

## Adherence with Secondary Prophylaxis among Children with Rheumatic Fever

Ebtisam M. Elsayed and Thanaa A. Elawany

Pediatric Nursing Department, Faculty of Nursing, Tanta University  
[ebtisamelsayed@yahoo.com](mailto:ebtisamelsayed@yahoo.com)

**Abstract:** Positive living with rheumatic fever however can be difficult because of pain and fatigue in addition to changes in the person's appearance leading to low self-image. Medical treatment regimens for pediatric rheumatic diseases are complex, have delayed beneficial effects, and require consistent adherence over a long period of time. So, this study aimed to assess adherence with secondary prophylaxis among children with rheumatic fever. The study was conducted at Pediatric Rheumatology Outpatient Clinic of Tanta University Hospital during the period of six months in 2010. The sample comprised 100 children suffering from rheumatic fever. Their ages ranged between 8 to 18 years. An Interview questionnaire sheet was used for data collection. It included personal data, past history of rheumatic fever and history related to adherence with the prophylactic treatment. Reviewing child's health record was utilized to obtain the required information. The results revealed that, male children were more affected with rheumatic fever than females, 58% were from rural areas and most of them (71%) had negative family history of rheumatic fever. Irregular adherence to prophylactic treatment was found in 53% of the total sample. The leading causes of irregular adherence as reported by the majority of children (87%) were mainly fear from painful injection. The findings revealed that there was significant relationship between children's adherence with follow up and Penicillin dose and their ages, sex, residence and family history. Furthermore, a significant relationship was detected between children's adherence and duration of the disease as well as recurrent episodes ( $P < 0.05$ ). Regarding to their knowledge; it was revealed that most of studied children (60%) were poor, 17% fair and 23% were good. The current study showed that children who had good and fair score were more regular adherent than who had poor score. In conclusion; factors contributing child non-adherence to prophylactic treatment included painful injection, lack of confidence in their treatment, inadequate counseling, and difficult traveling for long distance. There was significant correlation between children's regularity to treatment and their knowledge. It was recommended that, establishing continuous educational sessions for children and their mothers in outpatient rheumatology clinics about the importance of adherence with secondary prophylaxis is mandatory for positive living with the disease.

[Ebtisam M. Elsayed and Thanaa A. Elawany. **Adherence with Secondary Prophylaxis among Children with Rheumatic Fever.** Journal of American Science 2012; 8(3):701-708]. (ISSN: 1545-1003).  
<http://www.americanscience.org>. 94

**Key word:** Adherence, Secondary Prophylaxis treatment, Rheumatic Fever.

### 1. Introduction

Rheumatic fever is an inflammatory disease that may developed two to three weeks after group A- Beta hemolytic streptococcal infection. Worldwide, rheumatic fever remains a major health problem, occurring in approximately 100 in 100,000 children under 18 years, specially in under developed countries where access to medical care is limited and children live in poverty and unsanitary crowded conditions<sup>(1)</sup>. In developing countries, rheumatic fever is the predominant cause of acquired childhood cardiopathy. More than 15 million people worldwide have rheumatic fever and rheumatic heart disease due to rheumatic fever, with nearly a quarter million deaths occurring annually due to this condition<sup>(1,2)</sup>. The incidence of rheumatic fever in developed countries ranges between 0.2 to 0.5 per 1000 with variable rates from place to place reaching as high as 20 per 1000 children living in South Africa. Worldwide, an estimated 5-30 million children and young adults have chronic RHD, and 90,000 patients die from this disease each year<sup>(2)</sup>.

In Egypt, rheumatic fever is still affecting young children with 10% of cases having their first attack before 15 years of age. It represents a serious health problem, as it affected 8-9 per 10,000 of children between 6 to 12 years<sup>(3,4)</sup>.

The diagnosis of rheumatic fever may be difficult as the children may have one, two or more than five major manifestations (arthritis, carditis, chorea, Erythema marginatum and subcutaneous nodules). Some blood tests, serum tests, ceriatenin, X-Ray in addition to ECG can confirm the condition<sup>(5)</sup>.

