McGill University

Social and Emotional Problems of Rheumatic Fever in Children

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by

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PREFACE

The writer wishes to acknowledge the help received in gathering material for and in writing this thesis. First of all I would like to thank Dr.J.E. de Belle, medical superintendent of the Children's Memorial Hospital,Montreal, for allowing me to use the hospital records. To Dr.Arnold Johnson of the Children's Memorial Hospital I owe a particular debt of gratitude for his interest and assistance. I would also like to thank those other members of the hospital staff for their help in facilitating the collection of data and Mrs. D. Horn of the social service department in particular for her assistance in supplying the social information on the cases known to her. I would particularly like to acknowledge the help received from Mrs. C. H. Elledge and Miss E. Younge of the McGill School of Social Work. Their untiring effort on my behalf, and their assistance and encouragement made the writing of this thesis possible.

TABLE OF CONTENTS

LIST OF TABLES

MAP

CHAPTER I

INTRODUCTION

Rheumatic fever is one of the foremost problems in paediatrics because, except for accidents, it is the leading cause of death among school children (in the United States where statistics are available).[1] Those young people who survive an attack of the disease are often left with damaged hearts which make it necessary to limit normal activity. Many cases of adult heart disease can be traced to attacks of rheumatic fever in childhood. It is, therefore, understandable that increasing attention is being focussed on rheumatic fever. In the United States and England rheumatic fever control programs are being established for the purpose of studying, combatting, and controlling the disease. Research is continually being undertaken in an effort to uncover some of the unsolved mysteries of the disease.

Medical research in the area of rheumatic fever has resulted in more adequate means of diagnosis and treatment, and this has increased the child's chances of recovery. The cause of the disease has also been the subject of much research, but to date the emphasis has been more on the offending organism and to a lesser degree on the environmental factors. As research progresses, however, it is becoming increasingly evident that social and environmental factors play an even more important part than was heretofore imagined. This would seem to

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1. "The Toll of Rheumatic Fever" - The Child, Vol.13 (Dec. 1948) p.90.

be an area for research by the social scientists while medical scientists continue to pursue the mysteries of the disease itself.

Another area for social research is related to furthering the knowledge of the emotional effects of the disease on the child and his family.

These are two areas of research for the social worker who has been trained to understand the social and emotional needs of individuals. More specifically, it is the medical social worker who can use her knowledge of the effect of illness on individuals and family groups and apply it to a single disease group, namely, that of rheumatic fever.

This particular study was initiated at the request of a cardiologist who, as the doctor in charge of the clinic which cared for children with rheumatic fever and rheumatic heart disease, was interested in having a group studied by a social worker to see what social, emotional and environmental factors there might be in relation to the child and his family that could interfere with or help the child in making a satisfactory recovery and adjustment to life.

The initial approach of this thesis will be to use the identifying information, which will include age, sex, religion, family income, rent, area of residence, etc., of the sample group to determine those factors that present problems in relation to the group as a whole. The families' use of community agencies in endeavouring to meet their needs will also be considered. This part of the thesis then, will be a general discussion of the community welfare problems that this sample group presents.

The emotional traumas associated with rheumatic fever will be

considered by the use of case material on selected cases from within the sample group. The emphasis here will be on the types of emotional problems that arise in connection with rheumatic fever, and the role of the social worker in helping the child and his family to meet these problems through social case-work.

It is possible that a study of this type might point to a need for some community action in controlling and combatting rheumatic fever and in offering case-work and their services to the children and their families. Therefore, some consideration will be given to the formation of rheumatic fever control programs by reviewing those in existence in some areas of the United States and England.

This study is limited to a social, emotional and environmental evaluation of the group and will, therefore, not include specific medical information on the individual cases, although there will be a general discussion of the cause, diagnosis, and treatment of the disease to be used as background information.

There are three main groups of questions to be considered.

A. What social and environmental factors are present in relation to the group as a whole? Some of this information would pertain to the child himself, i.e., age, religion; other material would be related to the child's family, i.e., income, rent. Questions to be asked would be:

   1. What are the ages of the children?
   2. What are the religions of the children?
   3. From what areas of the city do the cases come?
      a. Do the children come from widely dispersed points or is there a concentration in any one area?

A. (cont'd)

b. What rent is paid?

4. What is the economic status of the families?

a. How many children come from families with adequate incomes?

b. Is there evidence of marked economic deprivation?

5. How many children are there in the families?

B. What are the emotional problems that arise in connection with rheumatic fever - for the child and for his parents? How is it possible to help the child and parents with these problems? Some of the questions to be considered will be:

1. What are the fears of children who have rheumatic heart disease and how do these affect the child and his family?

2. What effect has the long period of hospitalization on the child's school adjustment? Does this present an emotional problem?

3. Does the necessity to limit activities following an attack of rheumatic fever affect a child's vocational ambitions? If so, how can the child be helped to overcome the disappointment that this involves?

4. How do parents and children react to the limitations rheumatic fever frequently imposes?

5. What is the role of the social worker in helping the child and his parents with the above-mentioned emotional problems?

C. What is the value of control programs in controlling and combatting rheumatic fever?

1. What type of programs have been established in the United States and England?

C. (cont'd)

2. How effective have they been?

This sample group consists of 46 children who have had rheumatic fever and who were attending the cardiac clinic at the Children's Memorial Hospital, Montreal, in February, 1948. This group represents the total number of children with that diagnosis who were attending clinic at that time, and was so selected by the doctor because of his interest in having a social study of the total group.

The clinic group was used for this study because of the particular interest of the doctor in having a social evaluation done on these children. Similar studies could be undertaken on hospitalized rheumatic fever cases or on those children who are bed patients at home.

The structure of this thesis will be as follows. The second chapter will provide the medical information necessary to an understanding of the total situation. This will include a discussion of the cause, diagnosis, and treatment of the disease and will be presented immediately following the introduction to give the reader some background knowledge of rheumatic fever before discussing the children who have the disease.

The third chapter is divided into two sections. The identifying material on the sample group will be analysed; the distribution of patients according to age, sex, religion, economic status, area of residence and the families' use of community resources will be evaluated.

An analysis of all these factors will give a picture of the group as a whole and will indicate community welfare problems that exist in this community in relation to the care of the child with rheumatic fever.

The social and emotional problems will be discussed in the fourth

chapter with case material to illustrate the role of the social worker in helping with the problems that arise.

In chapter five consideration will be given to rheumatic fever control programs as a means of studying, controlling and combatting the disease. This will involve a review of the control programs in existence in the United States and England.

This, then, is to be a study of the social, environmental and emotional problems of rheumatic fever in children. Consideration will be given to a discussion of the effect of the disease on the child and his family and to a consideration of the community welfare problems that the disease presents.

CHAPTER II

CAUSE, DIAGNOSIS, AND TREATMENT OF RHEUMATIC FEVER

As was mentioned in the previous chapter, rheumatic fever is the leading cause of death among school children.[1] It is also the greatest child crippler; it disables seven times as many people as does poliomyelitis.[2] Many children must spend days, months and sometimes years in bed after developing the disease and much of adult heart disease can be traced to attacks of rheumatic fever in childhood.

In some respects rheumatic fever can be compared to tuberculosis in that a person is never cured of either disease. It can be said that a person's tuberculosis has been arrested and the same phrasing can be used in relation to rheumatic fever. But a child may at any time have a recurrence of rheumatic fever and with each recurrence the danger of cardiac damage is increased.

For many years rheumatic fever has presented a problem to the medical profession. As one doctor has said, "We don't know when it starts, we often cannot tell when it is here, we have no cure for it, and we cannot tell when it is gone."[3]

This chapter will cover the medical aspects of the disease cause,

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1. Supra, p.1

2. Kuttner, Ann G., "Prevention of Rheumatic Recurrences", New York State Journal of Medicine, Vol.43 (Oct. 1943), p.1947.

3. Martin, A.T. "Convalescent Care in Rheumatic Fever", Modern Concepts of Cardiovascular Disease, Vol.XII, No.5 (May, 1943).

symptoms, diagnosis, care during the acute and convalescent stages and prognosis. The types of convalescent care recommended for the different age groups will be discussed, and the facilities in Montreal for convalescence will be evaluated.

A. Symptoms of the disease

Rheumatic fever is a chronic disease that usually attacks the connective tissues of the body, causing inflammation of the muscles, valves and outer lining of the heart. It is not characterized by any one symptom, hence diagnosis is often difficult. Pain in the joints and fever are common manifestations but these may mark the onset of other diseases as well. Other symptoms that would warrant further investigation for rheumatic fever are pallor, loss of weight, repeated nosebleeds, and a poor appetite. Chorea might be another symptom of the disease. This is characterized by unexplained crying spells and awkward, jerky movements of the face, arms, and legs - especially when the child tries to dress himself or pick up objects.

Characteristic skin rashes, the appearance of small nodes or lumps under the skin, or rheumatic pneumonia or pleurisy may be the dominant characteristics. Fever, increase in the white blood cell count, acceleration of the blood sedimentation rate, anemia, and restlessness are usually among the clinical findings.

One of the most common symptoms, however, is a fleeting pain in one joint and then another. This symptom may be characterized by intense soreness, heat, swelling and redness, or, on the other hand the pain may be so slight it is not even noticed. In many instances the

joint pains of rheumatic fever have been labelled as "growing pains" and further investigation deemed unnecessary. The acute pain of rheumatic fever usually subsides after a few days and the child may feel perfectly well. The active disease process is still present, however, and this makes early diagnosis vital.

B. Cause

Rheumatic fever is usually preceded by a hemolytic streptoccocus infection which is one of the offending organisms in tonsilitis, scarlet fever and inflammation of the ear. Because of the close association between the disease and a streptoccocus infection, the environmental conditions that give rise to respiratory infections must be considered as factors contributing to the onset of the disease. Thus, unhygienic surroundings, malnutrition, poverty, inadequate housing, and crowded living conditions undoubtedly are factors that increase the chances of the child developing the disease. It is true that cases of rheumatic fever are found among children in families with high incomes but prevalence of the disease is undoubtedly found in the lower economic and social environments.[1] Thus it can be said that anything that undermines the child's general health - inadequate food and clothing, lack of rest, damp and crowded houses - increase his susceptibility to rheumatic fever.

Although it cannot be proved that rheumatic fever is inherited, there is a strong familial tendency toward the disease. Eight - ten per cent of the exposed persons in rheumatic families acquire the disease as

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1. Galvin, Louise. "Preventive and Public Health Aspects of Rheumatic Fever", Southern Medical Journal, Vol.36 (Feb. 1943), p.118.

against three per cent in control families.[1.]

Rheumatic fever seems to flourish in a temperate zone and is comparatively rare in the tropics. "The death rate from acute rheumatic fever varies among the geographic areas in the United States. The death rates are below average in the south while in the northeast, especially the middle Atlantic division, they are significantly above average".[2.]

C. Acute stage of the disease

During the past 20 years pathologists have shown that rheumatic fever is a systemic disease, probably an infection, producing lesions throughout the body. For some reason the heart seems particularly susceptible both to initial injury and to later, permanent scarring. These scars occur in one or more of the valves between the heart chambers and prevent complete closing of the valve following the release of blood. This causes a leakage of blood back into the heart with the result that it has to pump harder and faster in order to handle the oversupply. After one attack the leakage may not be serious enough to impair the normal activity of the individual, but rheumatic fever has a tendency to recur and with each new attack a greater strain is placed on the heart. The valves on the left side of the heart are most frequently affected and the resultant abnormality is called aortic insufficiency. Sometimes the edges of the valve become fused, thereby reducing the size of the valve opening. The limitation in the amount of blood that can pass through

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1. Huse, Betty. Report to Children's Bureau Advisory Committee on Services for Crippled Children, Children's Bureau Publication (Dec. 1944), p.8.

