

**PERCEIVED NEEDS OF CHILDREN WITH RHEUMATIC DISEASES
AND THEIR PARENTS**

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SUMMARY

Members of the Ontario Juvenile Arthritis Association (OJAA) and rheumatology staff from the Hugh MacMillan Rehabilitation Centre, the Hospital for Sick Children and The Arthritis Society Consultation and Therapy Service, developed a questionnaire to identify perceived service needs of children with rheumatic diseases and their parents in Metropolitan Toronto. The questionnaire was sent to 327 parents and children.

After two mailings and a telephone follow-up, 65.0% had responded, 27.8% with complete questionnaire data. The children were mainly female (75.7%) with a mean age of 12.6 years. The predominant diagnosis was juvenile rheumatoid arthritis (70.3%) and 68.9% reported mild disease. Fifty-eight percent of parents and 45% of children identified a need for additional services; most frequently education through newsletters and books and support groups for teens. On average, 3.2 items were mentioned by parents and 2.7 by children. Parents of male children selected more services than those of female. The only barrier to care identified in this study was the time to get a diagnosis, on average taking 5.8 months (range 1 month to 5 years).

Rheumatic diseases in this population of treated children were mainly of mild severity. Service needs were minimal and could presumably be met at low cost.

INTRODUCTION

The rheumatic diseases in children (aged 0 to 16) have an estimated prevalence of 2 to 10 cases per 10,000 children.^{1,2,3,4} In a recent survey of the Ontario population, arthritis or rheumatism was reported as a long-term health problem for 5.5 per 1,000 children under the age of 18, although this value should be viewed with caution as the sampling variability was high.⁵ Rheumatic diseases in children are an important cause of morbidity and disability. If left untreated, in severe cases, it can result in death or blindness and children can grow up with a potentially preventable degree of disability and handicap. Studies of children in comprehensive treatment programs show that 10 to 30% grow up to have functional limitations.^{6,7,8,9}

Arthritis in children is different from arthritis in adults in its onset, classification, clinical features, outcome and management. There are several factors contributing to the complexity of needs in this population, including age, course of disease, number of involved joints and response to medications and therapy.

The literature from the United States shows that needs of children with arthritis are perceived differently by children, teens, their parents, teachers and physicians, and that both physical and psychosocial needs exist in this population. None of the studies reviewed used a Canadian population.

Members of the Ontario Juvenile Arthritis Association, a parent support group, voiced concerns regarding additional service needs in the Metropolitan Toronto area. The present study was undertaken to address this issue. Metropolitan Toronto has a population of approximately 2.3 million, with approximately 427,000 under the age of fifteen. The purpose of this project was to identify the perceived service needs of children with rheumatic disease and their parents in this community in order to better plan and coordinate services. It was anticipated that the results of the project would provide the information necessary to carry out a similar province-wide survey in Ontario.

METHOD

Procedure

Rheumatology staff from the Hugh Macmillan Rehabilitation Centre (HMRC), the Hospital for Sick Children (HSC) and The Arthritis Society Consultation and Therapy Service (CTS) in Toronto and members of the Ontario Juvenile Arthritis Association (OJAA) developed a questionnaire to identify the characteristics and the perceived service needs of children with arthritis and their parents in Metropolitan Toronto.

Questionnaires were pretested on 10 children with rheumatic diseases from the CTS caseload and 10 parents of children attending the HSC rheumatology clinics.

Children were identified from the current caseloads and mailing lists of the involved agencies. The base for the sample comprised children seen in rheumatology clinics at the HSC or HMRC. This list was cross-checked with the children on the caseload of the CTS, and with the 1991 membership list of the OJAA. The final sample comprised 271 children (83%) seen at the rheumatology clinics in 1991 or 1992, 14 additional children on the caseload of CTS (4%) and 42 children from the 1991 member list of the OJAA (13%). Cases were excluded if the child was not seen by a health-care professional at one of the involved agencies in 1991 or 1992, the child was over 18 years of age, the family lived outside of Metro Toronto (ie. postal code not beginning with M1 to M9) or the diagnosis recorded was not arthritis-related.

The questionnaire was mailed to 327 parents. After six weeks, non-respondents were sent a second questionnaire. After a further nine weeks, non-respondents were called by trained volunteers. Volunteers had received 3 hours of training and attempted to contact all non-responders over a six-week period. Questions asked during the follow-up included whether or not a questionnaire was ever received, if the individual had problems filling it out, as well as the child's age, age at diagnosis, sex, diagnosis and the physician who supervised the child's care. A third questionnaire was sent to those with incorrect addresses identified by the telephone follow-up.

