Perception of parents whose children have rheumatic heart disease at a referral hospital, Kenya

Myra Koech, MD, Titus Ngeno MD
Moi Teaching and Referral Hospital Eldoret Kenya, Division of Cardiology, P.O. box 3, Eldoret.

*Corresponding author email: ttitongeno@gmail.com
Accepted 03 September, 2013

Abstract

Objectives; Rheumatic heart disease remains a leading cause of morbidity and mortality in Africa, especially amongst the young population. This paper set out to explore the views of parents whose children have rheumatic heart disease, in regard to their experiences in taking care of the affected child and its overall effect on their families. Study design; Focused group discussion. Methods; This was a study carried out at the Moi teaching and referral hospital, pediatrics cardiology clinic between October 2011 to October 2012. Ten parents comprising five mothers and five fathers of different children were randomly selected from a pool of telephone records of patients with rheumatic heart disease and were attending the pediatric clinic. Two separate focused groups comprising fathers and mothers were formed and piloted open ended questions were used to conduct the discussion. Results; Living with a child who has rheumatic heart disease causes financial difficulties’ and uncertainties, and parents are unable to afford the cost of surgery. The genesis of rheumatic heart disease is not well understood and there is a constant fear of the child’s impending death. Conclusions; For children with already set in rheumatic heart disease, subsidies for surgical care needs to be provided immediately so as to avoid complications and the chronicity associated with uncorrected rheumatic heart disease. Families need psychological support upon diagnosis of a child with rheumatic heart disease.

Keywords: rheumatic heart disease, parental perceptions, referral hospital

INTRODUCTION

Rheumatic fever is caused by Group A beta hemolytic environment for transmission of the causative bacteria streptococcus, causing rheumatic heart disease in 0.3- (WHO, 2001). RHD accounts for a major proportion of all 3% of patients who have pharyngitis from this organism. Cardiovascular disease in children and young adults in it is an autoimmune response triggered by the infecting African countries (Sani et al., 2007; (Koech et al., 2012). agent (Carapetis et al., 2005). It affects most parts of the Rheumatic heart disease progresses over time. body but the most devastating sequel is the post Valvular regurgitation or stenosis gets worse and this pharyngeal streptococcal non-suppurative may be expedited by recurrence of acute episodes of cardiovascular complications. Rheumatic fever and its attendant valvular inflammation.

The peak age of infection is 5 to 15 years, though its Ultimately patients need valve replacement surgery to chronicity can run for a lifetime. After post streptococcal remedy the defective valves. Moreover, it is often pharyngitis, more than a third of all affected children complicated by chronic congestive heart failure and
develop rheumatic heart disease (RHD) and if recurrent thrombo-embolic phenomena, both of which accompanied by recurrent infections, can later lead to pose a great challenge in management (Sani et al., permanent valvular damage (Guilherme et al., 2007). 2007).

RHD remains a great public health burden and causes. Unfortunately valve replacement surgery is up to 200,000 deaths worldwide (Carapetis et al., 2005). Unaffordable for most patients in Africa in general and in Whereas Africa has 10% of the world's population, as Kenya in particular (Connor et al., 2005). The cost of a many as half of the 2.4 million children affected by RHD mitral valve replacement in a public hospital in Kenya is globally live on the continent. RHD is associated with 6000 US dollars, approximately 7 times the annual per poor living conditions thought to provide an ideal capita income of an average Kenyan family (The World Bank group). As a result, many patients live with uncorrected heart lesions (Mocumbi, 2012; Mocumbi, 2012). This leads to many subsequent expensive trips to hospital as they live out the life history of the disease (Mocumbi, 2012).

Apart from the physical complications that a patient with rheumatic heart disease develops, there are other social, psychological and financial implications that the child and the family must face (Steer et al., 2006). Heart disease is almost always a family affair (Connor et al., 2005; Wray et al., 2013; Jean et al., 2010; Mughal et al., 2011), every member of the family has to adjust in order to accommodate the family member affected by the illness. The financial costs to the family are enormous (Jaiyesimi, 1982), hospital stays for patients with RHD are long, drugs, laboratory investigations and cardiac surgery costs are equally prohibitive (Mocumbi, 2012; Mocumbi, 2012; Jouyi-yuko, 2012). The parents and the other children have to adjust their lifestyles as they attempt to share their duties as care givers to the chronically ill child in the family. One or both of the parents has to stop working in order to be a full time care giver which can impact negatively on the family resources. (Jean et al., 2010) The other children may feel neglected as all the attention is paid to the sick sibling and having to live with a child with a chronic illness affecting a very vital organ, can lead to depression on the parents and other members of the family (Holmbeck et al., 2002; Mocumbi, 2012; Quittner et al., 200).

