Physician's Post-Polio Syndrome/Post-Polio Symptoms Education

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Introduction

Polio once caused 350,000 cases globally in 1988 but was nearly eradicated through vaccination[1]. However, COVID-19 disrupted immunization efforts, leading to new cases[2]. While polio is rare today, **Post-Polio Syndrome (PPS)** affects 12–20 million survivors, causing progressive muscle weakness, pain, and fatigue[3]. This syndrome can progress to the point of taking away the survivor's autonomy due to the atrophy of previously affected muscles.

Despite its impact, PPS remains poorly understood by physicians, compromising patient care. Studies highlight a global knowledge gap, but no similar research exists in the U.S. This study assesses physician awareness and practices in managing PPS to improve education and care. Findings will be archived by **Post-Polio Health International (PHI)** to support future research and training.

How do physicians educate themselves about medical practices related to PPS and Post-Polio symptoms, and how can the process be further improved?

Aims and Objectives

This study seeks to address the knowledge gap in post-polio syndrome (PPS) care by gathering insights from physicians experienced in treating PPS patients. Through qualitative Zoom interviews, the research will:

1.Document Medical Practices – Understand how physicians educate themselves and manage PPS to improve patient care.

2.Enhance Physician Education – Identify resources and strategies to better equip healthcare providers.

3.Support Preventive Efforts – Emphasize the importance of continued polio vaccination, given the recent rise in cases.

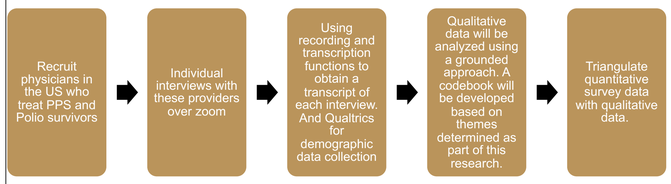
4.Contribute to Research Archives – Ensure findings are preserved by Post-Polio Health International (PHI) for historical and educational purposes.

This project aims to improve the healthcare experience of polio survivors while reinforcing the need for ongoing physician education and public health awareness.

Methods

In partnership with the *Southeast Michigan Post-Polio Support Group* and *Polio Health International (PHI),* we conducted a **mixed methods research study.**

Following the Common Rule IRB Requirements, we will make sure the appropriate consenting process is followed. The sample size has been discussed with OUWB statisticians, and for a statistically significant qualitative study, 10-12 participants were deemed appropriate. We are confident that we will reach our target sample size of 10-12 interviews/focus groups within six months of data collection.



Challenges

Despite exploring various strategies to recruit physicians with experience in treating post-polio syndrome (PPS), we were ultimately unable to meet our target number of participants. A total of four physicians were successfully interviewed. While this sample size limits the statistical significance of the study, the depth and richness of the qualitative data collected provide valuable insights that merit reporting. The perspectives shared by these physicians offer meaningful contributions to the understanding of PPS care and highlight the need for further research and broader physician engagement in this field.

Results

Table 1 reflects codes from answers to **topic 1** set of questions:

Polio Experience & Interest - What made you interested in Polio and treating its survivors?

1. Why do you think that polio/PPS patients are attracted to your practice?
2. What is the relevant history of your practice that you see/saw polio patients?

Category 1: Experience and interest		
Code	Definition	Representative Quote
Physicians background	The general public and many physicians have forgotten about polio, leading to a lack of understanding.	People forgot about polio, and many people do not understand the extent of involvement.
	Physicians interest in polio began through exposure during residency or medical school, which led to further curiosity	I was a resident in physical medicine rehabilitation at Northwestern and it happened that we were exposed to polio survivors.
	The physician's direct experience as a polio survivor influenced their career and approach to patient care	I'm a polio survivor, so yeah, my main reason was getting the information for myself.
Polio Community Needs	Initiating specialized care facilities for polio survivors due to lack of existing resources.	I started a postpolio clinic in 1985. So I've been seeing folks probably longer than you've been alive.
	Polio survivors seek out specialists who understand their complex medical needs.	Because I'm willing to listen to them. I understand their problems.
		One is because I'm sort of the only person who has a lot of expertise and experience with polio survivors.
	Patients referred each other, leading to a specialized practice.	Almost always by referral, occasionally self-referral, frequently a concerned spouse or older adult child.
		Their friends then started coming to me, and I started to kind of have a small little following.

Table 2 reflects codes from answers to **topic 2** set of questions:

Medical Practices. What are some of the major medical practices that you use when treating polio/PPS patients?

1. *What considerations should be taken into account when treating patients with post-polio syndrome?*
2. How has the experience treating polio patients helped you with treating other patients?