The Questionnaire

The questionnaire (attached) included questions about the characteristics of the children, such as age, age at diagnosis and sex, as well as information regarding diagnosis, referral, disease severity, effect on school activities, services used and the need for additional services. A modified version was included for the child to complete (attached).

Parents and children were asked to identify any additional services they would find helpful by answering 'yes' or 'no' to 32 services. Thirteen items were related to support services and counselling, eight were related to education, four were related to exercise, and seven were related to social/recreational or other activities. Respondents were asked to check only those program or group activities that they would be willing to attend.

RESULTS

The initial mailing comprised 327 questionnaires. Twenty-four questionnaires were returned from the post office with an unknown address; a further 17 were identified as moved or with an unknown address in the telephone follow-up and 4 were outside the Metro Toronto boundary leaving 282 potentially valid addresses.

After 2 mailings, a telephone follow-up, and a third mailing, questionnaires were returned by 97 parents and an additional 86 responses were obtained by telephone interview for an overall response rate of 65.0%. Five cases were excluded since the child was over 18 years and 11 were excluded because the parent stated the child did not have arthritis, leaving 266 cases for analysis, 74 of which (27.8% response rate) had full questionnaire data. Sixty-three completed questionnaires were returned by children, and after excluding those over 18 ($n=6$) and those living outside Metropolitan Toronto ($n=2$), 55 were available for analysis, for a response rate of 20%.

Characteristics of the Sample

Table 1 displays the demographic characteristics of the children based on the parents' responses as well as the characteristics of the children identified through telephone follow-up. Most questionnaire respondents' children were female (75.7%) compared to 53.8% of those contacted through the telephone follow-up. Age of the children among questionnaire respondents ranged from 2 to 18 years and from 3 to 18 for the telephone respondents. Mild disease was reported by 68.9% of questionnaire respondents, and 24.4% of telephone respondents, although 34.9% of the telephone respondents did not indicate the level of severity. The predominant diagnosis reported was juvenile rheumatoid arthritis (JRA), 70.3% among questionnaire respondents and 24.4% among those contacted through the telephone follow-up. There were more children with JRA ($p=0.00001$) and ankylosing spondylitis ($p=0.04$) in the questionnaire respondent group.

The children who responded by questionnaire ($n=55$) had a mean age of 13.5 years (range: 8 to 18), and most had mild disease (65.5%), pauciarticular JA (25.6%) and an average age at diagnosis of 9 years. The teen group (aged 12-18) represented 78% of the responses from children and this group was predominantly female (79.1%), with the majority having JRA (67.4%) and over half having mild disease (51.2%). The teen group had a mean age of 15.5 years and a mean age at diagnosis of 10.3 years.

Services Received

The services children had received or were still receiving are outlined in Table 2. Most children had their care supervised by a rheumatologist or paediatric rheumatologist (93.2%) and saw a doctor because of their arthritis 2-12 times a year (73.0%). Forty-one children (55.4%) had received physiotherapy (PT), 14 (18.9%) had received occupational therapy (OT) and 9 (12.2%) had received social work (SW) in the past two years. All the children receiving OT or SW also received PT and 6 children received all three services. Among children diagnosed with JRA ($n=52$), 33 (63.5%) had seen an ophthalmologist, and 42.3% (22) received splints (23.1% from an

OT and 19.2% from an orthotist).

Seventeen parents (23.0%) were members of the OJAA. Referral to PT, OT or SW was compared with whether or not parents were members of a support group. For all three services, there was an association between being a member of a support group and referral to PT, OT or SW (Fisher's exact test two-tailed $p=0.02$ for PT, $p=0.00007$ for OT and $p=0.001$ for SW).

Barriers to treatment were examined by looking at the mean length of time to get a diagnosis, the time to a first appointment with an allied health professional and reasons for discontinuing treatment. On average, it took 5.8 months (standard deviation=10.1) to get a diagnosis. This value ranged from as little as 1 month to a maximum of 5 years. Waiting time for referrals for therapy services ranged from 1.5 weeks for SW to 1.8 weeks for PT and OT. Among those parents that stated a reason for the discontinuation of treatment, "no further need" was indicated by 65.0% of those receiving PT, 75.0% of those receiving OT and 100% of those receiving SW. Therapy was stopped by the therapist in 25.0% of OT cases and in 20.0% of PT cases. In another 15.0% of those that had received PT, treatment was stopped because the child was given exercises to do at home, the times available were not suitable for the parent, they chose to contact the PT when the disease flared or the child was not interested in therapy.