Background

This study was conducted at the Moi teaching and referral hospital, the largest hospital in western Kenya which serves as the referral centre for the region and extending beyond the country’s borders into southern Sudan, with a catchment population of about 19 million people. It serves approximately 21800 sick children per year of whom an average of 3000 are admitted on a yearly basis. It is estimated that 4 percent of these hospital admissions have heart disease.

There is a dedicated weekly pediatric cardiac clinic, catering for approximately 800 per year children with electrocardiogram (ECG) and echocardiographic study facilities and adequate laboratory and radiology services. Patients attending this clinic are children aged from birth up to 14 years.

This study attempted to broadly explore how parents and children perceive the disease, cope with it and identify what impact, in their perspective, the disease has had on them. It also looked for possible solutions to the challenges that they face, from their own perspective.

METHODOLOGY

This was a cross sectional focused group discussion conducted amongst children and parents/guardians whose children have rheumatic heart disease, and were attending the cardiology clinic at the Moi teaching and referral hospital. It was part of a larger cross sectional descriptive study of the socio-economic impact of heart conditions on children and their families as seen at the hospital.

Ten parents comprising five mothers and five fathers of different children were randomly selected from a pool of telephone records of patients attending the clinic, who had previously been sequentially enrolled into the larger study. The parents/guardians were separated into two groups based on gender to allow women a chance to fully express themselves; the investigators felt that this being a patriarchal society women were less inclined to express their thoughts freely in the presence of men (Issaka et al., 2013).

The social demographic data of the participants is as shown on table 1.

The interview was conducted principally by a trained female qualitative research assistant, who is fluent in Kalenjin (the native language of the majority of patients) English and Kiswahili. The research assistant was assisted by a male medical doctor (investigator 2). The research assistant does not work in the cardiology clinic, but the medical doctor does. The interviews were conducted mainly in Kiswahili, but in some instances the participants resorted to Kalenjin when they felt they would best express their ideas. The principal investigator who is the chief doctor in the cardiology unit stayed away from the interview in order to allow the participants to freely express their experiences.

A pilot tested open-ended questions were used to conduct the interview, each focused group discussion took an average of four hours.

This information was audio taped, transcribed and translated into English, by the research assistant with the help of the authors. The analysis of the data and report writing was done by the authors. The analysis of the data...
had the following steps; 1) Familiarization with the material; 2) Formulation of emergent themes; 3) Coding of different themes; 4) Reorganization of data under different themes; and 5) Interpretation and explanation of findings. (Mays and Pope, 2000; Pope et al., 2000).

MS word and excel spread sheets were used for data organization.

Approval to conduct the study was obtained from the Moi teaching and referral hospital/ Moi university school of medicine institutional review and ethics board.

### RESULTS

#### Impact of the clinical evaluation and diagnostic process

The participants are mainly rural based and their first point of care is the dispensaries and the health centers. There is poor understanding and awareness of rheumatic heart disease amongst community members and even health practitioners in the dispensaries and health centers. All the parents reported that when the disease signs and symptoms first started, they had no idea as to what the matter could be. After many visits to the health delivery points usually two years, that is when they were given a referral to the Moi teaching and referral hospital (MTRH). It is at the referral hospital were the definite diagnosis by echo was accomplished, the appropriate drugs that seemed to help and further care was discussed. The participants wished to know;

- Why does it take so long to reach a diagnosis?
- Do the workers at the peripheral centers understand this disease?

