

ORIGINAL ARTICLE

BARRIERS TO EFFECTIVE FOLLOW-UP TREATMENT FOR RHEUMATIC HEART DISEASE IN JMMA, ETHIOPIA: A GROUNDED THEORY ANALYSIS OF THE PATIENT EXPERIENCE**Kadia Petricca¹, Yoseph Mamo², Abraham Haileamlak², Etalem Seid², Eldryd Parry^{1,3}**

ABSTRACT

BACKGROUND: *Rheumatic fever and rheumatic heart disease continue to be a major public health concern for many resource-poor countries. Although considered most cost-effective and sustainable for treatment programs to be integrated into existing health systems, such recommendations are difficult to up-scale in rural settings. Additionally, adherence to monthly follow-up treatment remains challenging for rheumatic fever/rheumatic heart disease patients who struggle to meet the costs required to seek treatment. More research is therefore required to enhance our understanding of the barriers patients encounter when seeking care in order to improve access to services and sustain follow-up treatment. The objective of this study was to identify the factors influencing the treatment seeking behavior of rheumatic fever/rheumatic heart disease patients and their caregivers and to develop a conceptual tool to improve health service utilization of rural patients.*

METHODS: *Using the principles of grounded theory, 20 patients with rheumatic fever/rheumatic heart disease and 13 caregivers of pediatric rheumatic fever/rheumatic heart disease patients were interviewed through a process of theoretical sampling. Participants were recruited at the Jimma University Hospital Chronic Illness Follow-up Clinic.*

RESULTS: *Three categories of barriers emerged as fundamental factors influencing patients and caregivers to seek care. Firstly, patient perception of illness and medication played a large role in the rationalization process of care seeking. The second category, quality of care and service delivery, was largely influenced by patient medication side effects, treatment schedule, clinic distance and rapport with health staff. The third category, costs associated with care, involved both the financial burden and opportunity costs of traveling to the clinic.*

CONCLUSIONS: *Disease perception, quality of service and cost associated are major factors affecting rheumatic fever/rheumatic heart disease follow-up at Jimma University Specialized Hospital follow-up clinic. These 3 categories led to the development of a conceptual tool that can be used by health providers and policy-makers to improve the use of health services for critical follow-up care.*

KEYWORDS: *Rheumatic Fever, Rheumatic Heart Disease, Grounded theory, Jimma*

INTRODUCTION

Rheumatic fever (RF) and rheumatic heart disease (RHD) are a major public health concern for many developing countries (1, 2, 3). While epidemiological trends of RF and RHD have progressively declined in economically developed countries over the past 50 years, they continue to increase at a striking rate in the developing world (4). Linked to poverty and poor access to health care facilities, estimates suggest that roughly 50% of cardiac patients in less developed countries have RF or RHD(5). To limit the progression of the disease, the World Health Organization recommends that patients take monthly treatment of penicillin (5). However, adherence to monthly treatment is not easy for poor populations who

struggle to meet the costs and constraints required to seek treatment.

In Ethiopia, RF/RHD are the major cause of cardiac pathology (6). Rates continue to increase as a result of minimal diagnostic assessments and low attendance for monthly follow-up treatment; issues which are further exacerbated in rural areas (5).

To improve health service provision, this study sought to identify the factors that influence RF and RHD patients' decision to seek treatment in Jimma, Ethiopia. The principles of grounded theory were used to heighten the understanding of patient treatment seeking in this context. It is intended that these results will provide an in-depth understanding of patient needs and experiences related to seeking treatment and guide the improvement of health care services for RF/RHD patients in rural areas.