2. Wolff, George M.D., "Childhood Mortality from Rheumatic Fever and Heart Disease", Children's Bureau Publication No.322, (1948),pp.24-25.

the valve is called mitral stenosis.

As previously described,[1] the first signs of rheumatic fever are those similar to many other childhood diseases, and this makes the illness difficult to recognize in its early stages. Care must be taken not to ignore any danger signals that might be present, for in early diagnosis and treatment lies the child's hope of a future free from cardiac impairment. In making the final diagnosis the doctor must take a careful history followed by a thorough physical examination. The fluoroscope and X-ray may also be used if there is any doubt and blood sedimentation rate and electrocardiogram aid in making a diagnosis. It is the opinion of many people that a heart murmur signifies the presence of rheumatic fever or the resultant heart disease, but this is misleading for many children have meaningless heart murmurs that disappear within a short time.

D. Care during the acute stage

During the acute stage of the disease the child can best be cared for in the hospital where diagnostic and treatment services are available. Many of these children require careful nursing attention and medical treatment, and it is necessary that testing facilities be available to measure the progress of the disease. For example, sedimentation rates must be determined frequently as a means of indicating whether the disease is still active. Temperature readings must be accurately charted and heart murmurs watched for. Then, too, a child's activities are easier to control in a hospital ward where there is constant supervision.

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1. Supra, p.8

Complete bed rest is usually recommended for the first few days or even weeks. If the clinical signs show a dropping sedimentation and pulse rate, a lowered temperature and no cardiac murmur, the child may be gradually mobilized. The body's reaction to this increase in activity must be watched, for frequently an elevation in sedimentation rate is noted after the child is first allowed out of bed. It is obviously impossible for most mothers to give their children the extensive care mentioned above and for that reason hospitalization is essential.

When the child's condition warrants increased activity, the sedimentation rate is approaching the limits of normal and the clinical signs have, for the most part, disappeared, it may be said that the child is entering the convalescent stage of the disease.

E. Convalescent care

Because of the long-term nature of the illness, discharge planning is of considerable importance and must be initiated shortly after the child's admission to hospital. It sometimes takes a considerable length of time before parents and the child will accept the fact that, although the child feels well, the active disease process is still present and a long period of convalescence is needed. Then, too, a thorough understanding of the child's physical and emotional needs is a prerequisite to sound convalescent planning. All these factors point to a need for careful social evaluation before a child is discharged from hospital after the acute stage of the disease.

The importance of the convalescent period is that it gives the heart a chance to rest after the strain it has been subjected to during

the acute stage of the disease. Consider what rest does for a child with a post rheumatic fever tachycardia of 110 beats per minute. If the heart can be slowed down 10 beats per minute by bed rest, in twenty-four hours it contracts 15,000 less times. One can readily see what a conserving process this is to a vital organ which is often so seriously affected by rheumatic fever.[1]

There are three types of convalescent care that have been used with success. The decision as to which of these would be most adequate in a given situation depends upon the needs of the individual child, the attitude of the parents, and the resources within the community to meet the needs. The most essential factors to keep in mind in planning convalescence for children are as follows:

1. Small children up to five need their own mother. Interruption of the relationship with her may lead to great distress, eating problems, bed wetting, regressive behaviour, thumb sucking, etc. This process can be reversed if a new attachment to a mother substitute can be established by the child. Complicating factors are, however, frequent loyalty conflicts in the child and hostility and withdrawal from his own mother, which, in its turn, often leads to special problems in the mother, such as jealousy, dissatisfaction and critical attitude toward the mother substitute.
2. The older child from six to pre-adolescence can take the separation more easily as the group becomes increasingly important to him. The process of learning and sublimation, the first moves

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1. Martin, A.T. Op. Cit.

2. (cont'd)
toward independence are part of his normal development. But even at this age frequent contacts with his own family are highly desirable.

3. The adolescent youngster has the best chance in a satisfactory life among contemporaries because of the importance at that age of the group ties, the group ideals, the attempt to become independent from the family. The search for new identification outside of the childhood environment, the adolescent struggle against his own family ties, the desire for a leader, facilitate life in a group.[1]

F. Types of convalescent care

1. Home care - Wherever possible a child should be cared for in his own home during the convalescent period. This is the most normal environment for the child who needs the emotional security of the family after the acute stage of illness. A comprehensive home care program for rheumatic fever cases has been worked out at Montefiore Hospital in New York[2] where complete services to the child have been carried into the home. All cases of rheumatic fever considered for home care are carefully evaluated by the social worker attached to that service, and if she feels that the case is an acceptable one, i.e., if the home conditions and

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1. Bibring, Dr. Grete L., The Child First, Bi-Regional Conference Report on Long-Term Care of Ill Children, Phoenix, Arizona (March, 1949), p. 16-17.

2. Eger, Saul, The Home Care Program of the Montefiore Hospital, Bi-Regional Conference Report on Long-Term Care of Ill Children, Phoenix, Arizona (March, 1949), pp.20-23.

1. Home care (cont'd)

parents' attitudes are satisfactory - the resources of the home care program are put at the family's and the child's disposal. A doctor and social worker from the hospital visit regularly, medicine is provided free of charge and there is a messenger service to carry it from the hospital to the home. Any necessary equipment is provided by the home care program. A nurse visits two or three times a week to supervise the nursing care, and the board of education of the city of New York provides the services of a child psychologist who does psychological testing and vocational guidance. There is also a home teaching program in which a teacher is sent from the board of education into the home to instruct the sick child. A psychiatrist does a psychiatric evaluation of every child, with follow-up interviews if necessary.

The staff doctor makes regular visits to the home and conferences are held where specific cases are discussed. There is a doctor on call twenty-four hours a day, seven days a week, because what may not be an emergency in other cases is always classed as an emergency in the rheumatic fever patients. The patient's siblings are also treated in the home when they have upper respiratory infections.

Weekly mothers' meetings are held where various common problems are discussed. The home care program provides housekeeper service, as needed, for mothers with more than one child. This consists of a maximum of four hours of housekeeping per week to relieve the mother of the heavy work such as scrubbing floors,

1. Home Care (cont'd)

washing windows, etc. The mother retains the status of employer, hiring her own housekeeper and paying the individual with the money received from the home care program.

The plan described above represents what one hospital has done in the way of home care for children with rheumatic fever. A modified form of home care is in operation in many children's hospitals because it is becoming increasingly evident that a child can best convalesce at home provided the social situation is conducive to such care.

2. Foster home care - There are many homes that cannot be made suitable for a convalescent child and there are many parents who, because of their own needs, attitudes and lack of understanding, cannot give the child adequate care. In these instances another type of convalescent care has to be arranged. As was mentioned previously, young children need a mother or mother substitute, and experience security when they are part of a family group. Thus a system of foster home placement of certain children convalescing from rheumatic fever has been worked out in many communities. This plan is based on the theory that "by and large younger children are able to profit from foster family care and to derive greater benefits through individualized relationships, individual expression, and parental relationships".[1]

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1. Williams, Bess R. Foster Home Care, Bi-Regional Conference Report on Long-Term Care of Ill Children, Phoenix, Arizona (March, 1949), p.27.

2. Foster home care (cont'd)

The choice of the foster home is, of course, important and it must be appraised on the basis of the attitudes of the members of the family; their feelings, their attitudes, their ability, as members of society, to provide a given service for a given child, their willingness to share the child with his parents, and to accept and understand the child's behaviour, feelings, and attitudes, and their capacity to give him security to grow and develop in an acceptable manner.

It is important to remember that not all children can accept foster home care, thus a careful social evaluation of all cases must be made before proceeding with plans for foster home care. Also to be kept in mind is the fact that whereas foster home placement might be the ideal solution for most convalescent children, it has been impossible in many communities to find enough of the proper type of homes to meet the demand for that type of care.

An example of the foster home program for convalescent children is seen in Boston.[1] The Children's Mission to Children is a privately supported agency in Boston which provides care for children with medical problems. Part of its program is the placement of convalescent children in foster homes when their own homes are unsatisfactory. Ninety per cent of the patients have had rheumatic

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1. Bissell, Elizabeth. "Foster Homes in Medical Care Programs for Children", The Child, Vol.15, (Feb. 1950), pp. 114-117.

2. Foster home care (cont'd)

fever.

> The boys and girls accepted for admission are, in general, from 2 to 21 years, without infectious disease, and not acutely ill, although the prognosis may be poor or questionable. There are no residence restrictions, and no restrictions based on race, religion, or finances. The family is expected to pay all, or part, of the child's expenses, if possible, but whether the family can pay is not considered in deciding about acceptance.1.

The medical director of the agency is a specialist in rheumatic fever. He serves the agency part-time and is on the staffs of the two children's hospitals. Because most of the children come to the foster home from these hospitals, they have the advantage of continuity of medical care during the acute and the convalescent stages of their illness. The medical director makes regular visits to the foster homes and is on call at all times. Agency laboratory technicians and occupational therapists visit the home, and the board of education provides a teacher.

The agency social worker co-ordinates the services of the foster home with the services of the medical director of hospitals, of clinics, and of private physicians, whose patients are in the home, and handles any social problems that arise in connection with any of the patients.

This agency has stated the requirements of a good program of medical foster care as being:

1. The teamwork of physician, nurse, foster mother, caseworker, occupational therapist, and other specialists as their services are needed.

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1. Ibid. p.115

2. Foster home care (cont'd)

   2. Adequate compensation to foster mothers.

   3. A planned program of activity in the homes, especially in homes giving bed care, because children confined to bed have such limited contacts.

   4. Case-work service that concentrates on family problems affecting the health of a child and which gives the counselling to the child and foster mother, that will make the placement of children with medical problems bring the results hoped for.[1]

3. Convalescent institutions - If care at home has proven to be impractical either for social or emotional reasons, consideration must be given to institutional convalescent care. This plan can prove successful particularly if the child is of pre-adolescent or adolescent age, for the reasons mentioned previously.[2] The opinion among authorities on the subject seems to be that the institution providing convalescent care must in some way be affiliated with the general hospital which provides the care during the acute stage. This assures more economical operation and a better means of providing and supervising professional services. "Well qualified professional staff want professional satisfaction from their jobs. That satisfaction is greater when personnel

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1. Ibid. p.125

2. Supra, pp.13 & 14

3. Convalescent institutions (cont'd)

can work in proximity with and have the stimulation of others in their own profession".[1.]

Besides providing a continuity of medical care for the child the convalescent institution should have facilities for occupational therapy, teaching, and any other services that would contribute to the child's general well being. The convalescent period should be as constructive as possible for the child for as Miss Jetter[2.] has said, "From an emotional point of view, the real danger period in a prolonged illness such as rheumatic fever ----- is in the convalescent period ----- . During convalescence gratifications from being ill should be reduced to an absolute minimum and at the same time the child should be consistently and firmly encouraged to get satisfaction from the things he can do for himself".

G. Convalescent facilities in Montreal

The situation in Montreal for the care of convalescent children is not clearly defined. It has not been possible to work out a system of foster home placement because the placement agencies have not been able to provide the necessary foster homes. The one convalescent institution for children is eighteen miles from the centre of the city and

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1. "How Can We Get Convalescent Institutions For Our Programs"? Bi-Regional Conference Report on Long-Term Care of Ill Children, Phoenix, Arizona, (March, 1949), p.29.