Is it not possible to have care close to us, instead of making trips to this far away referral center? Traditional medicine was tried extensively during the periods of uncertainty of the diagnosis. The parents wished that their first health providers were well versed in this disease and thought that it could have helped to reduce anxiety associated with it. As one father said: “this
disease has affected us since 2010 (2 years), I went to hospital where the child got some medications, which did not help. We then visited herbalists and the doctor who cuts epiglottis and this was of no use either. after moving from hospital to hospital, we were seen at a district hospital, a chest x-ray showed the child had a large heart and we were then referred here (mtrh), this year (2012) where we were admitted and the disease was finally given a name”.

#### Fears associated with rheumatic heart disease

As soon as the diagnosis of rheumatic heart disease was made, most of the parents reported feeling a profound sense of shock. To them heart disease equaled death and they became very anxious as manifested in their loss of sleep, anorexia, staying awake looking after child lest he dies in his sleep and inability to work effectively; One father said; “When this child starts snoring at night, my wife and I cannot sleep because we are worried he could die. We take turns watching over him the whole night and as soon as day light breaks we rush him to hospital”

A mother whose son is 14 years of age reported “Although he is of age, I cannot allow him to sleep in a separate bedroom. He sleeps in the same room as me so that in case he develops complications at night I can help him. I am so scared he will die alone at night”

When talking about their children some mothers freely wept on recollection of the difficulties they have to endure because of the children’s condition .Their concerns were fear of death, financial strain, community and family stigmatization, and the emotional exhaustion from being the constant sole primary care giver of the child

The men however were very stoic, explaining that although deep in their heart they were terrified, culturally it was not acceptable for them to show their emotions. And for the sake of their wives and children, they had to put up a strong front and not alarm the family with talks of death, high financial bills and other recurrent worries.

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Marital status</th>
<th>Religion</th>
<th>Occupation</th>
<th>Relationship to child</th>
<th>Child’s age Years since diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>42</td>
<td>Married</td>
<td>Christian</td>
<td>Farmer</td>
<td>Father</td>
<td>9</td>
</tr>
<tr>
<td>63</td>
<td>Married</td>
<td>Christian</td>
<td>Farmer</td>
<td>Father</td>
<td>13</td>
</tr>
<tr>
<td>28</td>
<td>Married</td>
<td>Christian</td>
<td>Business</td>
<td>Father</td>
<td>6</td>
</tr>
<tr>
<td>58</td>
<td>Married</td>
<td>Christian</td>
<td>Farmer</td>
<td>Father</td>
<td>13</td>
</tr>
<tr>
<td>41</td>
<td>Married</td>
<td>Christian</td>
<td>Farmer</td>
<td>Father</td>
<td>8</td>
</tr>
<tr>
<td>45</td>
<td>Married</td>
<td>Christian</td>
<td>Farmer</td>
<td>Mother</td>
<td>13</td>
</tr>
<tr>
<td>34</td>
<td>Single</td>
<td>Christian</td>
<td>Self employed</td>
<td>Mother</td>
<td>12</td>
</tr>
<tr>
<td>34</td>
<td>Single</td>
<td>Christian</td>
<td>Business</td>
<td>Mother</td>
<td>14</td>
</tr>
<tr>
<td>50</td>
<td>Married</td>
<td>Christian</td>
<td>Farmer</td>
<td>Mother</td>
<td>13</td>
</tr>
<tr>
<td>37</td>
<td>Married</td>
<td>Christian</td>
<td>House wife</td>
<td>Mother</td>
<td>14</td>
</tr>
</tbody>
</table>
However, one father who had previous experience with RHD, as he himself had been treated, did not seem to think the issue was all doom and gloom.

He said: “Let us say financially it is challenging and then even me myself I had the disease so it was easy to know because when the child fell sick, I came to ask them to diagnose and they diagnosed and they found the disease was there. And also issues of drugs, in school the child is doing well, hhm the child gets a little bit weak, the child cannot play, only playing but reading is okay and passes very well”.

Another parent whose children had undergone surgery encouraged others to do likewise because it had substantially improved his child’s well being and the financial pressure eased a little. Discussing the disease with teachers, neighbors and the family from a point of knowledge helped greatly with the child’s condition.

The extended family, community and school

The extended family and the community were viewed in an ambivalent manner. On one hand, this group of people offered both material and emotional support but on the flip side, their constant enquiring on the child’s well being was considered intrusive and disturbing to the affected child.