Rheumatic fever can be prevented well with early precautions and proper diagnosis. The antibiotics are preferred worldwide and the course could be for 10 days. Light diet is taken and other symptoms are treated symptomatically. In case of severe cardiac problem, it needs immediate medical treatment and it may be fatal. Penicillin is the drug of choice for eradication of streptococcus. Erythromycin may be used in penicillin-allergic children<sup>(6)</sup>.

Positive living with Rheumatic fever however can be difficult because of pain and fatigue in addition to changes in the person's appearance leading to low self-image. Medical treatment regimens for pediatric rheumatic diseases are complex, have delayed beneficial effects, and require consistent adherence over a long period of time. All of these factors place the child at risk for non-adherence that can compromise the benefits of treatment. So; Adherence to prophylactic therapy is an important component of effective treatment. For patients who receive prophylaxis, complete adherence is often reported to be quite low. Children younger than 12 years have been found to have the highest adherence, which is probably due to family supervision. The rate of adherence drops dramatically during adolescence<sup>(7)</sup>. Adherence may be defined as the extent to which a patient's behavior (in terms of taking medication, following a diet, modifying habits, or attending clinics) coincides with medical or health advice<sup>(8, 9)</sup>.

Nurses are uniquely positioned to play a major role in promoting adherence to treatment regimens. One key form of support provided by nurses is patient education, which is considered a critical step in promoting adherence<sup>(10)</sup>. The most effective forms of education are those that emphasize knowledge. Nurses can help to satisfy this need by providing information concerning rheumatic Fever and the benefits of prophylaxis<sup>(11, 12)</sup>.

From this perspective the study was carried out to assess the adherence with secondary prophylaxis among children with rheumatic fever in out patient rheumatology clinic of Tanta University Hospital.

## 2. Materials and Method:

### Settings:

A descriptive study was conducted in the Pediatric Rheumatology Outpatient clinic at Tanta University Hospital.

### Sample:

A selective sample was taken including 100 children with rheumatic fever of both sexes. Their ages ranged between 8-18 years. They were attending the previously mentioned setting for follow up in initiate prophylaxis treatment (Benzathine Penicillin injection) since one year at least.

### Tools and technique of data collection:

1-An Interview questionnaire sheet was developed and used to obtain:

- Socio - demographic information of the child such as: age, sex and residence.
- Clinical details and history regarding Rheumatic Fever and its recurrences.
- Duration of the disease.
- Children' knowledge about Rheumatic Fever and the importance of the Benzathine Penicillin.

- The extent of children's adherence to prophylactic treatment and causes of non- adherence.

Scoring for child knowledge was designed as follows:

Knowledge contained 8 questions each one was assigned 2 score; child who reported the correct answer

2 score was given, incorrect answer one score was given while no answer zero was given

The knowledge grand total score was 16. Child's knowledge was considered good if the grand total score was more than 70 %, fair if between 50- 70 % and poor if less than 50 %.

2- Children' Medical records were checked for: the initial initiation, past history of rheumatic fever recurrence, past history of pharyngitis or tonsillitis prior to rheumatic fever, types of diagnostic tests performed and history related to adherence with the prophylactic treatment

### Method:

An informed consent was obtained from the children and their parents for participation in the study.

Direct interview with children who were attending the previously mentioned setting for follow up during a period of 6 months in 2010 .

- Children were classified as "regular adherent" to prophylaxis treatment, when they received the recommended doses of Benzathine Penicillin G on time, and carry out penicillin test before each dose. (Three weeks regimen is considered the most appropriate for prophylaxis among Egyptian children)
- Irregular or non- adherence is considered if the child take improper doses of medication and /or who occasionally skipped doses, or those who don't take the prescribed medication at all.
- Data were organized, tabulated and statistically analyzed using SPSS soft ware statistical Computer package version 12. Chi-square test was used for comparisons between two or more groups regarding qualitative data. The level of significance was adopted at  $p < 0.05$ <sup>(13)</sup>

## 3. Results

Table (1) presents Socio-demographic characteristics of children with rheumatic fever. It was found that, 54% of children were males and 46% were females with the mean age of  $9.92 \pm 2.65$  years. More than half of them (58%) were from rural areas and 42% from urban areas. It was noted that, 51% of children were in primary schools while preparatory and secondary constituted 29% and 20 %, respectively.



