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Surviving polio in a post-polio world

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ABSTRACT

Excitement mounts as the global health and international development communities anticipate a polio-free world. Despite substantial political and logistical hurdles, only 223 cases of wild poliovirus in three countries were reported in 2012. Down 99% from the estimated 350,000 annual cases in 125 countries in 1988—this decline signals the imminent global eradication of polio.

However, elimination of new polio cases should not also signal an end to worldwide engagement with polio. As many as 20 million continue to live with the disabling consequences of the disease. In developed countries where polio immunization became universal after dissemination of the polio vaccine in the 1950s, almost all individuals who have had polio are now above age 50. But in many developing countries where polio vaccination campaigns reached large segments of the population only after 1988, millions disabled by polio are still children or young adults. Demographically, this group is also different. After three decades of immunization efforts, those children unvaccinated in the late 1980s were more likely to be from poorer rural and slum communities and to be girls—groups not only harder to reach than more affluent members of the population but also individuals who, if they contract polio, are less likely to have access to medical and rehabilitation programs or education, job training, employment and social support services.

The commitment to eradicate polio should not be considered complete while those living with the disabling sequelae of polio continue to live in poor health, poverty and social isolation. This paper reviews what is currently known about disabled survivors of polio and highlights areas of need in public health research, policy and programming. Based on a literature review, discussion and field observations, we identify continuing challenges posed by polio and argue that the attention, funding and commitment now being directed towards eradication be shifted to provide for the rehabilitative, medical, educational and social needs of those for whom the disabling sequelae of polio will remain a daily challenge for decades to come.

1. Introduction

According to the World Health Organization (WHO), polio wavers on the verge of extinction. Last year witnessed landmark victories in the fight against polio, with a record low 223 reported wild poliovirus cases and the declaration that India, once home to two-thirds of the global burden of this disease is now polio-free (WHO, 2013a,b). Although substantial political and logistical hurdles remain, including the targeted killings of medical workers in anti-polio campaigns in early 2013 and re-emergence of cases in Syria and Somalia in recent months, the global health and international development communities are optimistic. The Global Polio Eradication Initiative's (GPEI) new Eradication and Endgame Strategic Plan has set 2018 as the deadline for eradication certification, a strategy which has engendered an outpouring of endorsements and promises of financial backing (GPEI, 2013). If successful, polio would join smallpox as the only human diseases to be eradicated, sparing future generations from a devastating illness that once killed and disabled as many as 600,000 individuals annually.

Eradicating polio has been a public health priority since creation of the first effective vaccine in 1952. While most developed countries eliminated the disease in the 1970s and 1980s, the launching of the GPEI in 1988 at the World Health Assembly led to an international push for a polio-free world by 2000. Although this target was pushed back to 2018, campaign achievements have been impressive: polio rates have fallen by 99%, from an estimated

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350,000 cases of wild poliovirus in 125 countries in 1988 to just 223 cases in 3 countries (Afghanistan, Nigeria and Pakistan) in 2012 (WHO, 2013a,b). These numbers do not reflect WHO's new reports an additional 13 cases of polio in the Syria region and 183 in Somalia, however major vaccination initiatives in surrounding countries seek to avoid a regional re-emergence of the disease (GPEI, 2013). Due to the concerted global vaccination efforts by Rotary International, WHO, UNICEF, and more recently the Bill & Melinda Gates Foundation, more than 10 million cases of individuals permanently paralyzed and 1.5 million childhood deaths have been averted since 1988 (WHO, 2013a,b).

Yet, while an enormous amount of time and resources have been devoted to preventing polio, scant attention has been paid to the estimated 12 to 20 million individuals living with polio sequelae worldwide (Gonzalez et al., 2010). These include those who sustain permanent disability after the initial polio attack, as well as a more recently recognized group affected by post-polio syndrome. Post-polio syndrome (PPS) affects approximately 25–40% of all polio survivors, both those immediately disabled by the virus and those who recover with few or no symptoms from the initial infection (Lin and Lim, 2005), but who after years of stability in functioning, begin to experience new or worsening disabling symptoms as they age.

Individuals disabled through polio confront not only a range of physical disabilities but also significant social, financial and human rights barriers hindering integration and participation in families and communities. These barriers in turn, lead to chronic ill-health, social marginalization, limited access to education and employment, and high rates of poverty. Women are impacted disproportionately, as are individuals from poorer households, minority communities and from rural and urban slum areas (Tomas, 1991; Halder, 2008; Huang, 1999; Emmett and Alant, 2006; WHO/World Bank, 2011; Yeo, 2005). Children from areas where war or disaster has interfered with immunization and rehabilitation are also at increased risk (Aaby et al., 2002; Black, 1996; Boyce, 2000).