Financially the extended family helped with medical bills especially where large sums of money for surgery were needed. However because of the chronic nature of the disease, the extended family members could only do so much because they too had their own families to care for. One mother said; “In most cases, when the child has been diagnosed with heart condition, the relatives or the family members can run away from you because they know that you need financial support every now and then…

‘(Interviewee weeps/sobs).’‘...they see like you are useless’... (Weeps) Neighbors acted as creditors too

There was anxiety amongst the extended family members and community about the child’s well being. Relatives as well as neighbors kept asking about the child, always wondering whether the child is dead yet.

Many of the children would ask their mothers not to reveal their illnesses to others because the manner in which people would react with shock was disturbing to them. A mother said this; “And you know as a parent you ought to be close to the sick child, walk with him/her everywhere you go (Weeps). If you walk with her you may meet with friends and they will ask you, is this child who has the heart condition? I am sorry. With such a question the child will be concerned and will say it is like my illness is not normal because people are shocked when they see me. My son once told me not to tell anyone of my condition because people are always shocked. This disease has brought many issues and it is really feared by many people (Weeps)”. Sometimes neighbors would ask if the disease is contagious so that they can keep off the family and the sick child “Actually even my neighbors have been wondering and asking me whether the heart condition is contagious especially when children play together. So please one day just teach us and tell us if the condition is really contagious so that we know how to take care of our children so that they do not infect others” The siblings keep asking about their brother wondering whether he will die soon. The siblings become anxious; may refuse to go to school, to eat or to play as they constantly hover over the sick brother/ sister.

One father felt that discussing and not hiding the condition helped everyone from the family, neighbors and extended family to come to terms with the disease “at home we have discussed with the family I have explained to them, even if the child does wrong, no one should touch him because they understand the condition so this thing does not need to be hidden, if there is anything, inform even your neighbors so that they take good care of the child, that is what I did, I don’t know of others” Children spend a considerable amount of time in school and the parents and teachers who are well briefed on the child’s condition, are understanding and help the child in school to adhere to limited physical strain. A father said; “when I was discharged from hospital, I was given a letter on how the child should conduct himself, and I came to deliver it to the school and we discussed with the teachers in the staff room then the head teacher came to the parade and explained to students how the child should conduct himself, so I could see my child is well taken care of”. However, the teachers who are poorly conversant on the disease and are poorly briefed give the child a hectic time in school including demands for child to run marathons. A mother reported “You know in school all teachers are not the same. There those who are ignorant and even if they know a child’s problem, they do not take it seriously. For example in my daughter’s school, there was a new teacher who asked the pupils to go for cross country. My daughter went aside because she cannot run and told the teacher that she has a chest problem; she fears to say that it is a heart condition. The teacher asked her to run five laps so that she gets well (The group is shocked: WOII!!). She run while crying. In the evening the other children told me that Faith was asked to run. Later I went to school and the head teacher asked me to forgive because it was a new teacher. Now my big question is what happens should the child collapse and it is all because of ignorance. Teachers in school really need to be sensitized. When a child’s school grades start deteriorating, some teachers simply give up on the child and do not make any effort to help, sometimes because even they as educators do not know how to remedy the situation. One mother reported; “You know generally when the heart is good the brain will also work well. My son is no longer doing well in school. He may not write anything at all and when you
ask he tells you he was feeling too tired to write. When you go through the books you find that there is nothing he has written completely. Also there is that labeling that he is sick. Even the teachers are not very keen. I have been called several times to school and I ask about my son’s performance, I am told we know he is sick and there is nothing we can tell him. My son has also known that he is sick and does not do much in school. When he was serious, he would do very well in school but right now he is second last position in class!”

The child himself

The parents have observed that apart from the signs and symptoms that come with the disease the children are very temperamental. They get easily angered especially by their friends and their peers. This forces the other children to avoid their brother/ sister so as not to antagonize him. My son has also known that he is very temperamental. They get easily angered especially because he is usually very temperamental. My other children became very uncomfortable staying around their sick brother and I had to take them to my maternal home because the sick one would beat them every time he became sick because he would be temperamental. So my other children have kind of isolated or segregated themselves from the sick one and they are always unhappy. In fact when we came here this morning, the other children told me that they would have a lot of freedom today because their brother is not around thus they will not worry or be cautious while playing.

