knows my condition. He is supportive but he is scared to try to have babies after my two miscarriages and my RHD condition.' (P5)

who thought that their prognosis was poor and that it would be difficult to take care of them.

The present study showed that issues around reproductive health are an area of concern for women who have undergone heart surgery, and that the stigma surrounding RHD particularly affects women of childbearing age. Childbearing in many cultures is considered to be a woman's primary role, which is seen as being hindered by a heart condition. Childbearing is regarded as part of family reproduction, and failure to bear children in accordance with the family's expectations tends to provoke displeasure, which is centred on the woman rather than the man. One participant in our study, for instance, recalled how her boyfriend asked her about starting a family and was worried that her surgery would affect her ability to bear children. Other participants' experiences of reproductive health concerns after undergoing heart surgery revealed different perceptions on the issue. One participant described the misconceptions of women living with RHD in terms of reproductive health, stressing that there was a lack of information on this subject. Family members, particularly men such as boyfriends or husbands/partners, often lacked knowledge on reproductive health after RHD. There were also mixed experiences, with partners who were supportive, but still scared of living with the women.

To our knowledge, this is the first study to explore the experiences of women living with RHD in Namibia, a main strength in our findings. We acknowledge that our inclusion criteria are a potential limitation, as only women who could speak and understand English were included. However, we regard the findings to be representative of all women, as data saturation was reached in the data collection.

Conclusion

The study explored experiences of women after having heart surgery for RHD in Namibia. Key themes in the findings showed that the women had a positive attitude towards their life after a successful surgical outcome. Also, they reported experiencing good support from their family and social circle. However, the women were still subjected to stigma in the community and in the workplace. Furthermore, they reported possible victimisation in their relationships owing to the potential limitations imposed by the disease in terms of their ability to bear children. It is recommended that community RHD education programmes be enhanced to raise awareness and educate the communities in order to curb stigma and discrimination against women living with RHD. Programmes to support women with family planning and good maternal and child health are also recommended. Our findings have potential significance with regard to clinical practices involved in caring for women living with RHD, and efforts to improve their life experiences.

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