2. Jetter, Lucille. "Some Emotional Aspects of Prolonged Illness in Children", Public Health Nursing, Vol.40, (May 1948), p.259.

is not equipped for laboratory testing (electrocardiograms, sedimentation rate), and it has no facilities for occupational therapy or physiotherapy. There is no affiliation with the children's hospital and no continuity of medical service. Thus, this institution has not proven to be too practical for the placement of convalescent rheumatic fever patients.

A system of home care, worked out by the Children's Memorial Hospital within the last two years is providing a partial answer to the problem. The home situations of many of the cases are evaluated by the social worker, and where it is feasible the child is discharged home. He is then followed regularly at clinic, and his home care is supervised by a visiting nurse. The social worker continues her active interest in the case and helps the family with any social problems that arise. The hospital's occupational and recreational therapists and it's teacher visit the home regularly. This plan has worked satisfactorily for many children, but there are others who have had to remain in the hospital for months because there were no adequate convalescent facilities available.

H. Prevalence and prognosis

Any discussion of a disease is incomplete without some mention of prognosis. A study was undertaken in Boston[1]. where 1,000 rheumatic fever patients were followed for a period of at least ten years at the clinics at the House of the Good Samaritan and the Massachusetts General Hospital. Of the 1,000 cases, 342 had no detectable heart disease at

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1. Jones, T. Duckett and Edward F. Bland, "Rheumatic Fever and Heart Disease Completed Ten Year Observations on 1,000 Patients", Transaction of the Association of American Physicians, Vol.LVII, (1942), pp.268-269.

the time of their initial discharge and 658 had some degree of rheumatic heart disease. Of the 342 cases, 248 remained free of rheumatic heart disease at the end of ten years, whereas 94 developed rheumatic heart disease. Twenty-two per cent of the 658 cases improved, there was no change in 27 per cent, and in 51 per cent of the cases there was a progression of the rheumatic heart disease. Ten years after the onset of the rheumatic fever, 648 of the patients were able to lead normal lives, while 135 had entered adult life with sufficient rheumatic heart disease to restrict their physical activities and to alter considerably their life and life expectancy. In all, there were 203 fatalities. Although this study was confined to the Boston area, the figures give some indication of prognosis in rheumatic fever.

Recent figures on children's mortality show that in the United States there is a yearly minimum of 12,000 deaths caused by acute rheumatic fever and its after-effects in the years of childhood.[1.] The material presented here is for the United States because it has not been possible to obtain pertinent Canadian statistics.

The ratio of death by rheumatic fever as compared to death by other illnesses, for United States, can be seen in table I - see next page.

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1. Wolff, George. Childhood Mortality from Rheumatic Fever and Heart Disease, United States Children's Bureau Publication No.322 (1948), p.23.

TABLE I

Rank of 6 leading causes of death in childhood, 5-19 years, by age, race and sex, average annual death rates per 100,000, United States, 1939-41[a].

Leading causes of death in order of the rates for white males	5-9 years	
	Male	Female (rank in brackets)
Accidents	39.3	20.0 (1)
Pneumonia	10.2	9.0 (2)
Appendicitis	8.2	6.7 (4)
Rheumatic fever and diseases of the heart	7.6	8.0 (3)
Diseases of the ear, nose and throat	5.3	4.7 (5)
Diseases of the nervous system	4.9	4.1 (6)
	10-14 years	
Accidents	40.9	12.2 (1)
Rheumatic fever and diseases of the heart	11.2	11.7 (2)
Appendicitis	9.0	6.9 (4)
Pneumonia or influenza	7.0	7.1 (3)
Diseases of the nervous system	4.9	3.5 (5)
Diseases of the ear, nose and throat	3.3	3.2 (6)
	15-19 years	
Accidents	74.1	19.8 (1)
Rheumatic fever and diseases of the heart	14.3	12.6 (3)
Appendicitis	11.2	6.6 (6)
Tuberculosis	10.7	18.9 (2)
Pneumonia or influenza	10.4	7.5 (5)
Diseases of pregnancy	-	11.3 (4)

a. Wolff, George. Childhood Mortality from Rheumatic Fever and Heart Diseases, United States Children's Bureau Publication No.322, p.3.

It can be seen in the above table that in the 5-9 age group, rheumatic fever is the fourth leading cause of death. In the 10-14 and 15-19 age groups, rheumatic fever is the leading cause of death by disease.

There are no figures available to indicate the thousands of adults whose activities are restricted because of attacks of rheumatic fever they had when they were young, but the large number of people who die of heart disease between the ages of 30 and 40 years is indicative of the problem, for a prevalent type of heart disease in that age group is that caused by rheumatic fever.

Rheumatic fever, the leading cause of death among school children, is one of the foremost problems in paediatrics, and the effects of the disease cause much of the heart damage in adults. Diagnosis is difficult because the symptoms are similar to the first signs of many other diseases. Often a mild attack of rheumatic fever is overlooked because the symptoms disappear within a few days and the child appears to be well. Unfortunately the disease process is usually active long after all obvious signs have disappeared. Herein lies the danger, for rheumatic fever has a tendency to affect the heart and, unless the child receives treatment soon after the onset of the disease, serious heart damage may result.

The cause of rheumatic fever is not known although it is thought to be associated with a streptoccocus infection. Poor living conditions and inadequate diet doubtless have something to do with the onset of the disease.

All cases of rheumatic fever require hospitalization during the acute stage, and the utmost care is needed to determine the best plan for convalescence. The ultimate decision must be made by the doctor, the social worker, and the parents taking into consideration the need for continual medical supervision, the control of factors that might give

CHAPTER III

SOCIAL AND ENVIRONMENTAL FACTORS IN THE SAMPLE GROUP OF RHEUMATIC FEVER CASES

This study of children who have had rheumatic fever is intended to highlight some of the social and environmental factors that are present in the group as a whole. Any plan which might be worked out to control and combat rheumatic fever must be based on factual material on a group of cases, and therein lies the value of an analysis of this identifying material. It must again be emphasized that the forty-six cases discussed in this study are a selected group only, and in no way indicate the extent of the problem in this community. Many children go to other hospitals, or they convalesce in the ward at the Children's Memorial Hospital, or in a convalescent hospital. Since rheumatic fever is not a registered disease in this community and since there is no central clinic, it is impossible to estimate the number of children in the city suffering from the disease.

The identifying material in this chapter will be presented in the form of tables, with analysis. The topics to be considered will be religion, age, location of the homes of these children to be seen in the form of a spot map; income and rent, use of community agencies by the group and by the individual families, income per month, and the number of persons in the family.

A. Age

As far as this study is concerned the major concentration of cases is in the 8-11, 12-15 age groups. Thirty-nine of the cases are over eight years of age and seven are younger. The following table[1] gives an indication of the age distribution.

TABLE II

Distribution, according to religion and age, of 46 children who have had rheumatic fever, attending the cardiac clinic at the Children's Memorial Hospital, Montreal, in February, 1948

Age in years	Religion											
	Total			Protestant			Roman Catholic			Hebrew		
Total	T	M	F	T	M	F	T	M	F	T	M	F
	46	32	14	9	6	3	31	21	10	6	5	1
1 - 3	1	1	0	0	0	0	1	1	0	0	0	0
4 - 7	6	6	0	1	1	0	4	4	0	1	1	0
8 - 11	18	12	6	3	1	2	14	10	4	1	1	0
12 - 15	13	8	5	3	2	1	8	5	3	2	1	1
Over 15	8	5	3	2	2	0	4	1	3	2	2	0

The one child under four years who is attending clinic is statistically insignificant, and as far as this sample group is concerned the interest is not in planning for the care of young children but in trying to help the older child and adolescent, among whom the incidence of the

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1. The tables that follow will pertain to the same clinic group hence specific mention of the disease, clinic and hospital will be omitted.

disease is highest.[1] A large majority of the children (37) are of school age. At this age children are active and enthusiastic and are striving for a degree of independence.[2] For these very reasons the children in this group suffer psychologically from long periods of inactivity.

In relation to schooling, months of education are usually lost to the child during hospitalization and convalescence, unless there is a hospital teacher. Even after the disease has become quiescent the resultant heart damage might make it impossible for the child to attend an ordinary school. In some communities, as we shall see in chapter IV, successful efforts have been made by local boards of education in cooperation with the medical authorities, to carry the teaching program into the home. In this way the child can keep pace with his schoolmates and join them at a later date when he is declared fit to return to school. The cooperation of all people involved in the care of the child has broad application in the child's attendance at school. There have been instances when interpretation by the social worker has resulted in a whole class moving from the third to the ground floor because one of its members had had rheumatic fever and had been advised against climbing stairs.

The fact that children in this 8-15 year age group are characteristically very active physically also presents problems in relation to limitation in activity. It is very difficult for children to understand

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1. Proceedings of Conference on Rheumatic Fever, Washington, (1943,) United States Children's Bureau, Pub.308, p.2.

2. Supra, p.14.

why, when they are feeling well, they cannot run and play with their friends. The parents are sometimes persuaded by their child's constant demands to be allowed to go out with his friends or else they are sometimes so concerned about the possibility of overactivity that they restrict his activities more than is indicated by his medical condition. The inherent danger in either of these attitudes is discussed in chapter IV.

In the "over fifteen years" age group, which here includes eight boys and girls, there is yet another problem, for most young people at this age are considering employment and vocational training. Boys and girls who have had rheumatic fever must be helped to secure positions that will satisfy their desire for accomplishment but which, at the same time, will not prove to be too strenuous. It is often difficult for these young people to accept the fact that their physical condition prevents them from doing the things they had always wanted to do.

It may be noted in table II that there are more than twice as many boys as girls attending the clinic. Just why this is so cannot be determined from the material presented in this study but it does present difficulties as far as care of the child is concerned. Boys are less satisfied with passive activity than girls, hence their convalescence presents a greater problem than that of girls.

The fact that the majority of children in this group are over eight years of age, with an average age of 11.2 years, simplifies the problem of convalescence for those who cannot go home. Most of these children can be adequately cared for in institutions, because a characteristic of this age group is that the children are struggling to be indepen-

dent from their families, and the desire to become part of a group is strong.[1] An institution run on sound child care principles would, therefore, meet the needs of many of these children. In fact, a children's convalescent home could have a cardiac wing with a program geared to the requirements of these children.

B. Religion

Sixty-seven per cent of the cases in this study, as seen in table II, are of the Roman Catholic religion, twenty per cent are Protestant and thirteen per cent are Hebrew. The most noticeable feature about these figures is the predominance of the Roman Catholic children. This is not in itself too amazing when we consider that this city is predominantly French-speaking, but it does present a problem in relation to uniformity of service to rheumatic fever cases. The family and child care agencies in this city are rigid in their division according to religion and since the agencies vary in the type of service offered, it is not possible to offer uniform help to the rheumatic fever families. For example, because of sheer weight of numbers and lack of finances the French Catholic family agency is not able to accept cases for family service or for income supplementation. The Protestant family agency will accept service cases but they will not supplement low incomes, while the Jewish agency will accept cases for both service and for income supplementation.

On a doctor's recommendation, the Montreal Diet Dispensary will provide extra diet and instruction in preparing nourishing food to Protestant families, but there is no similar service for Catholic children. Thus

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1. Supra, p.14.

the uniformity of treatment, regardless of religion, which is characteristic of medical services in this city, breaks down when financial and family case-work service is required.

This points to a need for some type of program for rheumatic fever cases so that uniform medical and social services can be offered to the families of the children with the disease. Unless supplementary diet, clothing, equipment, etc., can be obtained it becomes impossible, in many instances, for the child to be cared for at home.