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METHODS AND PARTICIPANTS

A qualitative study was conducted on RF/RHD cases at Jimma University Specialized Hospital (JUSH) from June to July 2006. During the study period 110 pediatric and 400 adult RF/RHD cases were following treatment in chronic illness follow-up clinic of JUSH. Grounded theory guided the sampling of cases and the collection and analysis of interview data. Study subjects were cardiac patients with a history of RF/RHD receiving follow-up care and caregiver of a pediatric RF/RHD patient bringing their child for treatment to the Jimma Chronic Illness follow-up Clinic (CIFC). Caregivers were included due to their large influence over the health seeking behavior of their child. Thirty-three participants were interviewed at the CIFC based on theoretical sampling. New participants were included as new ideas and concepts emerged during data collection.

In depth interviews were conducted using semi-structured questionnaires. Two local interviewers were recruited and trained on questionnaire structure to allow for consistent administration. Selection criteria for the interviewers included non-affiliation with the CIFC and knowledge of basic health terminology.

All interviews were transcribed and color coded to facilitate in participant recognition when organized and compared thematically. To avoid researcher bias and ensure authenticity of the concepts elucidated, the principal investigator, two local interviewers and the head CIFC nurse engaged in the initial stages of data coding. Analysis of data consisted of a modified thematic analysis organized into two phases: open and axial coding (7). In open coding, the data were fractured into groups that related to particular ideas (i.e. service

quality, economic burden). In axial coding, these similar ideas were then organized into overarching themes. This iterative process allowed the emerging concepts and ideas to enrich subsequent interviews and verify the emerging concepts.

Validity of our findings was addressed via three pathways. First, triangulation of data was done by reviewing medical records and patient charts of all participants interviewed. Medical records were analyzed to assess patient follow-up history at the CIFC in order to validate the data inferred from the interview and verify the patients' diagnosis. Of thirty-three medical charts reviewed, six charts had missing information on the patient attendance log book. Attendance for monthly follow-up could not be validated in these instances. Secondly, interviews were taped and transcribed to further increase dependability of the data. Thirdly, two primary researchers coded and discussed raw data minimizing potential researcher bias.

Ethical approval was granted by the London School of Hygiene and Tropical Medicine Ethical Review Committee and by the Jimma University Ethical Review Committee. Written informed consent was obtained from each individual before being interviewed. All data were protected as confidential and available only to the research team.

RESULTS

Thirty-three (20 adult and 13 caregivers) participants were successfully interviewed, of which, 29 had chronic rheumatic heart disease and the rest acute rheumatic fever (Table 1).

Table 1. Number of participants interviewed by sex, age and diagnosis, JUSH, 2006.

Characteristics	Adult patients N= 20	Care givers/Pediatrics N=13
Sex		
Male	8	11
Female	12	2
Age in years		
Range	15-70	7-14
Mean	31.9	11.2
Diagnosis		
RHD	19	10
RF	1	3

Treatment seeking behavior in this context appeared to be largely influenced by three core categories including -

- perception of illness, quality of health services and costs associated with treatment.

Table 2. Tool for health care providers to encourage patient follow-up treatment

Core Category	Components to positive affects on treatment seeking care
1. Perception of Illness	<ul style="list-style-type: none"> Improved patient/caregiver education and understanding of disease etiology and treatment benefits/side effects Improved family education on understanding the impacts of the disease on the patient (tailored to forage familial support) Improved teacher/colleague education on understanding the impacts of the disease on the patient (tailored to forge work place support)
2. Good Quality Service Delivery	<ul style="list-style-type: none"> Working out a feasible/sustainable (bi-/tri-monthly) treatment plan with the patient before the commencement of treatment. Improve decentralization of cardiac health services to the rural health units. Build rapport with patients (being timely to appointments/ respectful of patients" effort to come to the clinic).
3. Cost to Seeking Care	<ul style="list-style-type: none"> Benefit outweighs distance Macro changes: Patients/caregivers receive work subsidies that allow them to seek treatment without missing work. Implementation of a travel subsidy program for patients living outside the vicinity of the clinic.

Perception of Illness:- Patient and caregiver perception of illness played a large role when deciding to seek treatment. This perception was heavily influenced by knowledge of disease causality and severity of disease. Patients were more inclined to seek treatment if they continued to suffer from the symptoms associated with their condition (i.e. shortness of breath, tiredness, chest pains, etc.) and had support from family, colleagues and teachers. Box 1 highlights comments from patients and caregivers regarding their initial perception of illness.

