Assessing the Scale of the Long-term Effects of Polio. The Twin Challenges of Measuring Risk and Effective Diagnosis

Cathy Davies



The Answer to the Ultimate Question of Life, the Universe, and Everything

42

So once you know what the question actually is,
you will know what the answer means
The Hitchhikers Guide to the Galaxy

Current PhD study with working title The Barriers and Facilitators to the Effective Diagnosis of Post Polio Syndrome; A Global Perspective

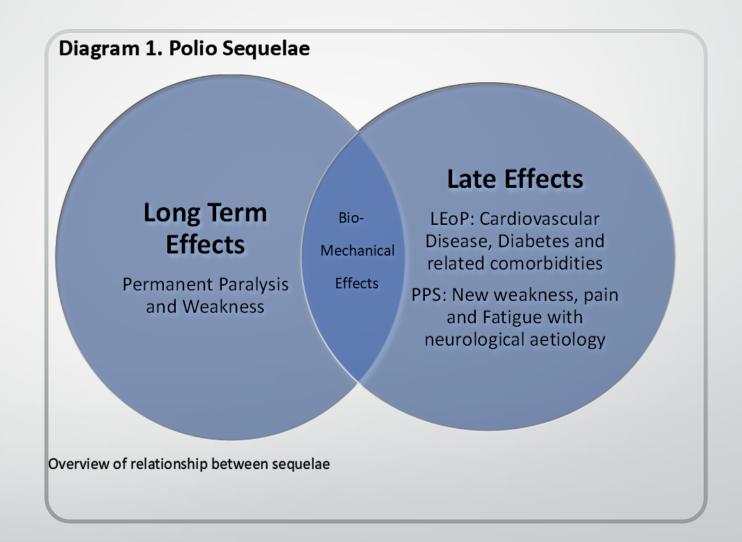
Cathleen Davies Dept of Epidemiology and Health Care UCL

Professor Nora Groce. Leonard Cheshire Chair of Disability and Inclusive Development

Institute for Global Health

cathleen.davies.19@ucl.ac.uk

Some Notes About Terminology



"20 Million Polio survivors globally"

World Health Organization

Post Polio Health International

What are we Counting?

Less than 1% of people exposed to polio exhibit lasting disability

Asymptomatic, 'abortive', nonparalytic aseptic meningitis, lasting paralysis(1,2)

The rate of diagnosis will vary hugely through geography and time

Looking At Risk

Risk is believed to be increase with severity of initial illness (3)

Risk of PPS from 15-85% (4)

Those with nonparalytic and abortive disease may represent largest risk of undiagnosed polio

But we just don't know how many people out there could potentially develop PPS

Sibling Research Sibling research suggests those with much milder or asymptomatic exposure may be at 'significant risk'(5) Even a low risk represents huge numbers globally



Our Second Question

Effective diagnosis

Difficulties of diagnosing paralytic vs non paralytic

Minor muscle weakness poses a PPS risk, but may not be evident.

Polio Survivors Experience of Diagnosis

Of those with confirmed paralytic polio around half of those who report PPS symptoms are formally diagnosed

Most report that they are not impressed with their physicians knowledge of the topic!

PPs without paralytic polio

- But people without paralytic polio are getting diagnosed.
- Some clinicians are going offpiste to successfully diagnose.



How is Successful Diagnosis Achieved?

Why do half of those reporting PPS achieve a diagnosis and not the other half?



Physical fatigue
 Mental fatigue
 Poor concentration
 Loss of ability to do actions of daily living
 Symptoms not believed by health professional
 Symptoms not believed by family member
 No diagnosis but continue to deteriorate

My Polio Life & Preparing for an Appointment
Polio survivors Network UK

Why does it Matter?

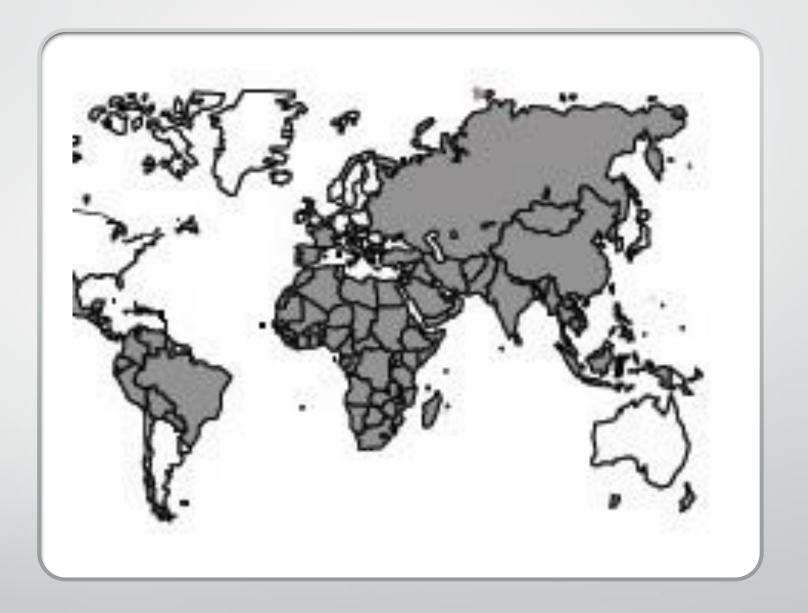
Management regimes, such as rest/ exercise balance.

Understanding increased risks

Because we want to know

Getting It right globally

- Younger global cohort
- Many treatment pathways are cheap and easy,





Goals

- Improved knowledge of the global scale of the late effects of Polio
- Putting PPS on the diagnostic table for those presenting with new neurological symptoms
- •Improving the patient journey to diagnosis



References

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