In relation to the need for co-ordination of services, the problems of children with rheumatic fever cannot be met by any one single person or agency, but call for the close cooperation of physicians, nurses, social workers, educationists, and others. As Dr. Galvin has said[1]. "The medical examination and orders are merely the hub of the wheel of the management of the rheumatic child which must include not only medical and nursing attention but education and occupational therapy, social and emotional adjustment and often outright financial aid".

C. Area of residence

Because of the significance of physical and environmental factors it was thought advisable to make a spot map of the cases to see if the families were equally distributed throughout the city or if there was a predominance of cases in any one area. Map No.1 gives a general picture of the area of residence.

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1. Galvin, op.cit. p.118.

MAP NO.1

Distribution of residences in greater Montreal of the families in the sample group

● -Indicates residence of one family

■ -Indicates the Children's Memorial Hospital clinic

It may be seen from the map that twenty-two of the children live above Pine Avenue between Park Avenue and Papineau Avenue, eleven west of Bleury Street and south of Dorchester Street and five east of Bleury Street and south of St.Catherine Street. The other six cases are in outlying districts of the city.

The significant fact about these figures is that 41 per cent of the children come from a comparatively small area in the northeast region of the city. This is an area characterized by a certain type of housing, namely, row upon row of three storey buildings, with each floor occupied by two or more families. These residences have very little light or air and are heated by stoves in the hall.

A significant aspect of the residence problem, so far as medical care is concerned, is that these children who live in the northern area of the city are far removed from the out-patient department of the hospital, which, as can be seen on the map, is on the corner of Guy Street and St.Antoine Street. Clinic visits for these children involve travelling a considerable distance. Long trips on public vehicles can be tiring and can result in the child being exposed to colds. This is important to consider in rheumatic fever where an upper respiratory infection could result in a recurrence.

It would, therefore, seem evident that where children live long distances from the clinic some arrangements would have to be made for transportation or else for home visits by the medical staff. Certainly transportation would seem to be an important factor in the follow-up of rheumatic fever cases and consideration should be given to the problems each case presents in this respect.

D. Rent

The rent that the families pay is important to consider because it is a means of indicating the type of housing. Generally speaking, it is true for the lower rental areas that the lower the rent the more inadequate the housing. This, of course, does not follow in all instances but rent paid does give an indication of housing factors. Then, too, if a family on a low income pays a high rent, it is obvious that sacrifices would have to be made in purchasing food, clothing or other necessities.

The following table gives an indication of the rental factors for the sample group.

TABLE III

Monthly income in dollars classified according to monthly rent

Monthly rent in dollars	Monthly income in dollars						
	Total	Under 100	100-120	121-140	141-160	Over 160	No data
Total	46	10	7	6	7	10	6
Under 10	2	0	1	0	1	0	0
10 - 14	10	3	2	2	1	2	0
15 - 19	10	3	1	2	2	2	0
20 - 24	7	2	0	2	1	1	1
25 - 29	2	0	1	0	0	1	0
30 - 34	4	0	0	0	1	2	1
Over 34	2	1	0	0	0	1	0
No data	9	1	2	0	1	1	4

In analysing the findings we observe that there are nine cases for which no rent data are available, and six where salary is undetermined. The former figure can be partially explained by the fact that five families own their own homes, and that one woman is a maid in a private home where she and her son have free board. One child is in St.Patrick's Orphanage and no data are available on two others. As far as salary is concerned, one man works on his own farm, thus has no definite salary. No information is available on the boy who lives in the orphanage and in four cases salary is unstated.

Subtracting the nine for which no rent data are available from the total of forty-six, we find that there are thirty-seven cases we can use for analysis of rent payment. Of these, thirteen pay rent of less than $15.00 per month, twenty-three pay less than $20.00 per month, and twenty-nine pay less than $25.00. Thus, just eight families pay rent over $26.00 per month. We must conclude, therefore, that the vast majority of these families live in low rental areas. The average rent paid by these families is $19.97.

E. Income

Perhaps the table that is most significant is table V which indicates the number in the family and income per month. The relationship between the size of the family and its income is the crux of whether this group of families live on a "below minimum", "minimum" or "adequate" standard. It is difficult to determine what the minimum adequate budget is for a family of a given size, but, in order to arrive at some estimate for this study, the Montreal Jewish Family Welfare budget was used as a

guide. This allows for rent, gas and light, heating, household supplies, clothing and special needs. The Jewish Family Welfare[1] budget was used because it is considered to be a minimum adequate budget.

Shown in table IV, therefore, is the approximate relief budget of a private family agency. It will be helpful in interpreting the next table. It must be pointed out, however, that the agency does provide special allowances where indicated and that there are different allowances for children of different ages, hence the figures given here are but a rough estimate. They do provide, however, a means of comparison.

TABLE IV

The Jewish Family Welfare budget
for families of different sizes

Number in family	Monthly budget in dollars J.F.W. budget [a]
3	114
4	136
5	160
6	170
7	193
8	226

a. Jewish Family and Child Welfare Bureau of Montreal - Clothing Budget 1948. Family Welfare Department. Baron de Hirsch Institute, Relief Allowance Budgets - 1948-49.

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1. Henceforth the Jewish Family Welfare will be referred to as the J.F.W.

The following table shows the distribution of cases according to income and size of family.

TABLE V

Monthly income of families classified according to the size of the family

Number of persons in family	Monthly income in dollars						
	Total	Under 100	100-120	121-140	141-160	Over 160	No data
Total	46	10	7	6	7	10	6
2	2	1	1	0	0	0	0
3	5	4	0	0	0	0	1
4	8	3	1	2	1	1	0
5	15	2	4	1	2	2	4
6	5	0	0	0	2	3	0
7	6	0	1	2	1	1	1
8	1	0	0	1	0	0	0
Over 8	4	0	0	0	1	3	0

In studying table V it can be observed that there are no salary data on six of the cases. Of the remaining forty there are two families consisting of a mother and one child. One of these mothers is a maid in a private home and the fact that she receives board as well as a salary makes her income difficult to determine. The other woman earns $113.00 a month which is above the J.F.W. minimum for a family of that size.

There are five families of three and the income of four of these

is less than $100.00. There is no information available on the fifth. Since the minimum J.F.W. budget for a family of three is $114.00 all of this group for which material is available are living on a "below minimum" standard.

Of the eight families of four, six have incomes of less than the minimum of $136.00 and two have larger incomes. Fifteen of the families have five members and of these, ten have below minimum incomes. Four of the five families of six members have incomes below the J.F.W. minimum as have five of the six families of seven members.

The one family of eight has an income of $130.00, as compared to a minimum-adequate of $226.00. Of the families over eight, one has nine members with an income of $178.00; one has twelve members with an income of $209.00; another ten with an income of $198.00; and the last, a family of nine with an income of $150.00. All of these families have an income of less than the J.F.W. minimum of $226.00 for a family of eight.

Thus it can be seen that of the forty cases thirty-two of the families, or seventy-eight per cent, have incomes of less than the J.F.W. minimum.

These are very striking and significant figures. They are indicative of the problem faced by the medical and other professions in trying to control rheumatic fever and help the child and his family. In many instances economic factors make it impossible for the parents to give the child, who is recovering from rheumatic fever, adequate care. Then, too, improper food over a period of time lowers resistance and makes a child more susceptible to disease than a well nourished child would be.

An example of the economic deprivation is shown in one of the families of six children. Here the eldest child is eight years old and the youngest six months, while the patient is a boy of six. An absolute minimum income[1] for this family would be between $200.00 and $220.00. This amount covers just the bare necessities. Actually, the income is $161.00, which is at least $40.00 less than the minimum. No agency is helping this family. It is not surprising that at least one of these children should become sick.

The problem now becomes one of trying to prevent the child who had rheumatic fever from having a recurrence. It is obvious that a family like this needs material help, if it is to be successful in caring for the child who has had rheumatic fever. Most of the other families in this study are faced with varying degrees of the same problem.

F. Use of community agencies

In discussing the use of community resources it must be understood that at the time of the study the newly formed social service department at the Children's Memorial Hospital had been in existence for only about a year. There was no full time worker on the cardiac service. Problem cases were handled on an individual referral basis. Therefore, just ten of the forty-six cases were known to the Social Service Department.

A review of the registrations on the forty-six families at the

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1. J.F.W. scale.

Social Service Index[1]. shows that health agencies such as the Victorian Order of Nurses, Child Health Association, etc., are registered thirty-eight times, case-work agencies such as Family Welfare Association, Children's Aid Society, Mental Hygene Institute, are registered fifty-seven times and other agencies such as the Red Cross Society, the Salvation Army and the Canadian National Institure for the Blind are registered nineteen times. This means that there are one hundred and fourteen registrations on the forty-six families, or an average of 2.6 registrations per family. The agency with the greatest number of registrations is the Child Health Association with fourteen, followed by the Victorian Order of Nurses with twelve, and the Social Service Department, Children's Memorial Hospital with ten. Eighteen of the cases are known to one of the four family agencies[2]. but interestingly enough just one family is registered with the Diet Dispensary. In a disease where diet[3]. plays such an important part, it would seem regrettable that more use has not been made of an agency that could be of inestimable help, both in supplementing inadequate diet and instructing in methods of preparing nourishing food. It must be pointed out, however, that the Diet Dispensary serves the Protestant Community only.

There are fifteen families, or one-third of the cases, which are not known to any agencies or at least are not registered at the Social

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1. The Social Service Index is a clearing house for agencies. They register their active cases there and find out what other agencies are interested in their families.

2. Family Welfare Association, Jewish Family Welfare Association, Catholic Welfare Bureau and Bureau d'Assistance Sociale Aux Familles.

3. Supra, p.9.

Service Index. Thus there is no social worker helping them with the many problems that rheumatic fever presents and no agency giving them material assistance. One of these cases is that of a boy in a family of five children and two adults whose income is $32.00 per week. Just how these parents are able to give the sick child adequate care and an adequate diet without depriving the other children is certainly difficult to imagine. This is not taking into consideration the difficulty they might encounter in giving the child a bed in his own room, and coping with the problems of convalescence. Yet, apparently, no one is helping them with their problems.

Each of four families is known to more than six agencies, two have seven registrations, one has eight and one thirteen. Where many agencies are interested in a family there would seem to be a need for a co-ordination of services in helping the family, for it is only in this way that community resources can be used to full advantage.

This analysis of the identifying material on the forty-six cases studied here has revealed some interesting facts in relation to the group as a whole. As far as the age of the children is concerned the majority of the children are of school age with an average age of 11.2 years. This presents problems in relation to education, recreation, vocation and convalescence. There are twice as many boys as girls in this group and two-thirds of the children are Roman Catholic, one-fifth Protestant and one-eighth Hebrew. The religion of the child assumes importance when attempts are made to obtain help from community agencies, for the uniformity of treatment, regardless of religion, which is characteristic of medical services, breaks down when problems are of

a social and economic nature.

Map 1, the spot map of the residences of the children, reveals a concentration of twenty-two cases in the northeast section of the city. Just why this is so cannot be determined from the material studied, but this would perhaps be a topic for further research. As far as residence is concerned, the distance from clinic is an important consideration.

These families come from low rental areas and the average monthly rent paid is $19.97. Using the Jewish Family Welfare Budget as a guide it was found that seventy-eight per cent of the families are living on "below minimum" incomes.

Community agencies were used to a varying degree by the families in this group. Fifteen families were unknown to agencies while four families were known to more than six agencies.