Perceived Service Needs

Thirty-two parents (58.2%) and 25 children (45.5%) identified additional services that they would find helpful.

Figure 1 outlines the top ten services identified by parents and children. An educational newsletter and educational books were the two most frequently identified by both parents and children. Support groups for teens ranked third for both groups. When similar types of services were grouped together, the top three areas of additional service requirements for parents and children were the same: education, pool programs and support groups.

Some of the services were listed in both an individual and group format (see Table 3). For example, pool programs for fun or exercise, physiotherapy and counselling for children were offered in individual and group formats and when compared, showed no significant difference ($p>0.05$ in all cases).

When looking at the group of parents as a whole ($n=74$), the mean number of services identified was 3.1. In 55 parent/child pairs, the average number of services was 3.2 (range 0-13) for parents and 2.7 (range 0-13) for children, and there was no significant difference between the two groups ($p=0.5$).

We looked at the relationship between the number of services identified by parents and children and various independent variables such as sex, problems in school because of arthritis, membership in a support group, diagnosis, treatment such as PT, OT or SW and disease severity. Parents of male children identified significantly more service needs than those of female children, an average of 2.7 services by parents of female children and 4.7 for parents of male children ($p<0.05$).

Children reporting problems in school activities as a result of their arthritis identified 3.9 service items compared with 1.8 identified by those reporting no school problems ($p=0.05$). As well, severity of disease was also significant ($p=0.01$), with

those having mild disease choosing 2.0 services and those with moderate or severe disease choosing an average of 4.8.

Parents and children were both asked about the severity of disease and problems the child had in school due to their arthritis. In all analyses comparing these two groups, parents whose children did not return a completed questionnaire were eliminated from the sample prior to analysis. According to the parental responses, most children had mild disease (72.7%). Responses by parents and their children were compared and the results are presented in Table 4. There were no significant differences between the responses of parents and children ($p>.05$ for all comparisons).

Forty-nine point one percent of parents (27) and 45.5% of children (25) reported problems in school (Figure 2). Parents and children reported similar problems, the top three being problems with gym, mobility and attendance. There was no significant difference between responses of parents and their children ($p>0.05$).

DISCUSSION

Our response rate was 65.0%. Other similar studies have shown rates between 30.7 and 81%.^{8,10,11,12,13} We used a paediatric rheumatology clinic population as our first source of information. Many children seen in clinic are seen as consultations and then ultimately diagnosed with something other than a rheumatic disease or found to have transient problems such as 'growing pains' or non-articular rheumatism. We feel that this was reflected in our sample in that 34.6% of those contacted by telephone stated they their child did not have arthritis. Two respondents reported unrelated disorders such as tenosynovitis and osteochondritis and were not included in the analysis. As well, 31.2% of non-respondents could not be contacted by phone and 7.3% of the surveys were returned by the post office with wrong addresses, perhaps reflecting a mobile urban population.

Parents were instructed to ask their child with arthritis to complete the questionnaire if they felt it was appropriate. This resulted in 55 valid responses from children. The youngest to respond was 8 years old (n=4) and their responses matched those of their parents on age, sex and diagnosis. This information may provide an indication of the age when children could self-administer other similar questionnaires.

There were no significant differences between parents' and children's perceptions of severity of disease and the impact of arthritis on school, though our sample size may have been too small to detect a statistically significant difference. Other studies have shown conflicting results, with parents, teachers and physicians either over or underestimating the severity of the arthritis and its impact on school.^{10,14,15,16,17,18,19}

Using open-ended questions, the top three problem areas in school identified by both parents and children were gym, mobility, and attendance. Twelve or 21.8% of the children who responded reported problems with gym classes. Other studies confirm that participation in physical education activities is frequently limited by arthritis.^{13,14}

Twelve point seven percent (n=7) of our sample of parents considered absenteeism a problem. This has been confirmed in other studies^{10,13} Stoff and colleagues surveyed 46 parents of school-aged children with rheumatic diseases and found increased fatigue and absenteeism were related to lower levels of school achievement measured by standardized achievement tests. The children had more than twice the absentee rate of the US national average.²⁰

Being a member of a support group was significantly associated with being referred to a health-care provider (PT, OT, SW). This perhaps reflects an increased awareness of resources by those in a support group or perhaps that those parents of children seen by a professional are more likely to be referred to a support group. Most respondents had been seen by a rheumatologist and this may increase the likelihood of being referred to both a therapy program and a support group.