Furthermore, knowledge and education of the disease causality and severity influenced their understanding of the importance to seek follow-up treatment. Ninety-two percent (20/22 patients) of patients who had a clearer understanding of the mechanism of disease stated that they sought treatment to improve their health and understood that follow-up treatment was crucial in this process. When asked where they believed their illness originated, 11 adult RF/RHD patients responded not knowing the causality. Nine of the 11

patients disclosed a number of causality beliefs including - *"I heard it is from tonsillitis"*, *"I am sick due to the stress of my mother's and father's death"*, *"My heart condition came from my bad temper"*, *"I believe it came from hard labor in the field and from child bearing."* Moreover, when asked directly why they continued to seek treatment, 7 patients indicated the need to take care of their children, 5 patients wanted to be able to work to provide food and shelter for their families and 8 patients desired a longer and better quality of life.

A sub-category of illness perception that also emerged among six caregivers was a reflective comparison between their child and other *"healthier and physically active"* children. Comments such as: *"...I want to see her playing like her friends"*, *"We seek treatment so he may go to school like his friends"* and *"...it is my satisfaction to see my son healthy"* indicated that caregivers were drawn to seeking care for their children based on an ideal physical state when compared to other children.

Box 1: Summary matrix of perception of illness

"I don't know where my disease originated from. I feel pain on and off and that is why I waited for the last 6 months. My family has no money and so discouraged me from seeking treatment" – Patient/Male/18yrs

"I suspected she had some heart condition when she had tiredness and a fast beating heart. At the moment she felt pain, I took her to the hospital." – Caregiver/Male/20yrs

"I have 11 children so I suspect that my heart condition is because of this. I started to feel sick, but thought it would go away so I stayed at home." – Patient/Female/58yrs

"The rural drug vendors told me that I had a urinary track infection and gastritis. Later on, when I went to the private clinic, they diagnosed me as a cardiac patient and referred me to the Jimma hospital. The disease is serious, so I need continuous medical attention." – Patient/Female/45yrs.

Desire for quality health services:- A further extension of this theory influencing treatment seeking behavior included patient and caregiver perceptions of service quality. Overall, 13/20 RF/RHD adult cases and 6/13 caregivers were satisfied with the care provided by the Jimma CIFC staff. The respondents generally appreciated the respectfulness of the clinic staff and were satisfied with the service as a result of the improvement in their health. Six patients stressed „respect“ as an important feature of their satisfaction with the service at the CIFE. “ I am satisfied with the care I am receiving at the clinic since the nurses treat me with respect and concern.” This appeared to forge a strong and lasting rapport between health provider and user.