This chapter has presented material on the sample group as a whole in order to give an indication of the socio-economic factors that bear consideration in planning for the care of children with rheumatic fever. In chapter IV the emotional problems that arise in connection with rheumatic fever will be discussed with case material to illustrate the problems presented.

CHAPTER IV

THE EMOTIONAL PROBLEMS OF RHEUMATIC FEVER

The effects of rheumatic fever and rheumatic heart disease on the child's emotional well-being will be discussed in this chapter with emphasis on the role of the medical social worker in helping these children and their families understand and meet the emotional traumas caused by the disease. The case illustrations used were obtained from the social service records of ten of the cases in the sample group. The problems discussed arise from the nature of the disease itself, its long course, the crippling results and its effect on the child's emotional well-being. The cases presented are not isolated instances of problems, they are examples of common difficulties arising from this one diagnostic group.

It is constantly stressed in the literature on rheumatic fever that consideration must be given to emotional factors if treatment of the total child is to be successful. If a child has appendicitis he is operated on, he must stay in bed for a few days and then he gradually resumes normal activities. In the majority of cases this presents no serious difficulties. But when a child is stricken with rheumatic fever the problems at once become apparent. He is faced with indefinite, but usually long-term, hospitalization, which he and his parents must be helped to accept. His schooling will be interrupted, his normal family relationships interfered with and his emotional stability will be threatened.

In comparing the effect of illness on the tuberculosis and cardiac

patients, Haselkorn and Bellak[1] state the emotional traumas clearly.

> The crushing incapacitating effects of the diagnosis, the heightened insecurity, the exaggerated feelings of uselessness, the shattered interpersonal relationships, due to ill health are common to both cardiacs and the tuberculous. These patients experience environmental frustrations and internal pressures which threaten self-esteem and engender attitudes more crippling than the disease itself. If generalizations can be made, cardiac sufferers are prone to even greater emotional reverberations because of the progressive nature of the disease and especially because the heart is symbolically focal for emotions.

Hospitalization might signify rejection by his parents to the insecure child and cause him to become hostile and uncooperative. He might have unexpressed fears of what will happen to him and become withdrawn and resistant to treatment. Thus an understanding of each child's social background, his attitude toward his family and contemporaries is of the utmost importance in helping the medical and nursing staff to treat the child as an individual personality with feelings and attitudes which must be understood if medical treatment is to be effective.

Dr. Josselyn,[2] child psychiatrist, has stated,

> There are two major reasons for considering the emotional implications of rheumatic fever seriously. On the one hand, it is difficult to function in the world at large with a physical handicap. It is equally difficult to do so with even a relatively benign emotional handicap. The two conditions existing in one person undoubtedly increase the difficulties geometrically, since each condition increases the problems presented by the other. A second consideration is the effect that anxiety has on the heart directly. We know that the arteriosclerotic heart is damaged by the additional strain anxiety places on it. There is no reason to assume that this is not equally true with the rheumatic heart.

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1. Haselkorn, Florence and Leopold Bellak, "A Multiple Service Approach to Cardiac Patients", The Journal of Social Casework, Vol.30, (July, 1950), pp.292-293.

2. Josselyn, Irene, "Emotional Implications of Rheumatic Heart Disease in Children", American Journal of Orthopsychiatry - Vol.19, (January, 1949), p.100.

A. Role of the social worker

To help the child with the emotional problems that so frequently accompany rheumatic fever is then part of the total treatment process, and the social worker is that member of the medical team whose responsibility it is to present a clear picture of the environmental and interpersonal relationships of the child and to help the child express his anxieties and fears. If he is not given an opportunity to do this, his anxiety may express itself in a denial of the illness or in an overdependence on it. Children who are hostile or withdrawn must be given an opportunity to establish a relationship of trust with an accepting adult before they can be helped to accept their illness. Social workers also help the child and his parents plan for convalescence, schooling and recreation, as can be seen in the case illustrations that follow.

The medical social worker's training enables her to understand what illness means to patients and to families. It also helps her to understand the interrelated social problems of illness, and it enables her to act as a representative of the hospital in relation to other agencies in the community. The need for community action in combatting this illness, as discussed in chapter V, makes the social worker's role as liaison between community agencies and hospital staff even more important. But the social worker's greatest contribution to the overall care of the rheumatic fever child lies in her ability to recognize and handle problems of an emotional nature. Some of these problems will be discussed in the pages that follow.

B. Fear of death

A basic fear of most people, who are acutely ill, is death. This is particularly true of people who have anything wrong with their hearts for it is only too obvious that when the heart stops beating the person dies.

The child, who suffers from rheumatic fever, often learns of the death of a fellow patient from the same disease as he has, and he frequently hears the doctor talk about the danger of heart damage. The constant emphasis on the heart and heart damage builds up in the child's mind a fear that he, too, will die. As Haselkorn and Bellak observed after long and intensive treatment of cardiac patients - "The heart is traditionally the most heavily libidinally invested organ in the body. Any affliction of it leads to particularly strong hypochondriacal investment".[1.]

It is difficult to reassure children about their heart conditions because their anxiety is frequently based upon reality. Often their activity must be sharply limited and "a doctor cannot say to a child 'If you let me govern the rapidity with which you return to active games and work, you will finally be able to play football'. He can only say that by carefully graded steps the child will finally reach a barrier which may permanently limit his participation in functions having physical strain upon his heart".[2.]

Children can become acutely anxious about this fear of death and

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1. Haselkorn and Bellak, op. cit. p.296.

2. Josselyn, op. cit. p.87.

this will aggravate their condition. In her experience at "Herrick House",[1] Dr.Josselyn found that there have been several cases where the most obvious explanation for the child's increased symptoms seemed to be the child's anxiety about death.

Help for these children must be directed toward enabling them to express their anxieties and their aggressions, and accept the limitations imposed by their condition. Physically safe outlets must be found for these aggressions.

Parents' anxieties about their children with rheumatic fever also have a reality basis, for they may have known adults with rheumatic heart disease so crippled that normal activity is impossible, or they may have had friends who died as a result of rheumatic fever and they are ever mindful of the fact that heart trouble is the leading cause of death. It is little wonder, therefore, that they react with terror to the doctor's diagnosis of rheumatic fever. They are immediately overcome by a fear that their child too will die. Psychiatrists say that often the fear that a child will die is an unconscious wish that he would die. In the case of rheumatic fever the fear is more likely to be based on a reality situation.

Accompanying this fear on the part of the parents is often found an acute sense of guilt that they should have permitted their child to become sick. Unless these fears and feelings of guilt are verbalized, there is danger that the parents will become so upset that they will be incapable of caring for the child.

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1. "Herrick House" is a year round cardiac camp for children in Illinois and Dr. Josselyn is their consulting psychiatrist.

An example of this problem is shown in the case of Sonja J.[1] who became known to the social worker when she was in the ward with acute rheumatic fever.

> Sonja was referred to social service for an evaluation of the home conditions and the parents' attitude. Mrs. J. came to the hospital to see the social worker and talked freely about the family set-up, home conditions and economic status. The worker, sensing that these remarks were but a cover-up for the woman's real concern for Sonja, brought the focus of the interview back to the child. Soon Mrs. J. was expressing her fear about her daughter's illness. She knew that rheumatic fever was a "terrible disease" and she was afraid Sonja was never going to recover. She was even dreaming that she was dead. She thought that had she been able to stay at home and look after the child instead of going to work this might never have happened. She then told the worker that she had never allowed herself to talk to anyone like that before. She had tried to keep all these feelings to herself with the result that she was becoming so upset and anxious she was afraid of what might happen. Actually, Mrs. J's fear of Sonja dying was not based on her physical condition for her attack had been comparatively mild with a minimum of cardiac damage. The worker asked Mrs. J. if she had ever had an opportunity to discuss Sonja's case with the doctor, whereupon she expressed her fear of approaching him because she was sure he would have discouraging news for her. After discussing this further with the social worker, Mrs. J. was able to make an appointment to see the doctor. The worker explained the situation to him before he saw Mrs. J. so that he would have a full understanding of the social factors. Mrs. J. was much relieved after speaking to the doctor, and in the course of a few interviews the worker was able to help her work through her feelings of guilt so that she was able to cope with the problem of Sonja's illness and convalescence with understanding and confidence. Sonja is now attending clinic for follow-up but has had no recurrences of the disease.

As far as the children themselves are concerned, four of the ten had an expressed fear of death. It is not always easy for children to verbalize their feelings about a subject that is vague to them and it often takes several intensive case-work interviews before the child will express his fears in this area.

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1. Case No.5

The fact that the children in the rheumatic fever ward are in all stages of the disease increases the possibility that the child will develop anxieties about death. Because of the lack of convalescent facilities children are left in the hospital longer than would otherwise be necessary. Thus, the convalescent cases and the acute cases are on the same floor and occasionally there is a death. If a child is dangerously ill he is wheeled out of the ward to a side room. The children have come to associate this removal with death, and a fear reaction results every time it happens. There is an understandable reasoning that, "If that girl had the same disease as I have and she died, I will die too".

Of the four children who expressed anxiety about death, one had a severe cardiac condition and her prognosis was poor. The other three had minimal heart damage which necessitated little restriction in activity. All four had suffered the experience of learning that someone, they had known on the ward, died as a result of the disease.

This fear can cause children to become extremely agitated and, as mentioned before, it can actually impede recovery. It would seem that for this, among other reasons, a convalescent home equipped to give the physical and emotional care, which the convalescent rheumatic fever patients need, is an urgent necessity in this community. From a psychological point of view a well-run convalescent home would certainly be a healthier environment than a hospital ward. Even in such an institution children with rheumatic heart disease might still fear death, and to overlook the need for some help in this area is to refute the theory that the total child must be treated and not merely the disease. Part of the social worker's role as a member of the medical team is to help each of

these children express and cope with their fears about their illness.

C. Problems associated with schooling

As was mentioned before[1]. most of the children in this study are in the school age group.

The education of children who have rheumatic fever or rheumatic heart disease frequently presents many problems. Because the acute and convalescent stages of the disease are so lengthy the child is often deprived of months of schooling. The result is that his eventual return to school is accompanied by the disappointment of being put back in class. "Nothing is more disturbing to some children than to be left behind their own age group in school. Under such circumstances children often lose interest, regress mentally, do poor work, or leave school entirely."[2].

The staffs of the hospitals and convalescent homes often include teachers whose responsibility it is to teach the children for as many hours as their medical condition will permit. By so doing the children can keep abreast of the classroom work and return to school when they are able to, without missing grades. If the child goes home to convalesce the social worker has the responsibility of enlisting the aid of the local board of education in providing a visiting teacher.

Frequently the child is left with a degree of cardiac impairment which makes it necessary to curtail school activities. In these cases there is a need to interpret this to the school authorities and to help

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1. Supra, p.28.

2. Cohen, Ethel, "Medical Social Problems of Rheumatic Children", American Journal of Public Health, Vol.31, (August, 1941), p.822

the child accept his limitations and develop substitute interests. This is not always easy to arrange for children are quick to use their sickness to control their environment and this is particularly true in regard to school. As Miss Cohen, prominent social worker, has observed, "A child may make capital of even a slight cardiac murmur as an advantage over his playmates or as a means of being excused from the school activities he dislikes. To retain his place among schoolmates he may indulge in excessive activity".[1.]

The schooling problem for those children who are unable to attend ordinary school is described by Dr.Josselyn,[2.] in the following terms:

> Many of the children after the convalescent period is over are unable to stand the physical strain of play, the intensity of the program and the stair-climbing that is a part of regular public school attendance. Therefore, in many large cities excellent special schools have been developed to which the child is brought in a bus. There his activity is controlled, and rest periods and opportunities to individualize his work are provided. While from a physical and educational stand-point this is all to the good, it again sets the child apart and deprives him of the normal social program of his age group.

