



## 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.

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### 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 stem 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-ennervate 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,

2012). PPS often results in decreased mobility, new need for assistive devices, increased difficulties in activities of daily living, and decreased life satisfaction (Kumakura et al., 2002; Stuijbergen, 2005; Harrison and Stuijbergen, 2006). Typically occurring 30–40 years after the original infection, researchers estimate PPS affects 25–40% of polio survivors (Lin and Lim, 2005).

Risk of developing PPS is more common in survivors who sustained permanent impairment and among women (Ramlow et al., 1992). Severity of the syndrome is associated with the level of paralysis incurred during infection and the degree of functional recovery, with individuals who suffered extensive paralysis during acute infection but had attained substantial recovery at greatest risk for a more severe case of PPS (NIH, 2012). Although the cause of PPS is still unknown, the most accepted hypothesis is that excessive long-term stress on the motor neurons that survived infection leads to their premature degeneration (Lin and Lim, 2005). The lack of definite cause and wide range of symptoms creates challenges for standardized treatment. Thus most PPS care has focused on individualized symptomatic relief (Lin and Lim, 2005).

## 2.2. Historical context and epidemiology

Polio has affected populations for millennia, with polio-induced paralysis depicted in Egyptians hieroglyphs by 1580 BCE (Nathanson and Kew, 2010). However, prior to the late nineteenth century, clinically identifiable polio cases were sporadic and poorly reported, thus gaining little attention (Trevelyan et al., 2005). Then, small outbreaks of polio appeared in the United States and several Scandinavian countries in the 1880s, most with fewer than thirty cases (Trevelyan et al., 2005). By 1900, case numbers swelled to hundreds and then thousands, leading to the first polio epidemics in Norway and Sweden, followed by other European countries and the United States (Trevelyan et al., 2005).

Attention to polio was initially concentrated in developed countries. Contrary to many communicable diseases, polio epidemics flourished in areas with advanced hygiene and sanitation (Nathanson and Kew, 2010). This pattern is often attributed to delayed age of first PV infection. In areas with poor sanitation, PVs and other enteroviruses prevalent in the environment infect infants aged 6–12 months, while still partially protected against infection through passive immunity (Nathanson and Kew, 2010). This overlap in passive and active immunity resulted in low susceptibility to more serious clinical outcomes (Nathanson and Kew, 2010). With improved hygiene, age of first infection was postponed past 12 months, at which point the child has neither passive nor active immunity against the enterovirus' spread to the central nervous system, resulting in more severe clinical outcomes (Nathanson and Kew, 2010). Since rates of paralysis increase substantially with age (1/1000 cases for infants versus 1/75 for adults), the disease burden rose as first infection was progressively delayed (Peters and Lynch, 2001).

In developed countries, polio epidemics peaked in the 1940s and 1950s (Trevelyan et al., 2005). Following introduction of the Salk polio vaccination in 1955 and subsequent national mass immunizations, polio incidence declined dramatically. By the early 1980s polio was largely eradicated in the developed world (Trevelyan et al., 2005). Consequently, most polio survivors in developed countries today are aged 50 and older.

Recognition of polio as a public health problem in the developing world followed a different route, only coming to international attention in the 1970s, following several lameness surveys (LaForce et al., 1980). In countries with high infant mortality rates and a significant burden of disease, polio was largely overlooked, and this was compounded by poor surveillance and reporting

(Ward et al., 1993). Furthermore, in contrast to polio in temperate developed countries, polio in tropical and subtropical developing countries presents as an endemic disease rather than in noticeable epidemics (LaForce et al., 1980). Polio transmission shows seasonal variation in temperate climates, as the virus survives best above 40% humidity, resulting in highly visible waves of cases in the summer months (Nathanson and Kew, 2010). In tropical and subtropical regions, PV can survive all year round, leading to relatively constant incidence rates (Nathanson and Kew, 2010). Even though poor sanitation and hygiene resulted in a lower mean age of first infection, high rates of continuous exposure and weakened immunity from sources such as malnutrition and persistent infections can lead to incidence rates comparable with epidemic countries in the pre-vaccine era (Ofosu-Amaah et al., 1977).

Estimating the global number and regional distribution of polio survivors is extremely challenging. In the years immediately preceding initiation of GPEI, it was estimated that only 11% of the global number of individuals paralyzed by polio were captured through national surveillance systems (Ward et al., 1993). Paralytic polio as a syndrome is also indistinguishable from diseases such as Guillain-Barré syndrome, so case detection and ascertainment requires high surveillance with rapid laboratory follow-up (Hull et al., 1994). Such protocols require substantial capacity building. Consequently, accurate global polio case counts were not achieved until mid-to-late 1990s, when substantial technical assistance was deployed by WHO to polio endemic countries (Aylward and Linkins, 2005). A further difficulty for estimating burden of disability from polio is the inconsistency in the literature regarding the term “polio survivor,” as it is often unclear whether this refers all those infected or only those sustaining residual disability.