The major barrier to services identified through this survey was the time taken to get a diagnosis, ranging from 1 to 60 months (mean 5.8 months). Since all questionnaire respondents were being seen by a rheumatologist, this could be due to a long wait time for referral. This issue was not addressed in this study so

conclusions cannot be drawn.

The wait time for therapy services was reasonable (ranging from 1.50 weeks for SW to 1.77 for PT and 1.82 for OT) and therapy was usually discontinued because it was no longer required. This is not a surprise since our sample was already receiving health care services through clinic, The Arthritis Society or the support group. In addition, the sample was living in a relatively well-serviced urban area, which may explain the fact that 54.5% of parents and 41.8% of children did not identify any need for additional services. This may also relate to the mild disease reported by this group.

The top three identified services were the same for both parents and children; education through newsletters and books and a support group for teens.

Parents of male children reported significantly more service requirements than parents of female children. Since the majority of children were in the teen group, this may reflect parents' general concerns about their male children rather than arthritis-specific concerns.

There was no preference for individual or group format in this sample. Children were equally likely to express an interest in pool programs, physiotherapy or counselling in either format.

About half of those who completed the questionnaire identified additional services that they felt might be helpful. This information, together with the fact that the response rate was low, most children had mild disease and the fact that many telephone respondents did not identify a rheumatological diagnosis, suggests that service needs of this population are generally low. Those services that were identified by parents and children who completed the questionnaire were related to education as opposed to therapy, a need which can presumably be met at low cost.

In view of the low response rate and the findings regarding the type and quantity of additional services thought to be helpful, the larger survey involving the province of Ontario was postponed. Other more cost-effective and productive methods of identifying the service needs of this population need to be explored. As well, it would be interesting to explore the differential service requirements of parents of male and female children and the long time to diagnosis identified in this study.

Acknowledgements: Laurie McAllister, Ruthann Lubin, Judy Maheu, Mea Renahan, Earl Silverman, Beverley Tobe. This study was sponsored by the Ontario Juvenile Arthritis Association.

TABLE 1
DEMOGRAPHIC CHARACTERISTICS OF TELEPHONE
AND QUESTIONNAIRE RESPONDENTS

	QUESTIONNAIRE RESPONDENTS (n=74)	TELEPHONE RESPONDENTS (n=86)
Age ± SD (years)	12.5 ± 4.2	11.6 ± 4.3
Age at diagnosis ± SD (mean years)	8.3 ± 4.8	7.3 ± 4.2
Sex (%female) ^a	75.7%	53.8% ^b
Diagnosis reported (%yes)	95.9%	54.7%
JRA ^{a,c}	70.3%	24.4%
Ankylosing Spondylitis ^a	5.4%	0.0%
Fibromyalgia	6.8%	2.3%
Systemic Lupus	10.8%	3.5%
Dermato/polymyositis	4.1%	0.0%
Other	13.5%	9.3%
Severity of disease (%yes)		
Mild	68.9%	24.4%
Moderate	21.6%	8.1%
Severe	2.7%	3.5%
Absent or in remission	5.4%	7.0%
Missing	1.4%	34.9%

^a p value <0.05, X² test

^b among the 52 telephone respondents that answered the question regarding the child's gender

^c subtypes of JRA included pauciarticular 36.5%, polyarticular 13.5%, systemic 5.4% and unknown type 14.9% for questionnaire respondents and these values were not stated among telephone respondents

SD=standard deviation

TABLE 2

SERVICES RECEIVED

SERVICE (n=74)	PERCENT THAT RECEIVED SERVICE
Care supervised by a rheumatologist or paediatric rheumatologist	93.2%
Child sees a physician 2-12 times per year	73.0%
Therapy received in past 2 years	
Physiotherapy	55.4%
Occupational Therapy	18.9%
Social Work	12.2%
Children with JRA seen by an ophthalmologist	63.0%
Splints received	42.0%
Occupational Therapist	23.0%
Orthotist	19.0%