Thus, all phases of rheumatic fever and heart disease present schooling problems and there is a definite need for cooperation among the medical team, the family and the school authorities to plan for the most satisfactory solution of the problem, ever bearing in mind the basic aim of total treatment - the return of the child to as near normal life as possible.

Of the ten cases studied six presented definite problems in relation to schooling. The case[3.] given below demonstrates the importance

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1. Ibid. p.822
2. Josselyn, op. cit. p.88
3. Case No.9

of making adequate school plans and it indicates the social worker's role in relation to this problem:

> This case is that of an adolescent boy with a rather severe cardiac condition as a result of repeated attacks of rheumatic fever. Steven, a thin, pale, boy of fifteen with a severe rheumatic heart condition, was referred to social service because the doctor felt that his condition contra-indicated his going to school, and wondered if perhaps a home teacher would be available. The social worker found that Steven had been going to the School for Crippled Children but since he lived in an outlying district of the city he had to get up at six every morning and take a local bus to the place the school bus picked him up. He was the first child in the bus and it was an hour before all the other children were collected. As a result, he was always exhausted when he arrived at school. The worker inquired into the possibility of obtaining the services of a visiting teacher but this proved more than the family could afford and, therefore, the plan was not practical. The worker then approached a local service club to see whether there were any men travelling in the vicinity of the school who could drive Steven there in the morning and home at night. This direct means of transportation would mean that Steven could stay in bed longer in the morning and would be spared the long drive around the city. A driver was available, so the worker discussed the plan with the doctor who gave his consent. By this time it was the middle of the school year and Steven, a shy, retiring boy did not like the idea of going into a class without knowing anyone. The worker, therefore, explained the situation to the school principal who arranged for one of the other pupils to meet Steven the first day and look after him. This worked very well; Steven loved school, turned out to be an excellent pupil, developed a wood-working hobby and made many friends.

This situation could have resulted in the boy staying at home and becoming increasingly withdrawn and apprehensive. As it is, he is now interested in his school work, has friends, feels that life is worthwhile, and the doctors are pleased with his physical condition. It so happened that it was just as well for Steven that a visiting teacher was not available because his attendance at the School for Crippled Children afforded him the opportunity to associate with other children, and to discover new and interesting things to do. One result was that his anxiety about his condition was lessened, and once again he felt that life was worth living.

In another case,[1] a fifteen year old girl's school career was threatened because the doctors did not think she could endure the climbing of the school stairs twice a day. The social worker discussed the problem with the school teacher who agreed to having the girl eat her lunch in the classroom. In order that she would not feel different from her friends, they, too, were permitted to eat in the classroom.

Yet another case was that of a thirteen year old girl.[2]

> This girl had had her first attack of rheumatic fever at the age of three with numerous recurrences since then. As a result, she has not been able to go to school. Her mother, preoccupied with looking after the other children, had never been able to teach her to read and write. The social worker, when the case was referred to her, was able to find a part-time volunteer who spent two days a week teaching the girl to read, with the result that life has a new meaning for her. Planning for this girl's bed-ridden future is as much a responsibility of the social worker as is helping a child with little cardiac damage accept the fact that he cannot play football. To deny her the opportunity to learn to read was depriving her of hours of enjoyment.

Schooling is an area which presents many problems for children who are recovering from rheumatic fever or who have rheumatic heart disease, not only in the actual studies but in extra-curricular activities as well. Not being able to participate in activities with the other children could have considerable meaning to the child. A child, who has derived considerable enjoyment and satisfaction from participation in school sports, finds it difficult to accept the fact that he can no longer undertake such activity. He must be helped to accept this and to develop other interests, such as woodwork, which would be a satisfying outlet for his energy. This, too, calls for a high degree of cooperation among school authorities, the family and the medical team.

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1. Case No.2

2. Case No.10

D. Problems associated with employment

Another area in which teen-age rheumatic fever and rheumatic heart disease patients often need considerable help is in relation to employment. Most adolescents find choosing a vocation one of the most difficult things they have to do in the course of their high school careers. They are undecided as to what kind of work they want to do, and if they have set a goal they often have difficulty in reaching it. The problem for the boy or girl who has rheumatic heart disease is even more acute. The case of Sandra[1]. is an example of the conflict that arises between what a girl might want to do and what she is physically able to do.

> Sandra is sixteen years old and has a degree of rheumatic heart disease that contra-indicates strenuous activity. She could not take gym at school and had to restrict her activities in other fields of endeavour. Ever since she could remember she had two vocational ambitions. She wanted to be either a reporter or a nurse. Both these occupations involved strenuous activity; in fact, the type of work that seemed indicated was employment in an office. But she said she did not like office work and would not consider that as a career. The social worker is trying to help Sandra find some employment that will be satisfying to her, and within the limits of her physical endurance.

The need for case-work help is well summed up by Miss Grace White[2]. who says:

> While it is true that physically handicapped individuals can have a wholesome interest in life and enjoy many of the activities of their associates, handicapped individuals frequently need special help in accepting the handicap, in adjusting to it and in choosing activities that are satisfying, and in accord with the limitations imposed on the individual.

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1. Case No.1

2. White, Grace, "The Role of the Medical Social Worker in the Management and Control of Rheumatic Fever and Rheumatic Heart Disease" - The American Journal of Medicine, Vol.11, (June, 1947), p.619.

E. Dependency patterns encouraged and/or fortified by illness

It is important to consider one phase of the normal emotional development of children if the child's reaction to limitations in activity, made necessary by rheumatic fever, is to be understood. All children have a struggle in trying to handle their normal feelings of aggression. The child fears his aggressive impulses towards others because of the danger of punishment. He might even lose the love of his parents. On the one hand the child's capacity for aggression is reassuring and on the other hand it presents some dangers. The child reacts by expressing his aggression in physical activity at the same time as he dilutes some of the intensity of his emotional attachment and need for his parents by directing it to a relationship with his contemporaries. Thus play with his friends is the normal outlet for aggressive impulses.

Children with rheumatic fever or heart disease cannot seek the foregoing solution to their problems of aggressive impulses. The medical regime required blocks this method of working out normal aggressive reactions in the child. In discussing this problem of release for feelings of aggression Dr. Josselyn has said:[1.]

> The long period of isolation from a social group and normal social activities lessens the opportunity for friendships to partially replace the parents. Furthermore, and more significant, aggressive behaviour, expressed in healthy patterns of aggressive behaviour, such as active games, is again dangerous. Such expression carries with it the possible punishment of death. The danger of aggressive behaviour thus becomes a real one and the sublimation usually found in children is forbidden.

Faced with this intolerable situation the child is apt to regress

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1. Josselyn - op. cit. pp.98-99

to a more infantile, dependent type of relationship with his parents and completely sublimate the natural feelings of aggression. He thus gains certain satisfaction from using his illness as a means of demanding more care from the parents. The parents, who perhaps found the aggressive impulses of the child difficult to understand and handle, often encourage him in his overdependency with the danger that the child will have a cardiac neurosis.

An example of this is Steven, the boy mentioned in connection with schooling problems:[1.]

> Steven had been brought up in a closely-knit family group in the suburbs of the city. As mentioned before, he was a quiet, shy boy who found it difficult to associate with other children. In his illness he found an acceptable way of withdrawing from association with others. His disease certainly imposed some limitations but, onto these, he superimposed further limitations because he derived too much satisfaction from overdependence on his parents.

In another case,[2.] an intelligent ten year old boy, who had been brought up in a broken home quickly realized that he could use his illness to get what he wanted from his father, who, though separated from his wife, visited the home regularly. The mother, not willing to share the boy's affection with the father, treated him as an invalid, thus making it necessary for him to remain dependent on her.

One can easily see how these boys could develop into narcissistic and demanding adults with cardiac neurosis.

A third example of overdependence on the disease is that of Mary:[3.]

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1. Supra, p.52.
2. Case No.3
3. Case No.7

She was first admitted to the hospital with rheumatic fever at the age of ten. She, too, had an emotionally deprived childhood. Her parents were separated and she lived a few months of each year with her mother and a few months with her father. When neither wanted her she was sent to a convent. During her attack of rheumatic fever she received considerable attention both from her parents and from the hospital staff. Her discharge from hospital meant a return to the unhappy life she had known. Whenever life became too difficult or uncomfortable for her she developed symptoms of rheumatic fever which made it necessary to attend clinic. No physical basis could ever be found for these complaints but they were nonetheless very real to her and could always be associated with some traumatic experience in her life. The social worker is now trying to help Mary make a satisfactory work adjustment, realizing that this girl needs a feeling of security and accomplishment, and, above all, a knowledge that someone is interested in helping her in spite of the fact that she is not sick.

It is part of the function of the social worker to help these children while they are still young to overcome the unconscious and sometimes conscious dependence on the disease. At the same time she must help the child to lead as full and useful a life as possible.

A problem often exists in trying to gear a child's activity to his physical condition. This requires the utmost ingenuity, understanding and acceptance by the parents. Often they cannot do it without help from the social worker who understands the medical situation and appreciates what this may mean to the child and his family.

F. Non-acceptance of necessary limitations

Whereas some children develop a dependency on the rheumatic fever as a means of controlling their environment, often children react to the curtailment of activity, as advised by the doctor, by a non-acceptance of the limitations. The child may not understand the need to restrict activity or to do so might seem so disagreeable to him he would decide to carry on as usual, even though realizing the risk involved. It is diffi-

cult for a child who feels well to understand the need to restrict activities just as it is hard for the parents to realize that a child may be disabled when there are no outward signs of impairment. The need for adequate interpretation of the illness by the doctor is obvious. It often becomes the responsibility of the social worker to help the parents and the child accept the doctor's recommendations. McBroom and Frohlich,[1] have had considerable experience in trying to help children accept their limitations and in this connection have stated:

> Interpretations of physical disability to children --- has as its aim promoting each child's understanding of his physical condition, and often the acceptance of difficult realities of permanent damage and limitation. The aim of such understanding and acceptance is to relieve the child of anxiety about his condition so that he will avoid extremes of unnecessary protectiveness or violent activity.

Another reason for non-acceptance of limitations is seen in the following case:[2]

> Carol's first attack of rheumatic fever was nine years ago and this resulted in some cardiac damage. The doctor recommended restriction in activities with regular followup at clinic. A few years later it come to the doctor's attention that Carol was not attending clinic regularly nor was she accepting the limitations. He referred the case to the social worker who found that Carol had an unhappy home life with no father or siblings. Her mother had to work leaving Carol in the care of her grandparents. She had little security at home thus her greatest source of satisfaction was her association with her friends. She felt that restricting her activities would make her different from the others in her "gang" ("individuals in that age group 'teen-age' are strict conformists --- . What the group approves of is right").[3] Hence she decided to live a "short but merry" life. After a few interviews with the social worker, arrangements were made for Carol to join a club group. The leader was told of her physical condition, and she was given responsibilities in the group that were

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1. McBroom and Frohlich - op. cit. p.159

2. Case No.9

3. Josselyn, Irene - Psychosocial Development of Children, Family Service Association of America, p.108.

within her physical limitations. She is now deriving a certain satisfaction from the club, her attitude toward her illness is changing and she is becoming more accepting of her limitations.

This case is but one example of the innumerable problems that arise in relation to non-acceptance of limitations and indicates the help that the social worker can be to these children.