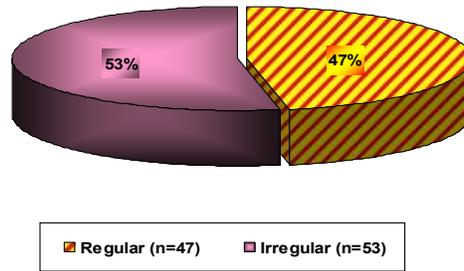


Figure (1): Adherence with follow up and penicillin dose of the studied children with rheumatic fever (n=100).

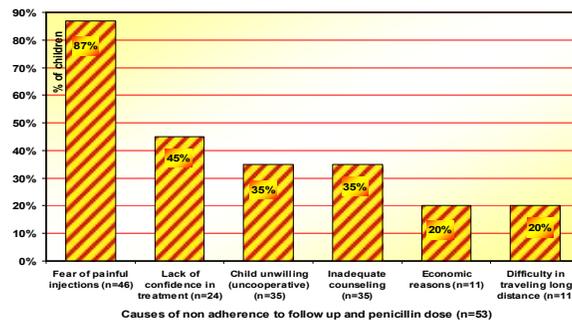


Figure (2) Causes of non adherence with follow up and penicillin dose of the studied children with rheumatic fever (n=53).

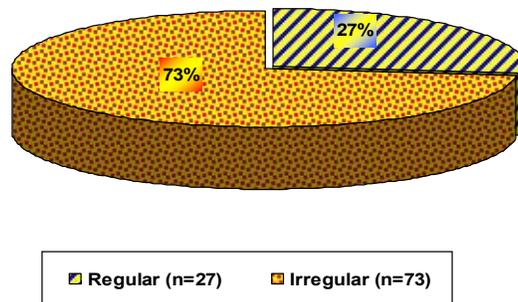


Figure (3): children's adherence with penicillin test at each dose (n=100).  
NB: More than one item was chosen

**Table (2): Relationship between the studied children's adherence with follow up and penicillin dose and their sociodemographic characteristics and family history of rheumatic fever**

Variables	Adherence to follow up and penicillin dose of the studied children with rheumatic fever (n=100)					$\chi^2$	P
	Regular (n=47)		Irregular (n=53)		Total (n=100)		
	n	%	n	%	n%		
•Sex:							
Males	17	31.5	37	68.5	54	10.04	0.001*
Females	30	65.2	16	34.8	46		
•Age (years):							
8-<13	30	73.2	11	26.8	41	17.37	0.0001*
13-18	17	28.8	42	71.2	59		
•Residence:							
Urban	28	66.7	14	33.3	42	9.924	0.002*
Rural	19	32.8	39	67.2	58		
•Family history:							
Positive	19	65.5	10	34.5	29	4.62	0.031*
Negative	28	39.4	43	60.6	71		

\*Significant ( $P<0.05$ )**Table (3): Relationship between the studied children's adherence with follow up and penicillin dose and duration, recurrent episodes and complications of the disease and side effects of penicillin injection**

Variables	Adherence to follow up and penicillin dose of the studied children with rheumatic fever (n=100)					$\chi^2$	P
	Regular (n=47)		Irregular (n=53)		Total (n=100)		
	n	%	n	%	n%		
•Duration of disease (years):							
1-<3	9	60.0	6	40.0	15	6.52	0.038*
3-<5	18	62.1	11	37.9	29		
5 & more	20	35.7	36	64.3	56		
•Recurrent episodes of RF:							
Yes	8	21.6	29	78.4	37	13.61	0.0002*
No	39	57.9	24	38.1	63		
•Complications of RF:							
Arthralgic pain	22	34.4	42	65.6	64	0.56	0.455
Fever	9	25.0	27	75.0	36		
•Side effects of penicillin injection:							
Yes	22	40.7	32	59.3	54	1.34	0.247
No	25	54.3	21	45.7	46		

