

Experience with Younger Patients in a Post Polio Clinic

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Objective

- To identify patient characteristics, new health and functional problems, as well as social and vocational status of patients with polio under 50 years of age.

Background

- As the polio population ages the mean age of patients seen in our clinic has increased.
- At the same time, we are also seeing a younger cohort of survivors under the age of 50.

Background

- Over the past 5 years, this younger cohort has steadily increased.

year	# of patients <50 years	Total # of patients seen	%
2006	4	81	4.9
2007	5	115	4.3
2008	11	87	12.6
2009	8	113	7.1
2010	15	160	9.4

Methods

- We performed a retrospective chart review of patients under 50 years of age who were evaluated in our post-polio clinic between 2009 and 2010.

Results: 1

Table 1: Subject Characteristics

# subjects	Average age	Gender (M:F)	Median age at onset	Involved limbs	Country of origin
23	37.5 years (27 to 47)	13:10	18 months (3 months to 14 years)	LE: 17 UE/LE: 6	A:11 B: 4 C: 4 D:2 E:2

Key: A=India/Pakistan, B=Asia, C=Africa, D=Columbia/Syria, E=USA

Results: 2

Table 2: Number and Percent of Patients with New Health and Functional Problems

	N	%
New Health Problems		
Weakness	17	73.9
Pain	12	52.2
Fatigue	18	78.3
New Functional Problems		
Walking	15	65.2
Stairs	8	34.8
Prolonged standing	8	34.8
Difficulty with ADL's	3	13.0

Results:3

Table 3: Social and Vocational Status

	N	%
Married	19	82.6
Single	3	13.0
Divorced	1	4.3
Subjects with Children	15	65.2
Number of children		
1-2	11	52.6
3-4	3	13.0
5	1	4.3
Work outside home	18	78.3
Students	3	13.0
Homemaker	1	4.3
Unemployed	1	4.3

Discussion/Conclusion

- In contrast to older patients in our clinic who typically contracted APP during the mid-20th century epidemics in this country, the younger group had polio as infants in developing countries and then immigrated here as teens or adults.
- Not surprisingly, we found that both the younger and older patients have similar complaints of late affects of polio: new weakness, pain and fatigue.
- In contrast to the typical older patient, the younger polio survivors present a different and challenging mix of issues such as schooling, demands of work, and raising a family.

Disclaimer: The following are unofficial notes which have not been read by or approved by the speaker.

- After working with Dr. Halstead at the National Rehabilitation Hospital in Washington, D.C., it became evident that there was a younger cohort of polio patients being seen in their clinic.
- The usual clinic patients seen are over 50 and into their 90's. The clinic was beginning to see younger patients – under 50 and as young as 27.
- The number of younger patients seen has increased significantly from 2006 to 2010, with five or six additional patients since November 2010.

- This group is different from the usual patient seen because they immigrated to the U.S. as teens or young adults.
- Research did not look into any cultural ideology of how they feel toward their disability.
- National Rehabilitation Hospital was the first place where these patients received any care. Many did not have care when they acquired polio in their home country.
- The study was a retrospective chart review of patients under 50 years of age who were evaluated in the post-polio clinic between January 1, 2009 and December 31, 2010.
- Study looked at patient characteristics, new health and functional problems as well as social and vocational status of the patients under 50 years of age.
- Twenty-three subjects with an average age of 37.5 years; 13 male and 10 female. Median age of onset of acute polio was 18 months with a large variation from 3 months to 14 years. Seventeen had lower extremity involvement and six had upper and lower extremity involvement.
- Most were immigrants except two. One acquired polio in 1969 and didn't know she had polio until she saw Dr. Halstead; had been diagnosed with muscular dystrophy. The other acquired polio in 1982 after she had the oral vaccine at the age of 14.
- Even though these patients are younger, they are experiencing a lot of difficulties.
- Pain varied a lot – they did not distinguish between muscle and other pain.
- Walking was the biggest frustration for patients.
- For younger patients with families, it was interfering with their lives. Few complained about difficulty with ADL's.
- The majority were married and most had children.
- Eighteen of the 23 worked outside the home.
- Conclusions drawn:
 - In contrast to older patients seen in the clinic who typically contracted polio during the mid-20th century epidemics in this country, the younger group had polio as infants in developing countries and then immigrated here as teens or adults.
 - Not surprisingly, they found that both the younger and older patients have similar complaints of late affects of polio: new weakness, pain and fatigue.
 - In contrast to the typical older patient, the younger polio survivors present a different and challenging mix of issues such as schooling, demands of work and raising a family.
- This group is grappling with different issues because they are married and have children.
- The issues they are dealing with are very foreign.
- Some of these patients are going to school and they are operating in a different culture because most did not grow up in the U.S.
- One woman is dealing with the stress of raising a family and working and on top of that, has a slowly progressing disability.
- The older group is in their twilight years and/or retired.