The parents felt that the children were being ridiculed by their peers and also the children were somewhat worried that they may never actualize their dreams due to the illness they suffer from; mum said;

“You know, even running they cannot. Now, the rest sometimes make fun of them. For example the young ones can ask that they compete knowing that they will definitely win and then make fun or ridicule them. One day my daughter said she wanted to be a world champion like Rudisha. The siblings laughed at her telling her you have always been the last how can you be a world running champion?”

The children with RHD sometimes feel overwhelmed by the disease burden and feel that they cannot keep up with their peers, their school work and in a way are letting their parents down some become depressed and suicidal. A mother reported;

“Yeah, even sensitization or education in school, sometimes my child does not want to go to school because the friends/classmates always sympathetic of his condition and cannot be disciplined by the teachers. He is left out on some activities because of his condition. Recently, I told my son to work hard in school so that he is promoted to standard Eight and we will not have to look for another school. He told me, mum I am becoming a burden to you, and I feel like committing suicide”

The parents lavished lots of care on these children for example ensured that they had special food, kept warm, protected from any bullying. And although the children appreciated all this, they were always wondering whether they will be forever labeled as sickling; mother reported;”

“My son is always told...you are sick do not to play ‘...because of his condition, so he feels kind of isolated and asks ,mum, I am I always sick?”

This extra attention would also sometimes elicit negative emotions amongst the other children who would feel deprived as all the money and attention would go to the sick child. Mothers especially, said they felt guilty that all her attention was focused on the sick child.

Financial

This is a very expensive disease, they need money for the clinical evaluation, diagnostic tests, drugs, transport to and from the MTRH, transport to other Centers such as Nairobi, the cost of hospitalizations and the required funds for surgery, are way beyond their financial abilities. As one parent put it “at the MTRH, in each room where you are sent to, money is required for one thing or the other, and no service is availed unless receipts are produced”. It has had a massive toll on them. One parent had sold his family land and they were now living on half an acre of land, down from five acres. Most farm produce is sold to meet medical bills. The financial stress affected them negatively and fathers reported many periods of insomnia wondering where finances would come from and how to prioritize expenses. One father said, “I wish to say that generally the heart condition is very expensive. This is because drugs have to be taken daily and they are very expensive. This actually brings conflicts in the family. For example one could be thinking of education for the other children and the other treatment. It turns out to be two problems; payment of school fees and treatment expenses. In that case, a spouse can meet the treatment costs but complains that it is even better to pay school fees. In fact some pay school fees for a whole term comfortably and says education is better and cheaper than the treatment of a chronic disease which you are not even sure if the child will live for long. So actually, this condition is very expensive and it can bring conflicts in the families”. Asking them to raise half a million Kenya shillings for surgery at a medical center in Nairobi or India looked like a cruel joke. Meeting the child’s needs means there is less money for the other family members; for food, school fees and clothing.
Relatives and neighbors, from whom they borrow money, many a time, feel that the parents are becoming a drain on them. Some mothers wept when they recalled how they have had to keep asking for money from their extended families or friends. They felt useless.

Government

The parents are mainly small scale farmers and their income is seasonal and inadequate according to them. This disease is very expensive to treat and the main clarion call was that they needed help from the government. They likened it to HIV/ TB which the government subsidizes.

A father said.” People always know the child affected will die anytime and that it is not like other diseases. Some even liken the heart condition to HIV/AIDS. What I can say is that provided the money or financial support is there, then the condition can be managed. If one million is required for surgery in India getting that amount is not easy even if one has to sell or dispose all the property like land, it will not be enough. How will one travel to India? Money is a great challenge. I also heard of the TB, even HIV/AIDS you don’t pay. It is better we be given such services because this is more less than HIV”

They wished that their nearest point of health delivery that is the dispensaries and the health centers were able to handle diagnosis and follow up comprehensively instead of them making journeys to MTRH and surgery at least should be available at the MTRH sparing them the need to make expensive trips to Nairobi or India.

The parents thought perhaps heart disease should be screened routinely like HIV. The felt like the way elderly people are screened for heart disease, so in children we should actively look for it

DISCUSSION

The children in this study predominantly had mitral valve disease, which is fulminant in nature, most of them needing surgery.