McBroom and Frohlich[1] have also found that some children persistently reject the efforts of the social worker to interpret their limitations to them. In dealing with this situation they have found that:

> Some (children) who have permanent damage and must always observe restrictions can, with safety, be allowed to overstep so that they can experience the symptoms of exceeding tolerance and adjust activities accordingly, rather than strain against the caution of counsellors, (social workers) which is felt as arbitrary discrimination or an equivalent of parental anxiety.

It must be stressed that in each case of rheumatic fever there is a danger that the child will either be overprotected and rely on his sickness to control those around him, or else that he and his parents may reject the limitations his condition imposes. In the one instance the child will grow up to be a demanding cardiac cripple, in the other his overactivity will probably cause a recurrence. Both situations can be avoided if the cases are evaluated, the dangers noted and the parents and the child helped by the social worker to understand and accept his illness and the limitations it imposes. This must be done in cooperation with the other members of the medical team and the community agencies.

In this chapter emphasis has been on rheumatic fever and rheumatic heart disease as illnesses that present many problems of an emotional nature. The course of the disease is usually lengthy and the results are

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1. McBroom and Frohlich - op. cit. p.158

sometimes crippling. A knowledge of the effect that this has on the child and his family is as important to the treatment of the total child as is an understanding of the physical aspects of the disease. The social worker is that member of the medical team whose function it is to evaluate the emotional problems and to aid the children and their families, wherever possible, in making satisfactory adjustment to the emotional traumas the disease presents.

The fear of death on the part of both the child and his family is one of the most frequent emotional problems encountered in relation to rheumatic fever. This is probably because the heart is so often affected and heart trouble is frequently synonymous with death.

Feelings of inadequacy may also be prominent in the mind of the rheumatic fever child because long periods of illness have deprived him not only of his schooling but also of his friends among other children in his normal social group. In relation to schooling, problems arise because of the lengthy periods during which the child is unable to attend school. Unless special arrangements are made for him to keep up with his studies, he finds on his return to school that he is in a grade behind his friends. Children frequently have a degree of cardiac damage which makes attendance at regular school impossible. Substitute means of obtaining an education must be found, such as the use of the School for Crippled Children and home teachers. Provision must also be made for recreational and social activities of which the child is deprived by not going to school.

In considering employment, adolescents who have had rheumatic fever are frequently thwarted in their ambitions by the fact that they

have cardiac damage that makes it necessary for them to seek less strenuous employment. This is often difficult for them to accept unless they receive help from the social worker who can use vocational guidance services as well as her own case-work skills in trying to bring about a satisfactory work adjustment.

The child's reaction to the illness might be an overdependence on it as a means of controlling his environment. The parents could overprotect him and thereby encourage his dependence. The danger in this response is that the child will grow up with a cardiac neurosis which is often more handicapping than the disease itself.

On the other hand, the child might be unable to accept the fact that his heart damage makes it necessary to restrict activities. This non-acceptance of limitation could lead to recurrences and further hospitalization.

In most cases of rheumatic fever varying degrees of these responses are found. As McBroom and Frohlich[1]. have said: "Many children need aid from case-workers and other professional people to achieve a balanced course between illness-born dependency and a tempo of life too strenuous for the damaged organism".

In chapters III and IV the social and emotional problems as seen in this sample group of cases have been discussed. In chapter V the methods used in other communities for meeting such problems and controlling and combatting the disease, will be considered.

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1. Ibid. p.155

CHAPTER V

RHEUMATIC FEVER CONTROL PROGRAMS

Increasing awareness on the part of the public of the ravages caused by rheumatic fever and rheumatic heart disease has resulted in efforts being made in many communities to establish Rheumatic Fever Control Programs. This is particularly true in the United States and in England where considerable progress has been made in co-ordinating services for the diagnosis and treatment of the disease and in making these services available to all, regardless of economic status.

These programs co-ordinate medical, nursing, social work and other services so that maximum assistance can be given to families in accordance with their physical and emotional needs. Besides improving the service to the child, this system affords an opportunity to collect data that will aid in research. Another aim of the control program is to acquaint the public with the facts about rheumatic fever so that parents will seek medical aid for their children as soon as symptoms appear. This is of the utmost importance, for in early diagnosis and treatment lie the child's greatest hope for a complete recovery.

Rheumatic fever is now commonly regarded as a community problem and any attempt to control the disease is therefore dependent upon community action.

In this chapter community action in the form of control programs will be discussed and various successful programs will be reviewed in detail in an effort to determine the value of such projects. More

specifically this chapter will trace the initiation of control programs in the United States and will examine the actual programs in effect in that country and in England.

A. Initiation of programs in the United States

In 1939 the United States Congress authorized the Children's Bureau to include boys and girls with rheumatic fever in it's program for crippled children. This program is financed by the Federal Government which makes grants-in-aid to States for the establishment of public programs for the care of crippled children. By May, 1945, eighteen States had approved programs for the care of children with rheumatic fever or heart disease and fifteen more were planning such programs. In 1945 Federal funds given to support such projects amounted to $3,870,000.00.[1.]

A State rheumatic fever program is usually initiated by providing service for a few counties only and then expanding the service as rapidly as possible to include other counties. The areas selected for the initial programs are where good medical, social and public health nursing services can be obtained most readily and where hospitals, clinics, sanatoria and convalescent homes are available.

B. Set-up of the programs

Once the area has been selected, special diagnostic and treatment services are made available, and parents, teachers, doctors, etc. are encouraged to refer children suspected of having the disease. If the tests prove that the child has rheumatic fever, hospital and convalescent

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1. Facts About Rheumatic Fever - United States Children's Bureau Pub.297, Washington, (1946) pp.5 & 6.

services are provided. Boys and girls under twenty-one years of age are eligible for care under most of the State programs, and the parents pay whatever they can afford toward the cost of the child's care. Care is provided free to those who cannot contribute toward the cost.

When a child is accepted for care under the State program a well trained paediatrician, employed by the State is responsible for his medical care. A medical social worker studies the social conditions, evaluates the child's and parents' attitudes toward the illness and is responsible for convalescent planning. A public health nurse supervises the care of children who are convalescing from rheumatic fever. She works closely with the paediatrician in seeing that his recommendations are understood and followed by families, teachers and any other people who are concerned with the everyday care of the child.

The type of care the control plan offers to the child is summarized below.[1.]

His condition is diagnosed by the paediatrician who makes use of the laboratory facilities that are available. A child who is acutely ill is given care in a special children's ward of a hospital. During this period the social worker is evaluating the home conditions and helping the family make plans for convalescence. If the home is adequate and the parents are capable of looking after the child, he is discharged home to convalesce. If it is impossible for his parents to care for him, he is placed in a special children's convalescent home where the program is designed to meet his physical and emotional needs. The staffs of most of

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1. Ibid. p.8

the convalescent homes used by the control programs include occupational and physical therapists and teachers.

The same paediatrician is responsible for the child's care whether he goes home or to a convalescent home.

When the child is at home, the local board of education provides a visiting teacher.

C. State of Michigan control program

An example of a successful control program is found in the State of Michigan.[1] This program, initiated in 1946, is operated by the Michigan State Medical Society with the cooperation and assistance of the Michigan Crippled Children's Commission, and the Michigan Society for Crippled Children and Adults. It is designed to include case finding, diagnostic services, treatment facilities, convalescent care and follow-up studies. The objective is to see that every case of rheumatic fever in the State is recognized and properly managed, regardless of the economic status of the patient's family.

The State has been divided into districts, each with one or more diagnostic and treatment centres to which any physician in the State may send patients who are suspected of having rheumatic fever, for diagnostic and consultative advice on treatment, prophylaxis, and follow-up. The centres are staffed by medical specialists.

A small examination fee is charged, but when the families cannot afford this, the costs are assumed by the Michigan Crippled Children's

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1. Rusk, Howard."Michigan Program is Hailed as Curb on Rheumatic Fever", The New York Times (October 26, 1947), p.30.

Commission. Auxiliary services such as stenographic assistance, nursing aid, transportation, and lay education are furnished by a National Sorority Alumnae.

Nearly one-third of the first six hundred children who were seen at the clinic were found to have or to have had rheumatic fever. As a next step in the program, the Michigan Society for Crippled Children and Adults is establishing a convalescent home for children who are unable to receive the proper convalescent care at home.

D. State of Virginia control program

Another type of rheumatic fever control program, made possible by the Children's Bureau, is the one initiated in the State of Virginia on May 1st, 1941.[1] This provides for a staff consisting of a full time paediatrician, a public health nurse consultant, a medical social work consultant, a part-time cardiological consultant, a part-time technician and a clerk. At the outset the program was set up on a small scale to determine the adequacy of the system. It was then slowly expanded to include other areas of the State. The first experimental area including Richmond and the surrounding Henrico county. The reason for this selection was that the best medical facilities are located there.

The program provides diagnostic and treatment facilities for all children suspected of having rheumatic fever or rheumatic heart disease.

The children are seen only by appointment, except in the case of an emergency. The appointment system decreases the length of time the

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1. Galvin, Louise, "The Virginian Program for Children with Rheumatic Fever" - The Child, Vol.6, (January, 1942), pp.164-168.

child must wait to be seen by the doctor. This is important because waiting for the doctor often causes the child to become apprehensive and upset.

If a case is referred to the program by a private physician, he specifies whether he wishes the patient to receive diagnostic service only or complete care. After the child's examination a detailed report is sent to the referring physician.

The clinics are held twice a week in the out-patient department of the Medical College of Virginia, and the clinic fees are paid by the Crippled Children's Bureau.

The consulting cardiologist is available to see special cases in the clinic, hospital, convalescent home or the patient's own home.

The public health nursing consultant, who is present throughout the medical examination, acquaints herself with the health problems of the family, keeps the doctor informed of the between-visits progress of the child and helps to interpret the doctor's recommendations to the parents and the child.

The medical social worker assists the families with social problems related to or contributing to the medical condition. If the child is in the hospital, she helps the family make plans for his convalescence and if he cannot return home, she helps the family and the child accept convalescent home placement.

Before the doctor sees the child for the first time, the social worker prepares a social history from material she has gathered from other interested social agencies or from interviews with the parents. This material is made available to the doctor in summary form so that he can

understand the social situation.

All acutely ill children are hospitalized in the paediatric wing of the Medical College of Virginia, where they remain under the care of the state program paediatrician. This assures a continuity of care.

After the acute stage of the disease is over, the paediatrician, social worker and public health nurse decide, on the basis of their knowledge of the home situation and the family attitudes, whether the needs of the child can be satisfactorily met at home or whether convalescent care in an institution is indicated. If the decision is to send him home, the nurse supervises his physical care, and the social worker helps the family adjust to having a convalescent child in the home. This involves helping the parents to understand the child's physical limitations yet to avoid treating him as a cardiac cripple, if there is no need to do so. Retaining a balance between overprotection on the one hand and a non-acceptance on the other is not always easy, as has been shown in chapter IV.

If the social situation or the parents' attitude contra-indicates care at home, arrangements are made for the child to go to the convalescent hospital which is controlled and administered by the program. At this institution there are facilities for occupational therapy, physiotherapy and education. Thus the convalescent period can become a very worthwhile experience for the child rather than "wasted time".

During the convalescent period the team of doctor, public health nurse and social worker continues to care for the child to insure that he benefits as much as possible from the period of rest. If he is in the convalescent home, then every effort is made to enable him to return to

his own home as soon as conditions will permit. It is often necessary to use other community agencies in helping the family prepare for the child's home-coming. They might require financial assistance, extra food from a diet dispensary or the loan of a hospital bed.

Meanwhile, the social worker continues her case-work with the parents to help them understand the child's needs and the problems that his illness presents.