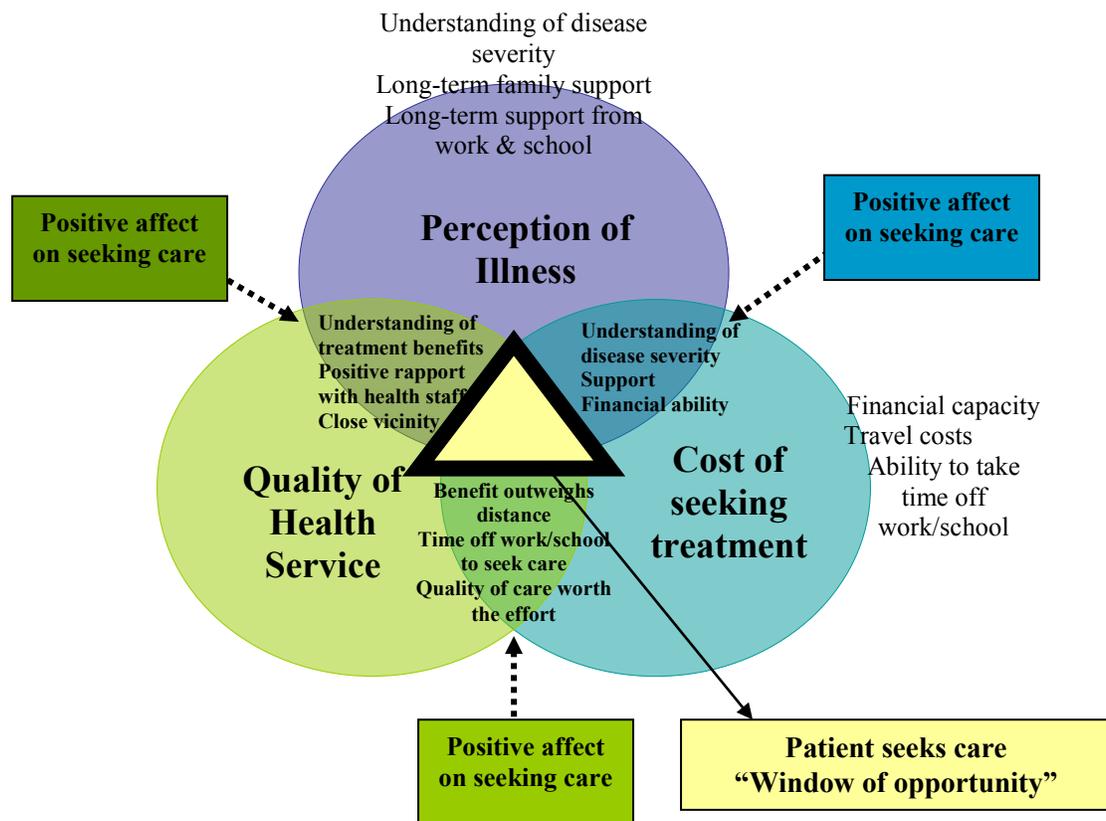


Figure 1. Conceptual framework for weighing the Costs

Additionally, in 96% of the participants, patients who noticed improvements in their health and in their child's health were more likely to be satisfied with the services. This progress appeared to encourage patients and caregivers to continue seeking treatment. *"Since taking the treatment, I have improvements in my health since I feel healthy now most of the time. Because of this, I feel positive that more treatment will further improve my health", "The treatment I am on makes me feel better. I*

take it to have better management and relief from my illness" (patient 5).

On the contrary, 14/33(42.4%) participants stressed dissatisfaction with the service at the CIFC. Seventy-six percent of this dissatisfied group stated that they preferred to be monitored by a cardiologist. Two patients further indicated a desire to be assessed by the same physician to ensure consistency in the monthly progress of their RHD. Three out of the seven patients and 1/7 caregivers stressed disappointment with the tardiness of

the physicians in meeting their appointments. Additional frustration regarding inadequate stocks of the medication in the hospital was voiced, which forced patients and caregivers to incur the cost of medication from private pharmacy. Distance of the CIFC also surfaced as a large cause of service dissatisfaction amongst the rural patients and caregivers. Of the 23 participants who lived outside Jimma Town, all of them stressed distance as a huge barrier to seeking care and consequently, an area that required immediate improvement through decentralization of care.

Costs Associated with Care:- Costs associated with treatment included financial, travel and opportunity costs involved with attending follow-up. The financial burden of travelling great distances and paying for medications acted as a deterrent in seeking treatment. This constraint is not a new phenomenon to this study. Twenty five patients disclosed a difficulty in obtaining money to travel to the clinic. *“The economic problem for transport expenses is very difficult for me”, “It takes me two days to get to the clinic and I pay 50 ETB⁺ which affects my ability to come to the clinic since my family is poor and they don’t have enough money...because of the long distance and financial problems, I sometimes default from my follow-up.”*

Additionally, although drugs are free for patients obtaining them from the clinic, 7 patients stressed the difficulty that purchasing the drugs posed when the stocks were periodically empty. One patient mentioned that *“sometimes I get my medication here [from Jimma CIFC], but when they prescribe me to buy it from outside, I just leave it because I have no money.”*

With reference to the opportunity cost, only two caregivers who had full-time jobs and 3 patients who attended school struggled with the loss of a productive day of work due to the length of travel required

DISCUSSION

Since grounded theory is suited for an exploratory investigation, this methodology allowed theory to emerge directly from the interview data. The findings elucidated led to the development of a substantive theory and regarding factors influencing the treatment seeking behavior for patients and caregivers in Jimma, Ethiopia.