Category 2: Medical Practices for Polio and Post-Polio Syndrome		
Code	Definition	Representative Quote
Rehabilitation and Treatment Strategies	Focus on maintaining independence and daily activities.	You're figuring out how to get them out of bed, how to get them walking, how to keep them fishing.
	Managing polio patients requires coordination among specialists, including rehab therapists and psychologists.	I would many times simply write a note to give specifics like post polio syndrome with issues of fatigue, coping, and something else to try to give them a context.
Physicians Misunderstanding Polio Symptoms	Polio syndrome is diagnosed by eliminating other conditions, making it complex to identify.	Postpolio syndrome is a diagnosis of exclusion and not everybody I see has postpolio syndrome.
	Postpolio patients experience gradual fatigue and loss of function, often misattributed to aging or other conditions.	Typically it's a vague sense of fatigue, can be pain, primary myalgias, but sometimes pain is secondary to arthritis and muscle malalignment.
	Medical professionals often misdiagnose or misunderstand polio-related conditions.	The residents all thought she was drug-seeking because she was paraplegic and people with paraplegia shouldn't have any sensation.
Importance of Patient History	Historical context of polio treatment and rehabilitation affects current care needs.	Considerations is just what their experiences around the time of their initial polio or the immediate rehab period afterwards are.
	A detailed patient history and physical examination are essential in diagnosing and managing polio-related conditions.	A detailed history is worth its weight in gold because it is from the history that you determine what is wrong.
Psychosocial Impact of Polio	Polio patients often experience psychological distress and social stigma due to their condition.	One of the major problems she had was alcoholism... but it was the one thing that made her feel better temporarily.
	Understanding polio's historical impact and emotional significance is crucial in patient care.	They remember kids in respiratory failure who had died. They remember the quarantine or partial quarantine and waving at their parents.
	Many survivors have psychological trauma due to past medical treatments and hospitalizations.	Most polio survivors, whether they admit it or not, have some psychological scars as well as physical scars.

Table 3 reflects codes from answers to **topic 3** set of questions:

Physician Education - How do you educate yourself further about polio and what are the resources that you use?

1. What do you think the average physician today should know about polio/PPS?
2. What do you think is the biggest obstacle in medical students/physician's post polio syndrome education?

Category 3: Physician Education		
Code	Definition	Representative Quote
Patient-Centered Learning	Medical professionals often learn more from direct patient interactions than from textbooks.	Every patient teaches me something new, sometimes more about myself than about them.
	Physicians often learn more about polio from interacting with survivors than from formal education.	It's more what I learn from the patients and survivors than from medical education.
Medical Education Gaps	Due to the success of the polio vaccine, research on postpolio syndrome has significantly declined.	With the successful introduction of effective vaccines, serious research in the area has slowed down dramatically.
	Medical students and physicians struggle to learn about polio due to a packed curriculum and a focus on more common conditions.	Time. There's so much crammed in the curriculum that there's just not enough time to learn everything.
	Limited availability of polio-related learning materials for medical professionals.	The biggest obstacle is that there are no updated resources available for physicians to learn from.
	Polio cases are rare, reducing physician familiarity and expertise.	We don't see it, so we think we'll never need to know that.
Self education strategies	Older medical literature provides essential insights into polio treatment that modern sources often overlook.	I go back to old literature, where some of the original descriptions were made, even in the eighteenth century.
Importance of Physician Awareness	Most modern physicians are unaware of postpolio syndrome and need access to educational resources.	The average physician should know it's a genuine entity, characterized by the most debilitating symptoms are usually fatigue, loss of function, and brain fog.
The Role of Research in Medical Knowledge	Medical research, even when rarely read, contributes to the long-term body of knowledge.	Even if it gets published and nobody reads it, at least it can be researched when the problem comes up.

Conclusions

This research highlights a critical and underexplored area in modern medicine: the care of post-polio syndrome (PPS) survivors. Despite the near-eradication of poliovirus, millions of individuals continue to suffer from its long-term effects decades after recovery. Through qualitative interviews with physicians experienced in treating PPS patients, this study sheds light on current medical practices, educational gaps, and the resources that providers rely on to manage this condition.

Our findings emphasize a pressing need for more structured education about PPS in both medical training and continuing education programs. The insights gathered not only reveal the resourcefulness and dedication of individual physicians but also underscore a collective deficiency in healthcare systems' preparedness to care for this unique population. Furthermore, the resurgence of polio cases due to disruptions in global immunization campaigns highlights the ongoing relevance of this condition and the importance of preventive measures.

By documenting these experiences and perspectives, this project contributes to a growing body of literature aimed at improving care for polio survivors. The archiving of these findings by Post-Polio Health International (PHI) ensures their long-term impact, supporting future research, education, and advocacy. Ultimately, this work serves as a call to action—to bridge the knowledge gap, uphold our moral obligation to this often-overlooked patient population, and strengthen preparedness for any future resurgence of the poliovirus.

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