Understanding the current health and rehabilitation needs as well as the socio-economic situation of polio survivors is critical for identifying their unmet needs. Access to resources on both national and global bases is a right guaranteed under the United Nations Convention on the Rights of Persons with Disabilities (CRPD; UN, 2006). And, we argue here, the obligation to continue to provide support and services to those millions of children and adults who live with disabilities caused by polio is a logical extension of the current global commitment to polio eradication. Accordingly, this paper reviews what is currently known about those disabled by polio and highlights areas in need of research to facilitate appropriate public health and better development policy and programming.

1.1. Methods

This paper is based on discussions and field observations of two authors (MS, NG) over the past decade which concluded that while a considerable amount of information exists on polio and disability, there was little effort to bring these topics together or provide an overview of the lack of attention to people disabled by polio within current global health agendas. It was decided that a review of existing literature and linking this literature with global Disability Studies was needed. In light of this, this study began with a comprehensive literature review, conducted between July and December 2012. Four electronic databases (PubMed, Google Scholar, Academic Search Complete and Global Health) and institutional websites (WHO, Post-Polio Health International, and Global Polio Eradication Initiative), were searched for relevant publications. Additional sources were identified through bibliographies and reference lists. (Relevant articles between 2012–September 2013 were added as they appeared).

Search terms included variants for polio survivor: disabled by polio*, paralytic polio*, polio* patient, paralyzed by polio*, infect* with polio*, post-polio* syndrome, adults/children/women (etc.) with polio. Search terms for the status of polio survivors, included terms that could measure their current situation: disability/handicap and employment, income, health status, marriage status, quality of life, social participation, assistive devices. No restrictions based on publication year, study type (qualitative/quantitative), study design or population characteristics were employed. Articles and reports were then grouped and analyzed by country by developing/developed status, and outcome measures (e.g. poverty, employment, quality of life) were reviewed for further insight.

2. Background

2.1. Polio survivors over the life-course

Polioviruses (PV) are enteroviruses spread through the oral-fecal route, when viruses from fecal matter are ingested via contaminated water or food by a child or adult (Knipe and Peter, 2007). Although highly contagious, the vast majority (90–95%) of infections are asymptomatic as the viruses are confined to the gastrointestinal tract (Knipe and Peter, 2007). In 4–8% of cases, infection spreads to the bloodstream, causing a range of minor, nonspecific symptoms, such as headache, sore throat, fever, and vomiting (Knipe and Peter, 2007). Paralytic poliomyelitis, a more serious clinical outcome, occurs in approximately 0.5% of all PV infections, when the virus invades the central nervous system, causing inflammation and destruction of motor neurons leading to muscle weakness and paralysis (Peters and Lynch, 2001; Knipe and Peter, 2007). The severity of the disease depends largely on the site of this destruction, with highest morbidity and mortality resulting from respiratory or brain steam involvement (Peters and Lynch, 2001; Knipe and Peter, 2007).

Many polio survivors with paralysis experience significant resolution of their paralysis, typically within 6–8 months of symptom onset (Neumann, 2004). During recovery, remaining motor neurons can develop new branches to re-enervate muscle fibers and restore some level of function (Peters and Lynch, 2001). Although statistics differ, 10–40% of survivors recover full muscle strength; however 60–90% are left with varying degrees of residual paralysis (Neumann, 2004). Intensive physiotherapy, exercise and surgery when available, can help maximize recovery (Howard, 2005).

Polio survivors also have increased risk of associated medical concerns, with higher rates of respiratory, heart and musculoskeletal diseases and gastrointestinal disorders (Nielsen et al., 2004; Kang and Lin, 2011). Female survivors are more likely to suffer complications during pregnancy and delivery, and their infants have lower mean birth weights (Veiby et al., 2007). These sequelae are associated with severity of residual impairment, degree of paralysis during acute illness and a young age of infection (Nielsen et al., 2004).

Until the 1980s, it was believed that after recovery from the acute stage of infection, the physical condition of a polio survivor with paralysis would remain stable for the rest of their life (Peters and Lynch, 2001). In the early 1980s in many developed countries, large cohorts of aging survivors from epidemics in the 1940s and 1950s began to experience worsening disability after decades of consistency or revival of symptoms long assumed overcome, leading to recognition of additional late-effects of polio. Coined "post-polio syndrome" (PPS), symptoms include pain, fatigue and new muscle weakness/atrophy in previously affected areas (NIH,