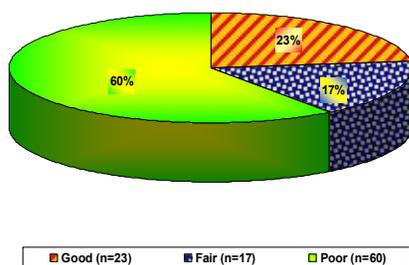
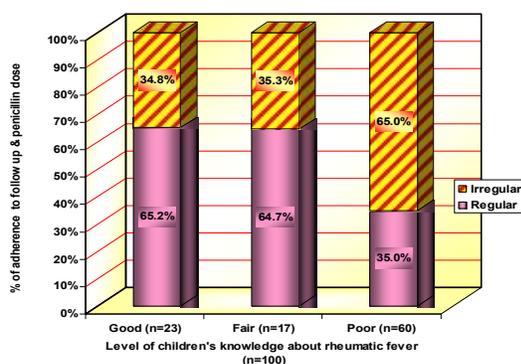
\*Significant ( $P<0.05$ )

**Table (4): Knowledge of the studied children with rheumatic fever about their disease**

Knowledge items about rheumatic fever	Knowledge of the studied children with rheumatic fever (n=100)		
	Complete answer	Incomplete answer	No answer
	n%	n%	n%
•Definition	9	15	76
•Causes	20	12	68
•Signs & symptoms	29	42	29
•Treatment	35	20	45
•Complications	15	8	77
•Preventive measures	0	2	98
•Purpose of prophylactic treatment	23	12	65
•Importance of penicillin test	49	25	26
Total knowledge	23	17	60

**Table (5): Relationship between the studied children's adherence with follow up and penicillin dose and their score of knowledge about rheumatic fever**

Total knowledge about rheumatic fever	Adherence to follow up and penicillin dose of the studied children with rheumatic fever (n=100)					$\chi^2$	P
	Regular (n=47)		Irregular (n=53)		Total (n=100)		
	n	%	n	%	n%		
Good	15	65.2	8	34.8	23	8.672	0.013*
Fair	11	64.7	6	35.3	17		
Poor	21	35.0	39	65.0	60		

\*Significant ( $P < 0.05$ )**Figure (4): Knowledge of the studied children with rheumatic fever about their disease.****Figure (5): Relationship between the studied children's adherence with follow up and penicillin dose and their score of knowledge about rheumatic fever.**

#### 4. Discussion

Medical treatment regimens for pediatric rheumatic diseases are complex, have delayed beneficial effects, and require consistent adherence over a long period of time. All of these factors place child at risk for non-adherence that can compromise the benefits of treatment and quality of life<sup>(14)</sup>.

Although the high prevalence of rheumatic fever in developing communities is mainly related to poverty and overcrowding, which favor the transmission of group A streptococcal infection specially in rural areas<sup>(4)</sup>; our finding revealed that forty two of studied children were from homes with reasonable living conditions in an urban environment. This was in agreement with other reported studies<sup>(4, 15)</sup>.

Compliance to Benzathine Penicillin injections is of great importance in secondary prevention of rheumatic diseases. The finding of this study revealed that, more than half of studied children were non-adherent with prophylactic treatment and penicillin test before each dose. However, non-adherence with secondary prophylaxis was found to be higher among children living in rural environments and male more females. These results might indicate the endemicity of the disease and the low level of health awareness about the condition among people living in disadvantaged conditions. Fear of painful injection,

inadequate counseling and lack of confidence in the treatment, as well as economic reasons or difficulty in traveling long distance were others barriers. This finding was congruent with other researches who reported that the major barriers of compliance with the prophylaxis treatment included, pain associated with injection, limited expertise of health care providers, and limited accessibility to health centers due to long distance of traveling<sup>(3,4,6)</sup>.

Children with pediatric rheumatic diseases are required to adhere with long-term treatment regimens. Children's reluctance or failure to commit to prescribed regimens reduces the effectiveness of treatment, often leading to additional care, higher costs, and serious, even deadly complications. To prevent recurrences of rheumatic fever and worsening of rheumatic carditis, prophylaxis with Benzathine penicillin is strongly recommended. Good adherence is a must for this prophylactic measure to be effective<sup>(18)</sup>. The current study revealed that rheumatic fever recurrence was encountered in more than one third of the studied sample. This could be related to their irregular or non adherence to follow up and penicillin dose as the significant relation was found concerning these aspects. This finding agreed with another study which reported similar results regarding rate of recurrent attacks of rheumatic fever<sup>(6,19)</sup>.