When the child returns home he is followed regularly at clinic. If he is found to be well enough to go to school, pertinent information regarding his condition is sent to the school principal and to the school nurse so that they can participate in carrying out the doctor's recommendations.

The rheumatic fever control program staff holds conferences twice a week to discuss children scheduled to appear in clinic and to review other cases that present problems.

Considerable emphasis is being placed on the importance of acquainting the public with the services available. Members of the staff are available at all times for talks before interested agencies, and they are encouraged to take every opportunity to inform county health officers, public health nurses, physicians, social workers, teachers, etc. about the program.

Thus we have an example of a well integrated program for the treatment and control of rheumatic fever.

E. National conference on rheumatic fever

So that the various States could benefit by one another's experiences in the field of rheumatic fever control programs, the first national

conference on rheumatic fever was called in October, 1943.[1] This provided an opportunity for the exchange of ideas and experiences in the administration of the state programs, to review medical, nursing and social problems affecting the rheumatic child, to consider new developments in diagnosis and therapy, to explore needs for extension and improvements in the programs, and to discuss the adequacy of present facilities and services for meeting the needs of rheumatic children.

Attending the meeting were representatives of state agencies concerned in the program, members of the Children's Bureau Advisory Committee on Services for Crippled Children, clinical investigators who had been working with rheumatic fever, and representatives of national, professional and lay organizations concerned with the health and welfare of the rheumatic child.

During the conference emphasis was placed on the importance of early diagnosis, referral of patients to special diagnostic clinics, examination of brothers and sisters, provision for care during the active stage of infection; educational and recreational activities for children confined to bed for long periods of time; schooling for children with heart disease, and co-ordination of community facilities and services for the care and management of the rheumatic child. It was stressed that the problems of children with rheumatic fever cannot be met by any one single person or agency, but call for close cooperation of physicians, nurses, social workers, educators and others.

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1. Proceedings of Conference on Rheumatic Fever - United States Children's Bureau Publication No.308, (1943), p. VIII (Preface).

F. Control programs in England

England has also had experience in rheumatic fever control programs. In 1926, the London County Council's Rheumatism Scheme was established. This was a cooperative effort by school and health authorities designed to diagnose and treat all school children with rheumatic fever. Both private and public institutions for the care of the rheumatic child came under this scheme, and all cases of rheumatic fever in children were registered. The child was hospitalized during the acute stage of the disease and follow-up care was arranged through regular medical examinations in school or in clinics supported by the program. The institutions used in giving the child medical treatment had an educational as well as a medical staff. This was thought to be important because the child could keep up with his studies and thus his schooling would not be interrupted. In this system emphasis was placed on the investigation of home conditions, and wherever possible attempts were made to help the parents with problems associated with the social situation.

Under this scheme the evidence of acquired heart disease among London school children dropped from 2 per cent to 0.8 per cent in ten years, and there was a considerable decrease in the number of chronic, cardiac invalids. To carry out this system the city of London provided one bed for every five hundred and fifty school children.[1.]

In 1944 the British Cardiac Society and the British Paediatric Association compiled a report in which they recommended the establishment of cardiac-rheumatic clinics, organization of hospital schools and compul-

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1. Yahraes, Herbert, Rheumatic Fever - Childhood's Greatest Enemy, Public Affairs Pamphlet, No.126, p.25.

sory notification of all cases of acute rheumatism.[1] The suggestions which they put forth are essentially the same as those which have been adopted by the state rheumatic fever programs in the United States.

G. Recommendations of British and American groups

These are briefly summarized below. In the first place care has been taken in both countries to start the programs in centres where it is possible to organize a complete program for the care of children with rheumatic fever or heart disease, including good medical, social and nursing services and facilities for adequate diagnostic, hospital, sanatorial and after care .

The British, in particular, recommend consultation by appointment. This curbs the long wait at clinic, keeps the child from becoming too upset and apprehensive, and enables the doctors to limit the number of clinic cases seen in one day. Thus the doctors are able to spend more time diagnosing and treating the individual child. Both the American and the British groups recommend the reporting of rheumatic fever cases to the health authorities. This would be a means of pointing out the extent of the problem.

As far as the clinic itself is concerned, the health authorities in both countries agree that it should be in a location easily accessible to the patients, and it should be closely associated with the key hospital in the area, so that good laboratory facilities may be readily available. The follow-up supervision should continue into adult life. The clinic

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1. Huse, Betty, "British Recommendations with Regard to Children with Rheumatic Fever"- The Child, Vol.9, (October, 1944), p.57.

should be staffed by experienced paediatricians and by heart specialists.

The function of the clinic should be the early diagnosis of acute rheumatism in children and adolescents, and the follow-up of those patients who have carditis, with the following objectives:[1.]

1. Securing the best possible treatment so as to minimize cardiac damage.
2. Supervising the life and activities of the rheumatic child.
3. The compilation of reliable data with the objective of securing prevention of acute rheumatism.
4. The direction of cardiac defectives into suitable occupation.
5. The education of medical practitioners in the diagnosis of acute rheumatic fever, chorea and rheumatism.

The British group strongly recommends the home supervision of all children who have recovered from rheumatic fever and the improvement of the home environment wherever possible.

The public health aspects of rheumatic fever are well summed up by Dr. Galvin,[2.] who says:

> Rheumatic fever is a chronic and recurrent disease requiring long and expensive medical and institutional care, which would be a severe drain on a fairly well-to-do family and quite beyond the reach of the marginal and submarginal group, among whom the disease has the highest incidence. The very economies of the situation and the numerous conditional and social problems which almost invariably arise, make it impossible for the ordinary relationships of physician or clinic to the patient to be effective. The medical examination and orders are merely the hub in the wheel of management of the rheumatic child, which must include not only medical and nursing attention, but education and occupational therapy, social and emotional adjustment, and often outright financial aid.

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1. Ibid. p.59

2. Galvin, Louise, "Preventive and Public Health Aspects of Rheumatic Fever in Children", Southern Medical Journal, Vol.36, (February, 1943), p.118.

Thus it may be seen that in both the United States and England efforts have been made to establish rheumatic fever control programs. In the United States the Children's Bureau has undertaken the responsibility for encouraging the states to set up programs designed to acquaint the public with the facts about rheumatic fever, and provide diagnostic treatment and follow-up services for children suspected of having, or with the disease. The aim of the British Cardiac Society and the British Paediatric Association has been much the same, and in both countries there has been conclusive evidence that it is possible to control rheumatic fever by means of such programs.

In all the programs that to date have been seen in operation emphasis has been placed on the value of team-work among the doctor, social worker and public health nurse to insure complete medical and social services to the child and his family. The continuity of medical service before, during and after hospitalization is considered to be important, and the value of reporting the cases to the public health authorities has been stressed.

Rheumatic fever is now considered to be a community problem, and as such it can best be controlled by planned community action in the form of control programs.

CHAPTER VI

CONCLUSION

Rheumatic fever has long been one of the foremost medical problems of childhood. It is the direct or indirect cause of many children's deaths and many other children are left with damaged hearts as a result of the disease. There has been considerable medical research into the cause of the disease, and one of the important considerations that has been raised is the relationship between social factors and the onset of the illness. Another area of the total problem receiving increasing attention is the effect rheumatic fever has on the child as a developing individual. The months of bed rest usually involved in the treatment of the disease and the heart damage that is frequently the result present many problems in the life of the child.

In this thesis an attempt has been made to highlight some of the social, environmental, and emotional factors that have been observed in studying a group of children who have had rheumatic fever.

In reading the literature on rheumatic fever it becomes evident that the control of this disease is not only a medical problem but also one which involves community planning. The findings of this thesis show this clearly since three-quarters of the families in the sample group are living on below-minimum incomes in very low rental areas. The problems of providing adequate care for the children in these families, who have had rheumatic fever, are manifold. Living on a below-minimum income, a family could not afford to buy enough of the kind of food which sick

children require, unless they curtailed purchases of adequate clothing or other necessities. The lowering of resistance to colds and sore throats is likely to occur where neither adequate food nor clothing can be assured. This is an important consideration in the care of the child who has had rheumatic fever, because of the ever present danger of a recurrence. To assure the most favourable circumstances towards the prevention of recurrences, therefore, would require provision of financial assistance for many of the families included in this study. In this community, however, neither the Catholic nor the Protestant family agencies are able to supplement low incomes regardless of the need, if the father is employable.

The impossibility of obtaining financial assistance for the families often means that a child cannot convalesce at home. The convalescent institution is this community, as discussed in chapter IV is inadequate for the care of children recovering from rheumatic fever; hence the only alternative is to keep the child in the hospital during this stage of medical care.

The majority of these families presented financial problems which would make it impossible for them to pay their hospital bills. Thus the community meets the cost of convalescent hospitalization. This is obviously a greater drain on public and voluntary funds than would be true of financial supplementation of the family budget if the child were permitted to return home. There is also the consideration that the use of a hospital bed for a convalescent child prevents its use for an acutely ill child or for a child on the waiting list.

As far as the child himself is concerned, it is very desirable, from an emotional point of view, that he convalesce at home. For the

sick child, even more than the well child, needs the security of his home and the understanding care of his parents.

As discussed in chapter IV, there are many emotional problems associated with rheumatic fever. It is not easy for a child to face long months of bed rest when he is feeling well and is anxious to be out playing with his friends. Nor is it easy for his parents to achieve a balance between over-protecting him on the one hand and on the other hand disregarding the necessity of limiting his activity.

Because of the fact that rheumatic fever is primarily a disease of late childhood and adolescence, schooling and vocational adjustment are of paramount importance. Frequently plans must be made for the child to attend a special school and he often needs help in accepting a selected kind of employment.

There is little use in treating the child for rheumatic fever and at the same time disregarding the emotional trauma that the disease presents. Under such circumstances the result might be a physically well child with a cardiac neurosis or a child who returns to the hospital with a recurrence because he could not accept the need to limit activities. Therefore, it is only by considering the total illness situation that treatment can be effectively undertaken. The medical social worker who is trained to understand the social, environmental and emotional effect of illness on individuals, has a definite place on the rheumatic fever treatment team. A careful evaluation of the social situation and of the effect of the illness on the child as a growing individual becomes an indispensable part of the total study of the child. Participation in convalescent planning and in helping the child and his family with social

and emotional problems are definite parts of the treatment plan. There should, therefore, be one hundred per cent coverage of rheumatic fever cases by social service.

It would seem that the only way to arrive at a comprehensive plan for combatting and controlling rheumatic fever and offering the services discussed above is by means of a control program. In chapter V examples of the programs in the United States and in England were given. These programs, which have proven successful in action, provide for complete diagnostic and treatment services, including social service coverage of the cases. In the Montreal community with its complex welfare organization, it would seem particularly important to work out a demonstration program of rheumatic fever control which would include diagnosis, treatment, social follow-up and the provision of material assistance where necessary. Such a program could be compared with attempts to offer organized home care services to other diagnostic groups, such as cancer patients.

This thesis also points to a need for further research in the area of physical environment as compared to the incidence of the disease. Why there should be a concentration of cases in one area of the city, cannot be answered from the material presented here. However, in a disease where environment plays an important part there would perhaps be value in a careful study of this area to see what the contributing factors might be.

Rheumatic fever is a devastating childhood disease which is yet to be brought under successful control. Medical research alone cannot solve the problem at the present time. Of paramount importance is the use of the combined efforts of medical and welfare resources to help the child

and the family to avoid recurrences wherever possible, and to assist in the total rehabilitation of the child as a future member of our adult society. This can only be done through planned community action.

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