Low adherence to secondary prophylaxis among clients diagnosed with rheumatic fever, Jamaica

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Objectives: To determine the level of adherence and possible barriers to secondary prophylaxis among clients with rheumatic fever in Kingston, Jamaica.

Methods: Cross-sectional survey of 39 clients diagnosed with rheumatic fever, receiving penicillin prophylaxis for more than a year using a 22-item self-administered questionnaire on adherence to secondary prophylaxis and knowledge of rheumatic fever. The patients' records were reviewed to determine the number of prophylaxis injections the patients received for the year 2010.

Results: The majority of participants (74%) were females and 51% were adults. Only 48.7% had a high level of adherence. The majority (72%) had low knowledge levels regarding their illness, while only 5% had a high knowledge level score. Most clients (70%) strongly agreed that nurses and doctors encouraged them to take their prophylaxis. However, over 60% reported that they travelled long distances and or waited long periods to get their injections. One-third reported that they missed appointments because of fear of injections and having to take time off from work or school.

Discussion: Clients attending the health centers studied had limited knowledge about rheumatic fever. Barriers to adherence included fear of the injections, long commutes, and long waiting periods at the facilities studied.

Keywords: Rheumatic fever, Barriers, Adherence, Secondary Prophylaxis, Jamaica

Introduction

Rheumatic fever is a multi-system inflammatory, chronic disease, which presents as delayed sequelae to streptococcal pharyngitis.¹ 'The most serious aspect of rheumatic fever is the development of chronic valvular disorders that produce permanent cardiac dysfunction' or rheumatic heart disease.² Rheumatic fever affects school-aged children primarily and remains a major health concern in developing countries where conditions such as overcrowding, poor nutrition, and inadequate health care persist.² The disease is commonly associated with significant morbidity and mortality among children and young adults and is the major cause of acquired cardiovascular disease in some endemic areas.³

Global incidence of rheumatic fever is estimated to be 470 000 new cases per year, while rheumatic heart disease affect 15.6–19.6 million persons globally.^{3–6}

In addition, deaths from rheumatic heart disease are estimated between 250 000 and 468 000 annually.^{4–6} Furthermore, over 330 000 children between the ages of 5 and 14 years are affected by rheumatic fever each year with global prevalence rates of 0.3/1000–5.7/1000.^{3,7}

Recurrent attacks of rheumatic fever can have devastating outcomes; therefore, regular administration of antibiotics is recommended to prevent reinfection with group A streptococci and subsequent possible acute rheumatic fever.⁸ The administration of Benzathine penicillin G has been shown to be a very cost effective strategy for primary and secondary prevention at both the community and individual levels.^{9–11} Secondary prevention strategies presume that individuals wish to avoid further events or illness and will tolerate any inconvenience associated with taking long-term medication to reduce their chances of illness.¹² If patients are to be compliant with medication, they must perceive it as necessary, have a good understanding of the severity of illness, and possess the ability to cope with their illness.^{4,13}

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Therefore, individuals must believe that the efficacy of a treatment is positively associated with adherence.¹⁴

The determinants of non-compliant behavior are generally complex and poorly understood.¹⁵ In the USA, several factors including psychosocial, demographic, and medical related characteristics have been identified as attributable to non-adherence with secondary prophylaxis for rheumatic fever among low-income families at a child and family therapy clinic.¹⁶ Barriers to adherence included the complexity of the treatment regimen, unpleasant side effects of the drugs, lack of apparent immediate benefits, and cultural, social, and behavioral factors.^{17,18} In addition, social barriers and miscommunication between clients and staff contribute to failure to comply with medication regimen.¹⁸ While there has been significant progress in the reduction in the incidence of acute rheumatic fever (ARF) in developed countries, developing countries have not seen comparable results.³

In Jamaica, the national rheumatic fever/rheumatic heart disease prevention and control programme was developed in 1985.¹⁹ The programme targeted primary prevention of rheumatic fever through identification and treatment of streptococcal throat infections and secondary rheumatic fever prophylaxis. The Ministry of Health, Jamaica (2002) recommended intramuscular benzathine penicillin G injections to be given every 21–28 days to clients with a history of rheumatic fever, or those with rheumatic heart disease. Data from the National Surveillance Unit, MOH in 2011, indicated that there were 2054 confirmed cases of rheumatic fever on the rheumatic fever register, and an additional 300 cases to be investigated in Jamaica.²⁰ The register (2011) reflected a national average prophylactic coverage of 61% and an average adherence rate of 42% (range: 25–65%) among patients. Wallace's (1993) study of factors contributing to the decline in adherence with rheumatic fever among 57 rheumatic fever/rheumatic heart disease clients attending selected health centers in Jamaica noted fear of injections and unavailability of doctors at health centers among the reasons for lack of adherence with rheumatic fever prophylaxis.²¹ The current level of adherence with rheumatic fever prophylaxis and enablers and barriers to adherence with prophylaxis is not known. This information is crucial the planning of continuing strategies for control of rheumatic fever and prevention of its complications.