Quality of health care outcome depends upon patient's adherence to the recommended treatment regimens. The regular adherence with secondary prophylaxis recorded in the present study was lower than other studies carried out in India<sup>(20)</sup> and South Africa<sup>(21)</sup>. Controversy, it was higher than recorded by another study<sup>(22)</sup>. The current study revealed that, most of studied children weren't adherent to penicillin sensitivity test at each dose, that was in turn affect children's positive living with their illness. This could be related to their misunderstanding of its importance. However; the percentage of regular adherence was not enough because the penicillin sensitivity test is very important to avoid allergy or any health problems that may occur to the child. This finding was supported by Abd-El-aall and Lancet, who confirmed the importance of penicillin sensitivity test<sup>(23,24)</sup>.

According to knowledge, attitude and practice model of promotion of health, knowledge is necessary in order to change individuals' behaviors<sup>(16,17)</sup>. Information gathered through the interviews showed that, there was lack of child's' knowledge concerning many aspects of the disease as poor score of knowledge constituted nearly two thirds of the total sample. This could be owing to the young age of a high percentage of studied groups who were less than 13 years. Out of Children who had good and fair

score there was more than two thirds for each them more regular adherent than who had poor score. This might be interpreted by the shortage of health education provided to them from the health care providers about the disease and importance of treatment.

Concerning the relationship between adherence of children to treatment and their socio demographic characteristics; the finding of the present study revealed that, there was a dramatic decrease in regular adherence to treatment regimens when children reach adolescence. In part, this could be owing to the fact that long-term health benefits of prophylaxis are not immediately obvious to adolescents as they are trying to assert independence and cope with physical changes. This finding was congruent with Steer & Mayosi whom reported that, half of adolescents with chronic illnesses did not adhere to treatment regimens<sup>(25,26)</sup>.

In Conclusion; more than half of children were non-adherent with prophylactic treatment. The leading causes as reported by the majority of them were the fear of painful injection, lack of confidence in their treatment, inadequate counseling, and difficult traveling for long distance. There was significant relationship of children' adherence with their age, duration and recurrent episodes of the disease. Most of children were poor in their knowledge, a significant relationship was found between regular adherence to prophylactic treatment, follow up and penicillin dose and their knowledge.

It was recommended that: establishing continuing educational sessions for children and their mothers in outpatient rheumatology clinic of Tanta university hospital about the importance of adherence with secondary prophylaxis is mandatory for positive living with the disease.

#### Corresponding author

**Ebtisam M. Elsayed**

Pediatric Nursing Department, Faculty of Nursing,  
Tanta University  
[ebtisamelsayed@yahoo.com](mailto:ebtisamelsayed@yahoo.com)

#### References

1. Rayamajhi A, Sharma D, Shakya U. First-episode versus recurrent acute rheumatic fever. Is it Different? *Pediatric Int*, 2009; 51:269-75
2. Carapetis J R, Mayosi B M and Kaplan E L. Controlling rheumatic heart disease in developing countries. *Cardiovasc J SAfr.*, 2006; 17:164-5
3. El-Nagar M. *Pediatric Clinical Diagnosis. Diagnostic Approach of the most Clinical Presentation*. 5th ed, University Book Centre, Cairo. Egypt. 2005; 189.