TABLE 3

PREFERENCES OF CHILDREN FOR GROUP/INDIVIDUAL PROGRAMS (n=55)

SERVICE	INDIVIDUAL FORMAT PREFERRED	GROUP FORMAT PREFERRED
Support/counselling	7.3%	5.5%
Pool programs for exercise	18.2%	14.5%
Pool programs for fun	9.1%	18.2%
Physiotherapy	18.2%	12.7%

TABLE 4
COMPARISON OF SEVERITY OF DISEASE, IMPACT ON SCHOOL
AND SERVICES IDENTIFIED BY PARENTS AND CHILDREN
(n=55)

	Parents	Children
Severity of disease (%yes)		
Mild	72.7%	65.5%
Moderate	21.8%	27.3%
Severe	1.8%	1.8%
Absent or in remission	3.6%	3.6%
Missing	0.0%	1.8%
Any impact on school (%yes)		
Gym class	16.4%	21.8%
Mobility	14.5%	18.2%
Attendance	12.7%	9.1%
Fatigue	9.1%	5.5%
Writing	9.1%	7.3%
Pain	9.1%	5.5%
Other	7.3%	3.6%
Services identified (top 3)		
Educational newsletter	38.2%	23.6%
Educational books	23.6%	21.8%
Support for teens	21.8%	20.0%