Aim

This study sought to determine the level of adherence among clients diagnosed with rheumatic fever at three Type 5 health centers in Kingston, Jamaica and to explore barriers to adherence with secondary prophylaxis among them.

Methods

Study design and setting

A descriptive cross-sectional survey was conducted among clients diagnosed with rheumatic fever at three Type 5 health centers in Kingston, Jamaica. These facilities are located in urban areas and serve populations of over 20 000 persons. They offer comprehensive health services including maternal and child care, curative and laboratory services, and vaccination programmes.

Population and sampling strategy

The target population consisted of all clients listed on the rheumatic fever register at the health centers who had been diagnosed with rheumatic fever for more than 1 year and who were scheduled to receive secondary prophylaxis ($N = 78$). The ages of clients ranged from 8 to 37 years.

Raosoft Sample Size calculator was used to determine the required sample size for the study.²² A margin of error of 5%, a confidence interval of 95%, and a distribution of 50%; were accepted and this yielded a recommended sample size of 65 clients. Based on the attendance records at the rheumatic fever clinics of two parishes, a non-response rate of 20–30% among the clients diagnosed with rheumatic fever was anticipated. This led to the conduct of a census of all the clients on the register who met the inclusion criteria of the study.

A survey instrument was used to determine levels of adherence with rheumatic fever prophylaxis. In addition, clients' records were reviewed to determine adherence rates with rheumatic fever prophylaxis using the Ministry of Health, Jamaica (2002) definition of adherence.²⁰ An adherent client is one who has completed at least 90% of the prescribed prophylaxis for each year.²⁰

Exclusion criteria

Clients with rheumatic fever who are not currently on the register, not receiving prophylactic penicillin at the Type 5 health centers and clients diagnosed with rheumatic fever for less than a year were excluded from the study.

Ethical consideration

The study was approved by the institution's Ethics Committee and the Ministry of Health, Jamaica. Written informed consent and assent (where applicable) were obtained from all study participants.

Measuring adherence and data collection

The clients' records were used to determine the total number of prophylactic penicillin injections received for the year 2010. Adherence with rheumatic fever prophylaxis was measured for the period from January to December 2010 in categories of low (8 or fewer), moderate (9–11), and high adherence (12–13).

Participants were asked to complete a 22-item structured self-administered questionnaire eliciting demographic information, participants' knowledge of and level of rheumatic fever adherence. A five-point Likert scale was used to identify barriers to adherence. The instrument was pilot tested on 19 clients with rheumatic fever from health facilities which were not in Kingston. The Cronbach Alpha for internal reliability was 0.75 for the pilot test and 0.77 on the instrument when used in the current study.

Data analysis

Data were analyzed using the SPSS® V 17.0 for Windows®. Descriptive statistics were used to summarize data including measures of central tendency. Knowledge levels were determined by assigning a score of 5 to each knowledge question (to obtain a maximum possible total of 30) for each participant.

Results

The total number of clients listed on the rheumatic fever register in the three health centers was 78; however, only 39 (50%) visited during the study period and the study had a response rate of 89.7% (35/39). The majority of the participants studied were females (74.4%) and their ages ranged from 8 to 37 years. Just over a half (51%) were adults 18 years or older (mean age: 23.65 ± 5.59 years), while 49% were children (mean age: 14.05 ± 2.53 years). Most clients (70%) were diagnosed with rheumatic fever before their 13th birthday. Among the adults, 50% were employed, 35% were unemployed and 15% were students. The adults were all educated, with (60%) reporting secondary education as their highest level of educational achievement and 40% reporting tertiary level education.

Level of adherence among clients with rheumatic fever

The total number of injections for the year 2010 was ascertained and the scores were placed in categories of low, moderate, and high adherence. During the year 2010, the median number of injections received by study participants was 12 and the mean number of injections received was not different between adults (10.37 ± 3.1) and children (11.81 ± 1.8) ($t = 1.74$; $P = 0.09$). Just under a half of the participants were rated as having high levels of adherence (48.7%), 23.1% had moderate adherence levels, and 17.9% had low levels of adherence.

