

Post-Polio Syndrome and Polio Survivor Biographies

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Introduction

- Prior to the development of vaccines in 1954 and 1960, polio virus infected over 55,000 children per year in the United States; approximately 21,000 of those infections lead to paralysis¹.
- 30-40 years following recovery from polio virus infection, many survivors suffer from **post-polio syndrome (PPS)** – a new weakening in muscles that were previously affected by polio, as well as in muscles that were not originally affected².
- There are no studies to the authors' knowledge that explore the combination of **polio experience and PPS**, major experiences that polio survivors share in terms of **life history**, and how they managed to deal with certain **disruptions** in their lives, such as being taken away from school and separation from family.

Aims and Objectives

The objective of this mixed-method study is to explore the intersection of **quality of life** and **life course theory** as it relates to a sample of polio survivors in the United States by working with the Southeast Michigan Post-Polio Support Group.

Methods

- 3 Focus Groups & 6 One-on-One Interviews
- Open-Ended Questions & T/F Quality-of-Life Surveys
- Developed a script for questions and used rev.com for transcription following analysis by at least 2 research personnel
- Approved by OU IRB: 1400610-1

Results

A)

	TRUE	NOT TRUE
1. I get frustrated because I cannot do as much as I want	<input type="radio"/>	<input type="radio"/>
2. I am fearful my condition will deteriorate	<input type="radio"/>	<input type="radio"/>
3. I do not want to have to ask other people to do things for me	<input type="radio"/>	<input type="radio"/>
4. I have lost friends as they do not understand my condition	<input type="radio"/>	<input type="radio"/>
5. I hate that others have taken over the things I used to do	<input type="radio"/>	<input type="radio"/>
6. Being less able sometimes makes me angry	<input type="radio"/>	<input type="radio"/>
7. I sometimes feel I am letting people down	<input type="radio"/>	<input type="radio"/>
8. Sometimes I don't have the energy to talk to anyone	<input type="radio"/>	<input type="radio"/>

B) Interview Questions

Could you please describe for me your earliest memories of contracting/living with polio?

Did you also experience post-polio symptoms? Can you describe how this impacted your life at the time?

Knowing what you know now, what advice could you give to HCPs when providing care for people with polio or other chronic illnesses?

What advice would you give to other patients who might be experiencing chronic illness for the first time?

Table 1: Characteristics of Polio Survivors Interviewed (N=18)

Current Age (Average)	71
Age of polio diagnosis	5
Biological Sex	
Male	2
Female	16
Have Children	
Yes	12
No	6
College Graduate	
Yes	8
No	10

Fig 1: Sample of the quality-of-life questionnaire (a) and open-ended interview questions used for focus groups and individual interviews (b)

Table 2: A sample of recurrent themes with frequencies from each interview highlighting quotes of polio survivors interviewed

Theme	Description/Representative Quotes
Stigma	"Even long after we had polio and we were, you know, fine, people said 'Oh, kids can't come play at your house because that's a polio house.' ... I remember our neighbor had a Slip 'n Slide and he said 'Oh, you can't go on it because you had polio and we might get it.'"
Attempts at Returning to "Normal Life" with Physical Assistance	Most participants missed school for several months while they recovered. After being told they were "healed," their return to school emphasized their disabilities. This is especially true for those who had to climb stairs as well as those who had to attend gym classes.
Isolation & Loneliness	"The [hospital] had to have their own spinal tap, [my second one of the day]...so a few more men held me down there. They put me in a room with an iron lung, a small room. There was just a bed and the iron lung and they shut the door because I was crying so much. And I just, I mean, I remember that horror."
Optimism & Social Support	When asked the titles of their hypothetical autobiographies, one participant responded with "Polio as a Springboard, Not a Dead-End Street" because "my life would not have been as rich and full without polio."
Struggles Breeding Determination	"We attended regular school. It was initially recommended that we attend handicapped school. [Mom] said there was nothing wrong with our minds, so off to regular school we went. We did just fine."