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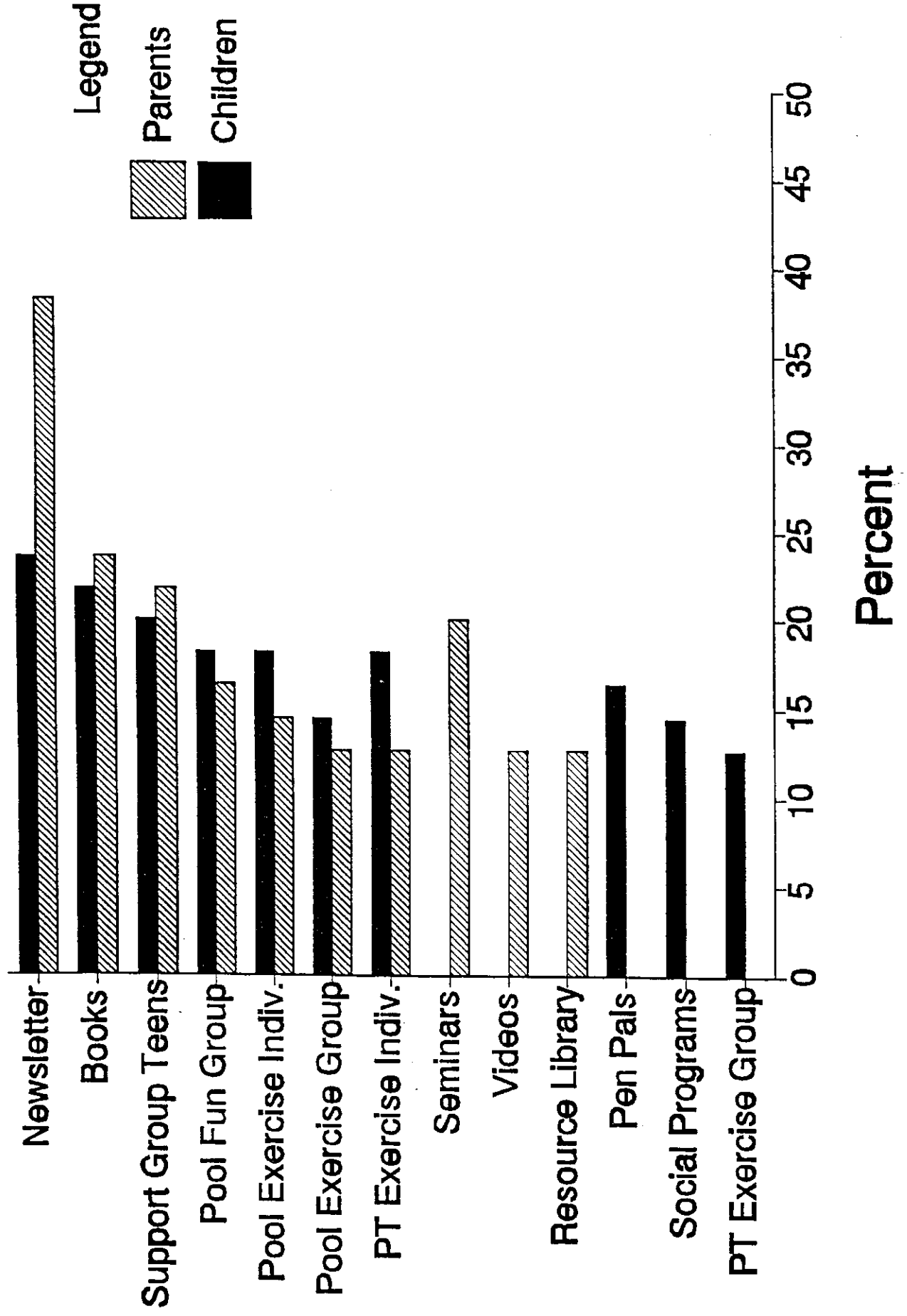
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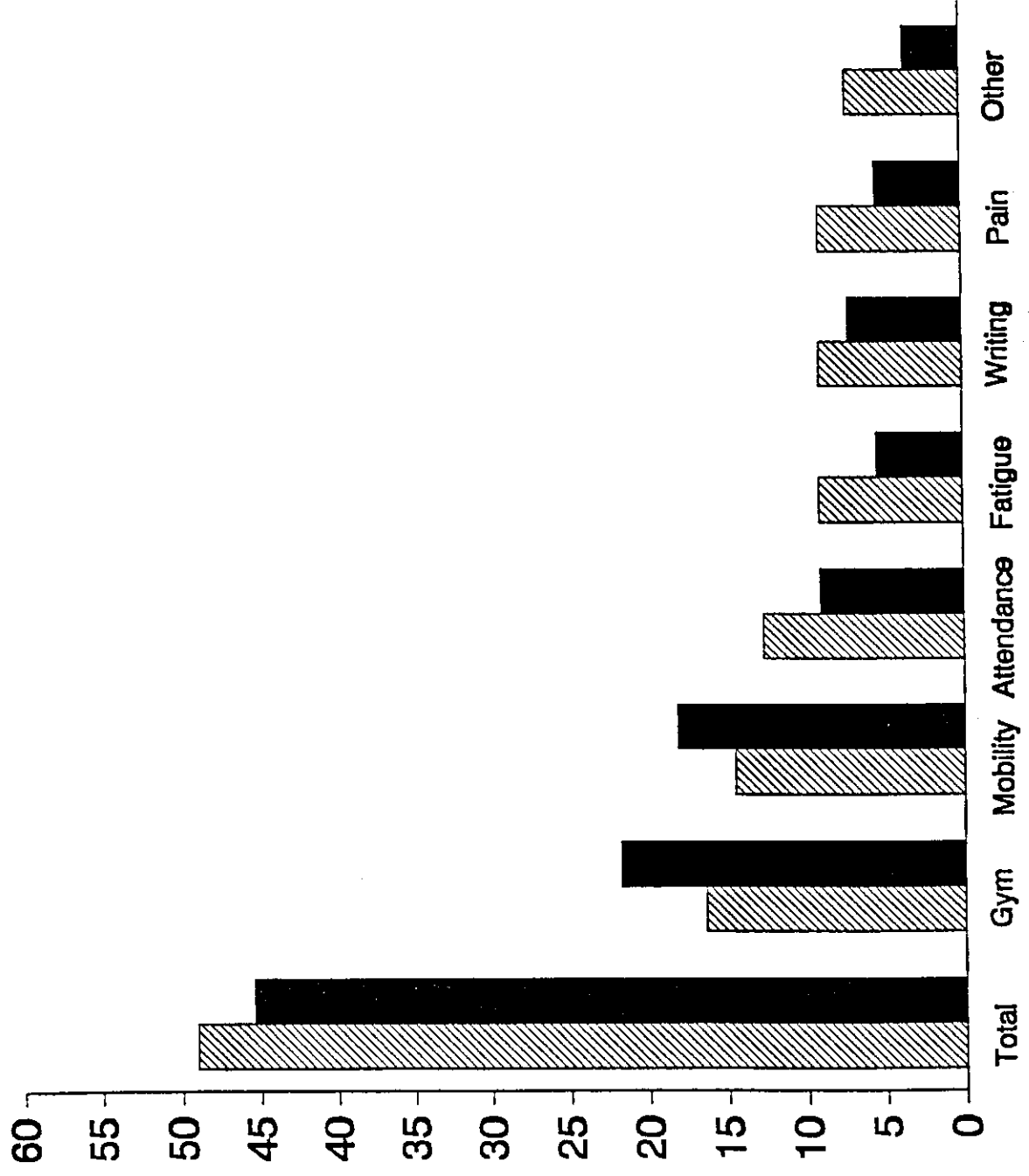
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- Figure 2: Comparison of problems encountered in school by children. Reported by both children (n=55) and and their parents (n=55). Percent reporting the particular problem.