Each patient and caregiver has a set of beliefs, perceptions and capabilities that influence his/her pursuit to seeking health services. Patients/caregivers perception of illnesses, especially a reflective comparison has been noted in other studies whereby parents understanding of their child’s illness is largely constructed based on the perception of other children (8,9). Participants who noticed improvements in their/ their child’s health were satisfied by the service highlighting the necessity of

CIFC health staff to ensure that patients and caregivers do not have false expectations of the medication and understand that continued monthly treatment is essential to improve their well-being. The chronic nature of their illness should be clarified in association with the importance of the monthly needed penicillin treatment.

Although 62% of patients were unemployed and did not voice this as a direct concern, advocacy and reimbursement schemes should be strengthened to allow patient’s to seek follow-up medication without penalty to their salary. This awareness could perhaps be in form of educational material and in the provision of a follow-up schedule so coworkers may also play a role in supporting the patient’s attendance for follow-up treatment. A study in Vietnam defined economic constraints as a factor hindering TB patients from seeking care (10).

The dynamic process described by Strauss and Corbin allows us to “understand the involvements of the participants with their pursuits (11).” Based on the core categories, a literature review on health-seeking behavior and the clinical manifestation of RF/RHD, the theory of *weighing the costs* emerged as a consistent theory across patient and caregiver testimonials (Figure 1). This theory outlines the conditions that affect the decision-making process of patients and caregivers when contemplating to seek monthly follow-up treatment. The interaction between each core category showcases the theory in action, whereby patients weigh their personal economic and opportunity costs when seeking treatment. It is when the benefit to health outweighs the cost incurred that patients will attend follow-up treatment. Each participant conveyed a sense of struggle with weighing various costs associated with seeking care such as financial, travel and opportunity costs.

Adapted from the conceptual framework depicted in Figure 1, Table 2 outlines a tool that can be used by health providers to improve the provision of health services to RF/RHD patient and caregiver needs. A number of key components including education, feasible treatment plans, decentralized services and forging a strong patient-physician relationship have been elucidated as major areas for improvement.

LIMITATIONS OF THE STUDY

Although certain themes and concepts recurred consistently throughout the study, true saturation of the data may not have been totally achieved given the limited timeframe. With a slightly longer period and perhaps further theoretical sampling of participants, additional concepts may have been elicited.

In conclusion, this study complements evidence-based planning rather than working on previous assumptions that are not based on patient/caregiver accounts. The theory of *weighing the costs* illuminates a strong desire by patients to be healthy and caregivers to

⁺ ETB=Ethiopian Birr [15ETB=£1].

see their children healthy. It acknowledges the heavy economic burden experienced by rural dwellers who are required to travel lengthy distances to reach the Jimma cardiac clinic on their designated appointment day. It also highlights the importance that quality of health services plays in patients and caregivers decision-making process to seek care.

Experience from other settings reinforces that the secondary prevention for RF/RHD is ideally delivered when it is part of a program that provides health education for parents, children, teachers and co-workers with a constant availability of penicillin and maintenance of surveillance registers to track the follow-up of RF/RHD cases. Thus, decentralization of health services for RF/RHD for patients from rural Jimma and the surrounding is recommended. Further research to broaden and test the theory generated in this study; exploring the role of gender dynamics in seeking care and tracing defaulted patients to understand their reasoning for not seeking care is also recommended.

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