Assessment of clients' knowledge of rheumatic fever and its prophylaxis

All participants answered in the affirmative when asked, 'have you been ever told about rheumatic fever?'. The mean knowledge score achieved by the children studied was 7.63 ± 4.96 and for adults 9.74 ± 4.21 of a maximum 30. In addition, 80% of participants recorded low knowledge levels, 14.2%

had moderate knowledge, and only 5.5% displayed a high level of knowledge of rheumatic fever and its prophylaxis. There was no relationship between knowledge scores and the number of injections received ($P > 0.05$).

In order to identify factors which influenced adherence, participants were asked to state whether encouragement from a doctor or nurse was one of the reasons they took their injections; similar responses were recorded for both children and adults as the majority answered in the affirmative with 88% and 80% agreeing, respectively ($P > 0.05$). In the same way, 61% of children and 65% of adults indicated that they took secondary prophylaxis injections because it was free ($P > 0.05$). On the other hand, fear of the condition worsening was cited as a reason for taking rheumatic fever prophylaxis by more adults (100%) than children (70%) (Fisher's exact test, $P = 0.024$).

More than three quarters of children (78%) and 65.0% adults agreed that they had missed appointments because of fear of injections. Taking time off from school or work in order to receive their prophylaxis affected adherence of 71% of the children and 60% of adults. The distance travelled to access rheumatic fever prophylaxis affected the adherence of fewer participants as 22% of children and 32% of adults responded positively to this question. Likewise, 33% of the children and 20% adults agreed that the long waiting periods affected their adherence with rheumatic fever prophylaxis ($P > 0.05$).

Discussion

The rate of adherence with secondary prophylaxis among patients with rheumatic fever at five health centers in Kingston, Jamaica was 48.7%. This rate of adherence was far from acceptable as 52.1% of patients with a previous history of rheumatic fever were at risk for recurrence of the disease. This was well below reported levels in a study conducted in India which indicated 90% adherence with prophylaxis.¹ Similarly, high levels of adherence 80–100% were reported in New Zealand where the majority of prophylaxes were given at school, work, home, or at a community nurse-run clinic.⁸ However, adherence levels in the current study were comparable to reports from the island of Lifou, New Caledonia, where 46% of patients receiving antibiotic prophylaxis for ARF or rheumatic heart disease (RHD) studied had a rate of adherence $< 80\%$.⁴ Additionally, the median number of injections reported for the clients in Lifou was 14 and ranged from 2 to 18, while the current study recorded 12 and ranged from 3 to 13.⁴

Poor adherence to secondary prophylaxis for rheumatic fever was observed in the face of poor knowledge. According to Eissa *et al.*, 'Knowledge and understanding of the rheumatic fever are

important factors in treatment uptake'.²³ An earlier study reported that among the Jamaican population studied, 74% of defaulters stated that they had been told about rheumatic fever and respondents had 'a good knowledge' of the symptoms of their illnesses.²¹ However, in the current study which was conducted two decades later, despite relative high education levels, it was evident that the participants were not knowledgeable about the disease and prophylaxis as only 5% of participants achieved a high knowledge score and the mean knowledge score was less than 10 of a possible 30 for both adults and children. Notwithstanding low knowledge scores, all participants answered in the affirmative when asked, 'have you been ever told about rheumatic fever?'. This suggests that information about rheumatic fever had been disseminated.

The Jamaica National guidelines for the management of rheumatic fever stipulate that rheumatic fever clients receive education at diagnosis and at each visit for prophylaxis.²⁰ The fact that clients recalled that they were educated about rheumatic fever and its complications, but had difficulty recalling the details of the information, supports Robertson *et al.*'s characterization of the volume and complex nature of the information to be disseminated to similar clients in South Africa.²⁴ The authors further asserted that rheumatic fever clients and their guardians were unable to retain initial information provided at the time of diagnosis, and emphasized the need for effectiveness in the communication of knowledge to clients.²⁴