Type of Service Identified



Percent



Legend

- Parents
- Children

Type of Problem in School

THE ARTHRITIS SOCIETY
ONTARIO DIVISION

CONFIDENTIAL QUESTIONNAIRE

PARENT SURVEY

1. Child's Age ____ years ____ months Age at diagnosis ____ years ____ months

How long did it take to get a diagnosis? _____ (months)

Who made the diagnosis? _____

2. Where do you live? City _____

Postal Code _____

3. Child's Sex: Male Female

4. What is your child's diagnosis? (check one)

- Juvenile rheumatoid arthritis. If yes, check one:
- polyarticular - more than 4 joints involved
 - pauciarticular - 4 or less joints involved
 - systemic - having fever or rash
 - don't know

Ankylosing spondylitis

Systemic lupus erythematosus

Dermatomyositis/polymyositis

Fibrositis/fibromyalgia

Systemic vasculitis

Other, please specify _____

5. How bad is the disease at present?

mild

moderate

severe

6. Who currently **supervises** the care of your child's arthritis? (check all that apply)

Family Doctor

Paediatric Rheumatologist

Rheumatologist

Paediatrician

Orthopaedic Surgeon

Other (please specify) _____

If a rheumatologist, where is he/she located? _____

How long did it take to get referred? _____ weeks

Other physicians seen
because of arthritis:

Ophthalmologist

Dermatologist

Psychiatrist

Sports Medicine Specialist

Gastroenterologist

Other (specify) _____

How many times a year does your child see a doctor related to his/her arthritis?
Include visits to all doctors.

_____ times a year

7. Are you a member of any support group because of your child's arthritis?

Yes No

If yes, which group? _____

8. Are you currently a member of the Ontario Juvenile Arthritis Association (OJAA)?

Yes No

9. Does your child's arthritis affect how he/she manages in school?

Yes No

If so, how? _____

10. Has your child been referred to: Yes No
 Physiotherapy } If no, to all
 Occupational Therapy } three, go to
 Social Work } question 13

If referred, did your child get treatment?

	No	Reason Why Not	Yes	How Long to First Appointment?
PT	<input type="checkbox"/>	_____	<input type="checkbox"/>	_____
OT	<input type="checkbox"/>	_____	<input type="checkbox"/>	_____
SW	<input type="checkbox"/>	_____	<input type="checkbox"/>	_____

Is your child still receiving treatment?

	PT	OT	SW
Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If not, why was treatment stopped?

	PT	OT	SW
<input type="checkbox"/> too far away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> treatment not helping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> therapist discontinued treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> no further need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> child not interested	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> unable to get there	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. Have you paid for physiotherapy for your child that was not covered by OHIP?

Yes No

If yes, who covered the cost? family private insurance other (specify)

12. Therapy services used within the last 2 years (please check all that apply).

Service	Agency/Institution	City	How Often				
			Daily	Weekly	Monthly	Yearly	Other
<input type="checkbox"/> Physiotherapy							
<input type="checkbox"/> exercise	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> exercise in water	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> heat	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> ice	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> education/ information	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> pain management	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> relaxation techniques	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> other (specify) _____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Occupational Therapy							
<input type="checkbox"/> splints	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> footwear/shoes (insoles)	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> changes to the house	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> education/ information	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> equipment	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> other (specify) _____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Social Work							
<input type="checkbox"/> counselling	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> financial assistance	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> other (specify) _____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13. Other services used in the last 2 years (please check all that apply).