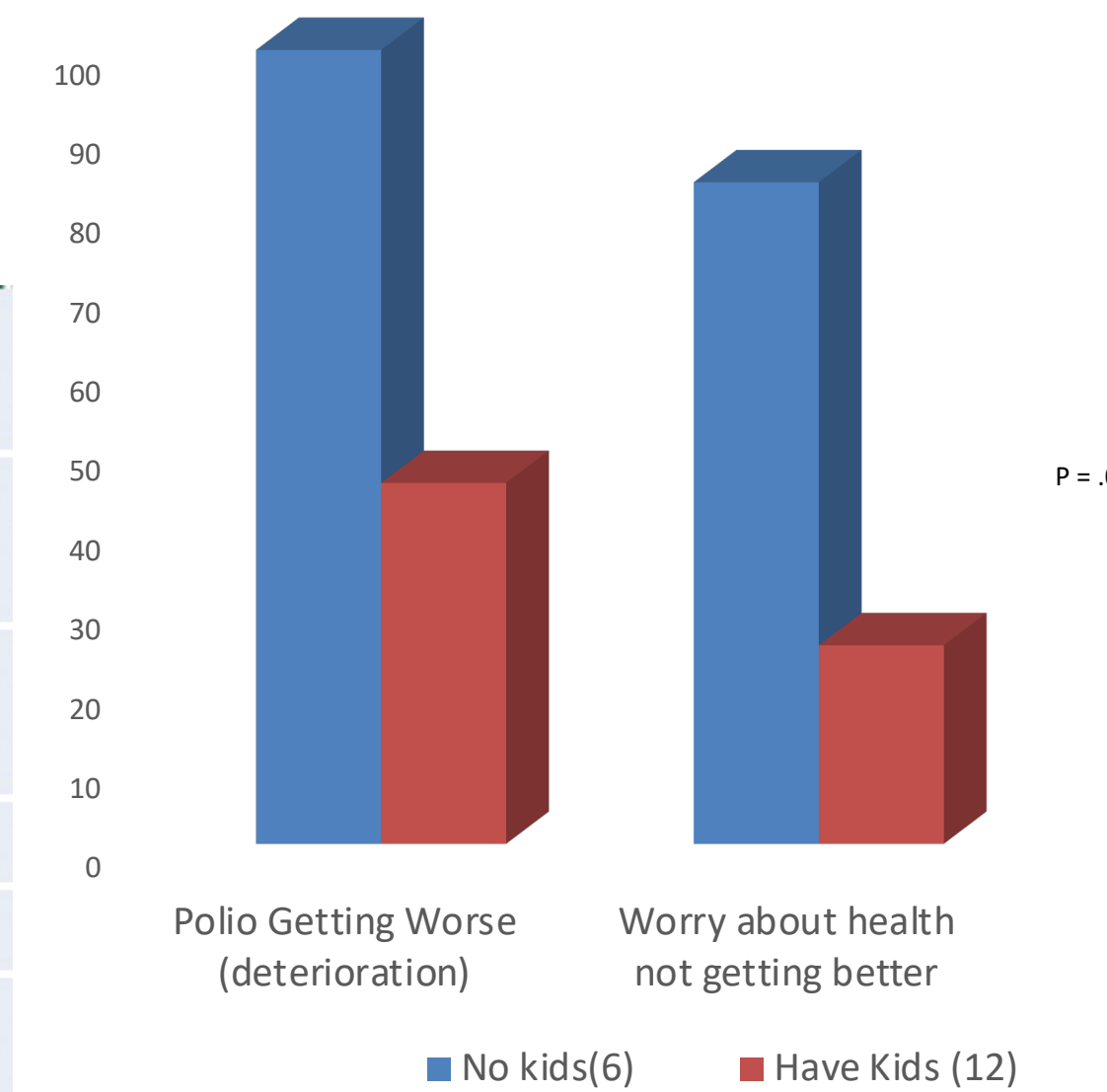


Fig 2: Having children was associated with being fearful that patient's condition will deteriorate ($P = 0.0427$). Having children was associated with worry of not being able to get better ($P = 0.0430$).

Conclusions

Qualitative: Major themes highlighted in Table 2 shows that chronic illness has major implications in one's life and physicians need to be aware of them when treating patients

Quantitative: The significance of having kids with worrying less about health conditions deteriorating or health not getting better shows that support systems plays a big role in health outcomes on patients living with chronic conditions

Discussion

The long-term goal is to **illuminate physicians and society** about caring for **polio survivors** as well as individuals living with **other chronic illness/disease** physicians may not be always familiar with.

Additional projects could include **interviewing the physician** that most of the survivors follow up with.

Regardless of patient's condition, it is important to have good **listening skills** and patients tend to remember those physicians who are **willing to educate themselves** and learn from their patients.

References

1. CDC Global Health: Polio. Centers for Disease Control and Prevention.
2. Baj A, Colombo M, Headley JL, McFarlane JR, Liethof M-A, Toniolo A. Post-poliomyelitis syndrome as a possible viral disease. *Int J Infect Dis.* 2015;35:107-116.

Acknowledgement

We would like to personally thank Bonnie Levitan and Timothy Brown from the Post-Polio Support Group (<https://www.michiganpolionetwork.com/>) for all their assistance with this project. Also, big thanks to Patrick Karabon for helping with the statistical analysis of the quality-of-life surveys.