Additional research examining health literacy among rheumatic fever clients and guardians, methods of delivering health messages, and the level of community awareness of rheumatic fever is urgently needed in our setting. The findings of these studies could be useful in planning health promotion programmes for rheumatic fever/rheumatic heart disease, with the aim of improving knowledge about the condition and its management. High adherence with rheumatic fever prophylaxis in India was credited to the training of health workers, school teachers, and pupils to recognize the signs of rheumatic fever and refer suspected persons to a health center.¹ Targeted education for clients who have had rheumatic fever and those recently diagnosed is required and should include specific therapeutic information.⁴

Another possible barrier to adherence to secondary prophylaxis was fear of receiving injections. More than 75% of children and 50% of adults admitted to missing their appointments because of fear of injections. This was a much higher response than the 15.8% response in a similar Jamaican study by Wallace conducted in 1993.²¹ Amir *et al.* provided

evidence that the administration of benzathine penicillin injection with lidocaine significantly reduced injection pain without affecting the pharmacokinetic properties of the penicillin.²⁵ It is recommended that health authorities in Jamaica explore the use of this combination for secondary prophylaxis, to reduce pain and improve adherence. Fear of painful injections and travelling long distances were also cited as barriers among pediatric clients in Mumbai, India.¹ In Jamaica, clients were encouraged to receive penicillin injections at the nearest health center to their work or home and if the health center is inconvenient, then the nearest hospital was selected.²⁰ However, approximately a quarter of participants cited travelling long distances and long waiting periods as reasons for missing penicillin injections. Secondary prophylaxis for rheumatic fever can be safely administered in schools and settings other than hospital and health centers with few incidents of life-threatening allergic reactions reported.^{26–29} Of 17 641 penicillin injections administered among 535 children diagnosed with rheumatic fever in Turkey, there were only 11 reported allergies of which one was confirmed as a penicillin allergy. According to Grayson *et al.*, in the New Zealand health system, the delivery of rheumatic fever prophylaxis at the community level (school, work, home, and clinic) resulted in high rates of adherence.⁸ These were considered effective ways to deliver the rheumatic fever prophylaxis.²⁹ Further studies should be conducted in Jamaica to determine if administration of secondary prophylaxis in other sites such as in schools by the nurse is likely to improve adherence.^{4,7}

Dissatisfaction with service has been cited as a barrier to care in a qualitative study of 20 patients with rheumatic fever/rheumatic heart disease and 13 caregivers in Ethiopia. Health centers should implement special fast tracking for patients who attend clinics for rheumatic fever prophylaxis.³⁰

Despite these barriers, the majority of participants (83.8%) strongly agreed that an important reason for taking the injection was encouragement by a nurse or doctor who showed interest in their care. This indicated that a close nurse/patient and doctor/patient relationship was also important in improving adherence in clients with rheumatic fever/rheumatic heart disease.⁹ Furthermore, adults were more likely to take their injections because they did not want their condition to get worse.

Levels of adherence in Lifou, New Caledonia were associated with having more than six individuals per household, adequate healthcare coverage, and the presence of a history of symptoms related to ARF.⁴ Economic constraints such as poverty, under-nutrition, overcrowding, and poor housing were major impediments to prevention and control of rheumatic

fever and rheumatic heart disease.¹ Limited expertise of healthcare providers in the prevention and management of rheumatic fever, limited supplies of penicillin, and limited accessibility to health centers have also major obstacles in the efforts to combat rheumatic fever and rheumatic heart disease.¹ More than half of the adults and children studied, agreed that they took their injection because it was free. Given the current debate in Jamaica regarding the re-introduction of user fees by the MOH, this may be a cause for concern for health planners.

The majority of participants in this study were female (74%) which reflected observed trends.^{18,21} This may be a reflection of health seeking practices of Jamaican women who are more likely to seek medical attention than men.³¹ The fact that most participants acquired the condition before age 13 years coincides with the proposition of the Ministry of Health, Jamaica (MOH, 2002) which asserts that peak incidence of rheumatic fever occurs between 5 and 15 years.²⁰

A sub-optimal level of adherence with rheumatic fever prophylaxis was prevalent at the institutions studied and many of the clients listed on the rheumatic fever prophylaxis register missed their scheduled appointments during the study period. Low levels of knowledge of rheumatic fever and its prophylaxis, missing appointments because of fear of the injection, and travelling far distances for the injection were identified as barriers to rheumatic fever prophylaxis in the current study. More robust case findings, additional health education and health promotion activity, and improved access should be included in efforts to strengthen the rheumatic heart disease programme for the participants studied.⁷ There is a clear need for additional research in this area.

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Conflicts of interest None. The work was the MSc project of Mrs Boswell Thompson.

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