Service	Agency/Institution	City
<input type="checkbox"/> Psychology <input type="checkbox"/> counselling <input type="checkbox"/> other (specify)	<hr/> <hr/>	<hr/> <hr/>
<input type="checkbox"/> Psychiatry <input type="checkbox"/> counselling <input type="checkbox"/> other (specify)	<hr/> <hr/>	<hr/> <hr/>
<input type="checkbox"/> Easter Seal Society <input type="checkbox"/> transportation <input type="checkbox"/> financial assistance <input type="checkbox"/> support <input type="checkbox"/> other (specify)	<hr/> <hr/> <hr/> <hr/>	<hr/> <hr/> <hr/> <hr/>
<input type="checkbox"/> Orthotist <input type="checkbox"/> insoles <input type="checkbox"/> splints <input type="checkbox"/> casting <input type="checkbox"/> other (specify)	<hr/> <hr/> <hr/> <hr/>	<hr/> <hr/> <hr/> <hr/>
<input type="checkbox"/> Nutritionist <input type="checkbox"/> special diet <input type="checkbox"/> education/information <input type="checkbox"/> other (specify)	<hr/> <hr/> <hr/>	<hr/> <hr/> <hr/>
<input type="checkbox"/> Other (specify) <input type="checkbox"/> vocational assessment & training <input type="checkbox"/> career counselling <input type="checkbox"/> other (specify)	<hr/> <hr/> <hr/>	<hr/> <hr/> <hr/>

15. During the last year did your child participate in these programs in Toronto?

	Yes	No
Camp at Hugh MacMillan Rehabilitation Centre	<input type="checkbox"/>	<input type="checkbox"/>
Variety Village swim program	<input type="checkbox"/>	<input type="checkbox"/>
Ontario Juvenile Arthritis Association swim program	<input type="checkbox"/>	<input type="checkbox"/>

Any comments: _____

16. Who completed this questionnaire?

mother father other (specify) _____

17. Other comments _____

18. We are also asking doctors about the services and support that this group needs. We need to identify who those doctors are who treat children with arthritis. Please help us by telling us about the doctors who treat your child's arthritis. Your child's name will not be used when we contact the doctors, nor will we ask for any details about your child.

	Family doctor	Paediatrician	Rheumatologist
Name	_____	_____	_____
Address	_____	_____	_____
	_____	_____	_____
	_____	_____	_____
Phone #	_____	_____	_____

Thank you!!

Please mail this questionnaire to:

Sydney Lineker
Director of Program Development
The Arthritis Society
250 Bloor St. E., Suite 401
Toronto, Ont.
M4W 3P2

**THE ARTHRITIS SOCIETY
ONTARIO DIVISION**

CONFIDENTIAL QUESTIONNAIRE

TEEN/CHILD SURVEY

1. Your Age ____years ____months
2. Where do you live? City _____
Postal Code _____
3. Your Sex: Male Female
4. What is your diagnosis? (check one)
 - Juvenile rheumatoid arthritis. If yes, check one:
 - polyarticular - more than 4 joints involved
 - pauciarticular - 4 or less joints involved
 - systemic - having fever or rash
 - don't know
 - Ankylosing spondylitis
 - Systemic lupus erythematosus
 - Dermatomyositis/polymyositis
 - Fibrositis/fibromyalgia
 - Systemic vasculitis
 - Other, please specify _____

5. How bad is your arthritis right now?

mild

moderate

severe

6. Have you been referred to: Physiotherapy
Occupational Therapy
Social Work

Yes

No

} If no, to all
} three, go to
} question 7

If referred, did you get treatment?

No

Reason Why Not

PT

OT

SW

Are you still receiving treatment?

PT

OT

SW

Yes

If not, why was treatment stopped?

- too far away
- treatment not helping
- therapist discontinued treatment
- no further need
- not interested
- unable to get there
- other (please specify)

PT

OT

SW

7. Are you a member of any support group because of your arthritis?
 Yes No

If yes, which group? _____

8. Does your arthritis affect how you manage in school?
 Yes No

If so, how? _____

9. During the last year did you participate in these programs in Toronto?

	Yes	No
Camp at Hugh MacMillan Rehabilitation Centre	<input type="checkbox"/>	<input type="checkbox"/>
Variety Village swim program	<input type="checkbox"/>	<input type="checkbox"/>
Ontario Juvenile Arthritis Association swim program	<input type="checkbox"/>	<input type="checkbox"/>

Any comments: _____

Please turn the page

11. Other comments: _____

Thank you!!

Please mail this questionnaire to:

**Sydney Lineker
Director of Program Development
The Arthritis Society
250 Bloor St. E.
Suite 401
Toronto, Ont.
M4W 3P2**