Question:

- Who else around the country and around the globe is seeing this immigrant population coming into this country and into their clinic?
 - JPMNPI has only seen a few.
 - Baylor has not seen as many as the National Rehabilitation Hospital.
- Are any of these individuals on disability or are they able to meet the guidelines for disability?

- The majority is not.
- Understand the majority of the people have muscular pain but some is arthritic pain?
 - Did not specify – perception is not arthritic - the majority are younger so their joints do not have much wear and tear.
- How many are using braces?
 - The majority (over 50%) use braces.
- What would be the number of polio survivors that you see in a year (unduplicated numbers) (Chart on Page 4)
 - Statistics show patients not visits.
 - Distinction should be made in any document that comes out of this study.
- How many of these people are vegetarians and what is the possible relationship between the level of their weakness and fatigue with their diet?
 - Did not find that in the review.
 - At Baylor many of the patients are vegetarians (the younger group). A large number come from Asian countries.
 - They are advised about the value of eating meat for amino acid content; or soy if they are vegetarian.
 - Milk has everything they can get from meat.
- Since 11 or 12 patients were from Asian countries, how many had problems with only one arm or leg or did they have both affected?
- There is a condition in Asia – Monomelic Atrophy - which makes it difficult to differentiate from poliomyelitis.
 - EMGs were used to confirm diagnosis and on exam, weakness was found in the unaffected leg.
- Monomelic atrophy progresses, then slows down.
 - Cautioned to follow the six with one leg involvement for awhile to see if there is any progression. If the progression stops, it could be monomelic atrophy.
- Liked the fact that the study talked about the challenges of the younger people with regard to work and school. A study in 1988-89 of a cohort in their 40s and 50s and working because they were younger - clearly they had a lot of disability and in part that level of psychological stress and even fatigue and pain were related to the work and extra responsibilities.
- Some of the women did admit their fatigue got worse after their last child was born. It was probably more their life situation than the polio.
- Do you know anything about their pregnancy and child birth experiences?
 - No
- When you reflect on the differences between the immigrant population coming into the states and what they are going through with late effects of polio, a significant difference – do not think the immigrant population had cohort experience – even the vaccine experience.
 - The Americans were treated and had rehabilitation with other people around who had the same problems.
 - They were received back into a society that was trying to help them.
 - Appears different than the majority of immigrant population who had polio and dealt with as individuals not dealt with by their families, no support group at the time – no cohort experience going through it as the Americans did.
 - If you look at the Asian onset of this group – 18 months – most people were infants and could not appreciate the cohort group.

- When they got older, they probably did not have the support as we had in the states.
- Interesting to think about the older polio population – folks who were dealing with it in the 50's, there was not much acceptance. Most people we're seeing, there wasn't a lot of cohort experience there. They were struggling through their disability and being told they would be normal.
- There is a rare opportunity to study a population who will have beliefs about disability different than we see in the U.S. It would be interesting to see what those beliefs are.
 - National Rehabilitation Hospital is working on a questionnaire on culture.
 - When did they actually immigrate to the U.S.? Did they have significant amount of rehabilitation treatment in the U.S. because they were young?
 - Use of adaptive technology could relate to when they came into the country and their beliefs.
 - If they are coming over with their family, did they bring their culture with them?
- Speaker was encouraged to put this information in a document and include information about pregnancy and childbirth experience.
- One question PHI periodically receives is from young women in other countries asking if they can have children.
- Also add ADL's – how did people cope with carrying a baby, getting them off the floor, what kind of difficulties did they have?
- Rate of employment for polio survivors is probably higher than almost any other disability. Also the marriage rate. Polio survivors do much better than other physical disabilities.
- People who are employed are very highly educated – computer programmers, accountants.
- Those who immigrated to the U.S. with a disability are likely to be ones who are highly educated.
- The Rotarians are making progress in eradicating polio in other countries. Bill Gates is providing funds. Suggestion was made to approach him for funds to help those who have polio who will have problems in the next 40-50 years.
- Group was encouraged to start a registry of their international patients.