4. Hassan N M, Abd-Elrahim A. and Awany M M. Compliance of rheumatic school children with secondary prophylaxis in Elmahala El-Kobra discrete ,Gharbia Governorate. *Tanta Medical Journal*.2006; 34: 575-582.
5. World Health Organization. Rheumatic fever and rheumatic heart disease. WHO tech-Rep,2004;No. 923: 1-122.
6. Carapetis J R. Rheumatic heart disease in developing countries. *N Engl J Med.*, 2007; 357:439-41
7. Harrington Z, Thomas D P, Currie B J and Bulkanhawuy J: Challenging perceptions of non-compliance with rheumatic fever prophylaxis in a remote Aboriginal community. *Med J Aust.*, 2006; 184:514-7.
8. Haynes R B. Improving patient adherence: state of the art, with a special focus on medication taking for cardiovascular disorders. In: *Compliance in Health Care and Research*. Burke LE, Ockene 1<sup>st</sup> , ed, New York: Futura Publishing Company Inc.; 2001;3-21.
- 9- Haynes R B, McDonald H and Garg AX. Interventions for helping patients to follow prescriptions for medications.Oxford, England: Cochrane Library, Update Software, 2002; issue 2.
- 10.Khair K and Geraghty S J. Haemophilia A: Meeting the needs of individual patients. *British Journal of Nursing*, 2007; 16(16): 987-993.
- 11- Behrman R E and Kligmen R M. *Nelson Essential of pediatric*.4<sup>th</sup>ed, Philadelphia: W.B.Saunders Company, 2002. 590-592.
- 12-Gerber M. *Nelson textbook of pediatrics* .17<sup>th</sup> ed, Philadelphia :WB Saunders company, 2004. 870-878.
- 13--Dawson B and Trapp R G. *Basic and Clinical Biostatistics*. 3<sup>rd</sup> ed, Lange Medical Book/ McGraw-Hill: Medical Publishing Division, 2001; 161-218,
- 14- James S R, Ashwell J W and Drosk S C. *Nursing Care of Children*. 2<sup>nd</sup> ed, Philadelphia: W B Saunders Company, 2002,724-727.
- 15- Bassili SR, Zaher A, Zaki M and Abdel-Fattah G. Profile of secondary prophylaxis among children with rheumatic heart disease in Alexandria, Egypt. *East Mediterr health J.*, 2000; 6 (2/3): 437-446.
- 16- Haynes R B, McDonald H P and Garg A X. Helping patients follow prescribed Treatment. clinical applications. *JAMA*, 2002; 288:2880-3.
- 17- Robertson K A, Volmink J A and Mayosi B M. Lack of adherence to the national guidelines on the prevention of rheumatic fever. *SAfr Med J.*, 2005; 95:52-6.
- 18- Roberson K A, Volmink J A and Mayosi B M. Towards a uniform plan for the control of rheumatic fever and rheumatic heart disease in Africa – The Awareness, Surveillance, Advocacy, Prevention (ASAP) programme. *SAfr Med J.*, 2006; 96(3): 241–245.
- 19- Kassem A ,Zaher S, El Kholy A, and Madkour A. Rheumatic fever prophylaxis using benzathine penicillin G (BPG): two-week versus four-week regimens: comparison of two brands of BPG. *Pediatrics*,1996; 97(6 Pt 2):992-5.
- 20- Kumar R, Raizada A, Aggarwal A K and Ganguly N K. A community-based rheumatic fever/rheumatic heart disease cohort: twelve-year experience .*Indian Heart J.*, 2002;54: 54-58.
- 21-Nordet P,Lopez R,Duenas A and Sarmiento L.Prevention and control of rheumatic fever and rheumatic heart disease:the Cuban experience(1986–1996–2002).*Cardiovasc JAfr.*, 2008;19:135–140.
- 22 Grayson S, Horsburgh M and Lennon D. An Aucklandregional audit of the nurse-led rheumatic fever secondary prophylaxis programme.NZ Med J., 2006;119:U2255.
- 23- Abd-El-aall NA. Recent trends in diagnosis and management of rheumatic fever. MS thesis, Faculty of Medicine, Cairo University, 2005; 42-43.
- 24- Lancet. Centre for International Child Health. University of Melbourne Department of Paediatrics and Murdoch Children’s Research Institute. Melbourne, Australia, 2005; 366: 155–6
- 25-Steer A C, Carapetis J R, Nolan TM and Shann F. Systematic review of rheumatic heart disease prevalence in children in developing countries. The role of environmental factors. *J Paediatric Child Health*, 2002; 38: 229–234
- 26 -Mayosi B, Robertson K, Volmink J and Adebo W. The Drakensberg declaration on the control of rheumatic fever and rheumatic heart disease in Africa. *SAfr Med J.*, 2006; 96(3): 246.

3/2/2012