Our participants were farmers from the rural area, who observed that is, took an average of two years from the child’s initial presentation at the health center to the time a definitive diagnosis was made at the referral center.

The delay in the eventual diagnosis may be attributed to the fact that the primary health care workers at the periphery are heavily dependent on their clinical acumen for diagnosis and may misdiagnose Rheumatic fever / rheumatic heart disease for other common tropical illnesses such as malaria (Hansen, 1943).

In Africa, children are undeserved; there are few pediatricians in general and pediatric cardiologists in particular and most of them are urban based (Mocumbi, 2012). Moreover confirmation of rheumatic heart disease is dependent on echocardiography, which is only available in a few referral centers with scarce cardiovascular workers (Mocumbi, 2012). Despite being referred, patients also may take along time to make appointments due to financial constraints and traveling distance (Mocumbi, 2012).

Few countries in Africa have adequate cardiovascular drugs and are not compliant with the World health organization essential drug list due to poor political will, lack of funding and human personnel. Even with a clinical diagnosis of rheumatic heart disease in the periphery, the health work and the patient may not have access to the cardiac drugs leading to worsening of the heart condition (Mocumbi, 2012).

In an Australian study (Mincham et al., 2003) patients knowledge on acute rheumatic fever/ rheumatic heart disease was variable. With their compliance to prophylaxis being good if the staff-patient relationship was positive, while living far from health facilities impacted negatively on the utilization of health care. The patients in the Australian study voiced the need to have accessible health care and information that was delivered in a culturally acceptable manner. These views were echoed our participants concerns.

Even with the confirmation of the disease, parents opted for herbal drugs in the belief that this would cure their child. Acceptance of a heart disease diagnosis takes some time and was initially received with shock and denial.

In a study by Garson (Garson et al., 1978), once a diagnosis of heart disease has been made, parents need to be informed of the disease etiology, pathophysiology, symptoms and normalcy of the affected child. A psychological process similar to mourning is required at the time of diagnosis and at the time of corrective surgery in order for the parents to adapt to the child’s condition. The children, as reported by their parents, have tired of being viewed differently from their peers, with an uncertain future, where death is always impending and are always anxious and depressed. Like other children elsewhere with heart disease, low self efficacy coupled with fears of being excluded made them decline to be active in any appropriate sporting activity (Moola et al., 2008).

In a study looking at the emotional well being of toddlers with congenital heart disease a correlation was found between increased levels of anxiety in toddlers with moderate to severe congenital heart disease (Larsen et al., 2011). Heart disease for these parents was synonymous with imminent death and these brought a lot of fear and uncertainty about their children’s mortality as it occurs in parents of children with long QT syndrome (Farnsworth et al., 2006). It therefore calls upon the better education of the health workers on these conditions to better assist the families and of course provide tangible solution to make the children well again.

The financial burden of this disease cannot be over...
emphasized; money is needed for transportation to the hospital, diagnosis, consultation, laboratory tests, admission, drugs and surgical operation. Most of the participants are peasant farmers with seasonal income and the average per capita in Kenya is 808 US Dollars classifying it as a low income country (The World Bank group) Kenyans like many others in sub Saharan Africa have no comprehensive social and health insurance (Damasceno et al., 2007) and therefore the cost of out-of-pocket care is very steep on the families. This impacts negatively economically on the entire family members.

The average cost of monthly clinic visits to our referral centers are 35 dollars to cover for transport, investigations consultations and drugs. Surgical intervention on average is about 6000 dollars, a sum out of reach for most of our patients (The World Bank group).

Our recommendations are, first, Improvement of cardiology and cardiac diagnostic services by the government to facilitate early diagnosis and intervention as need be. Secondly, training of more cardiovascular personnel to be deployed in all health facilities and equipping them with information to share with patients about rheumatic heart disease. Thirdly dissemination of information to the community especially schools about the chronic nature and treatment of the disease and finally there should be a systematic psychological support for parents and children with rheumatic heart disease.

Bibliography


Mocumbi AO(2012); Lack of focus on cardiovascular disease in Sub-Saharan cardiovascular diag Ther:2:747.DOI:10.3978/J.issn.2223-3652.2012.01.03.