Taking into account these challenges, WHO estimates that before vaccine development, global annual incidence of polio was over 600,000 (WHO, 2001). As polio vaccination became routine in developed countries, global rates fell to 350,000 paralytic cases per year by the 1980s (WHO, 2013a). Launch of the Global Polio Eradication Initiative in 1988 brought further reductions, with cases dwindling to 136,000 annually in the early 1990s and declining to just 223 in 2012 (WHO, 2013a,b).

While mass immunization has resulted in a precipitously fall in the number of new infections in the past two decades, by conservative estimates, as many as 20 million people have sequelae of poliomyelitis (Gonzalez et al., 2010). Regional prevalence estimates are often crude and fragmentary, particularly in developing countries. In the U.S., there are approximately 400,000 polio survivors with paralysis (Becker, 2006) and PPS is reported to be the most prevalent progressive neuromuscular disease in North America (Elrod et al., 2005). A further 700,000 polio survivors with paralysis reside in Europe (European Polio Union, 2012). In Latin America and the Caribbean, polio-free for two decades due to an intensive eradication campaign by the Pan American Health Organization in the 1980s, survivors now surpass 500,000 based on a pre-elimination annual incidence of 15,000 (Kinder, 2006). Estimating the prevalence of polio survivors with paralysis in Africa is more challenging: based on an average annual incidence of 10–55 cases per 100,000 reported in lameness surveys the 1980s (Joseph et al., 1983; Ofosu-Amaah, 1984), at least a million survivors live on the continent. Asia, particularly the Indian subcontinent, has had high infection rates over the past two decades, with Pakistan and Afghanistan two of the three remaining areas of endemic PV transmission. India, now certified polio-free for two years, faces a particularly high burden of polio survivors with paralysis. The country has regularly accounted for half to two-thirds of all reported cases, with annual cases reaching over 200,000 through the 1990s (Hull, 2001). Consequently, polio survivors with paralysis number in the millions, many of whom are still young.

### 3. Polio today

The issue is not simply how many people live with the clinical sequelae of polio. Equally important, the social and economic ramifications of polio, including PPS, over the life-course of survivors must be considered.

#### 3.1. Situation in developed countries

Because the vast majority of infections were contracted in the pre-vaccine era, most developed countries have not seen new polio cases for half a century. Consequently, polio survivors in these areas are almost exclusively aged 50 and older (Becker, 2006). As members of this population age, they are more likely to suffer from a number of secondary conditions, and many will experience worsening disability due to PPS (NIH, 2012).

The degree to which polio and residual disability have affected long-term outcomes such as education, employment, and life satisfaction in developed countries is inconclusive, but appears to be largely correlated with severity of disability and the medical and social conditions within the country of residence. In countries with the highest levels of development, with extensive supports and an accessible physical and social environment, the residual effects of polio appear to be less of an impediment to full participation in life activities. Some evidence suggests that these country-level factors may be a greater predictor of employment status, income and independence than severity of disability (Rekand et al., 2003).

Several Scandinavian studies indicate polio survivors in developed countries achieve comparable levels of education, but slightly lower rates of employment compared to their non-affected peers (Schanke, 1997; Farbu et al., 2001; Farbu and Gilhus, 2002). Choice of occupation depended partly on level of disability, with those with more pronounced muscle weakness opting less often for manual jobs (Farbu et al., 2001). However, while employment rates tend to be similar to the general population, a much higher proportion of polio survivors work part-time rather than full-time (Farbu and Gilhus, 1997; Thorén-Jönsson et al., 2001). Several small studies examining the effects of various disabilities, including polio, in developed countries with lower levels of social support indicate that differences in employment rates, income earned and hours worked may be more significant (Rekand et al., 2003; Mitchell et al., 2006; Park et al., 2007).

Onset of PPS creates further challenges to employment. While employment rates decrease over the lifespan for the general population, the decline begins earlier and is much more extensive in polio survivors (Mitchell et al., 2006). Even in countries with the highest levels of development, employment at age 40 is significantly lower for polio survivors than their age- and sex-matched siblings (Farbu and Gilhus, 2002). Functional declines frequently create challenges to work, which often require new accommodations (McNeal et al., 1999; Ten Katen et al., 2011). Such health problems and the lack of adequate support can cause PPS patients to change or leave jobs, retire early, or decrease working hours (Saeki et al., 2001; Elrod et al., 2005; Harrison and Stuijbergen, 2006; Atwal et al., 2013). This loss in paid employment often leads to financial problems and increased need for disability benefits (Rekand et al., 2003; Atwal et al., 2013).

The process of secondary disablement by PPS not only affects employment, but also has psychosocial implications. Frequently, functional declines limit independence, social participation and the ability to maintain previous lifestyles (Marincek, 2000; Thorén-Jönsson et al., 2001; Stuijbergen and Brillhart, 2005; Harrison and Stuijbergen, 2006). Consequently, numerous studies have shown positive correlations between PPS, depression and decreased life satisfaction (Kemp et al., 1997; Schanke, 1997; Marincek, 2000;

Farbu and Gilhus, 2002; Stuijbergen and Brillhart, 2005; On et al., 2006). Strong social support, especially from family, and low levels of physical and structural barriers mediate this effect (Kemp et al., 1997; Lund and Lexell, 2009). Furthermore, some evidence indicates that with proper education and rehabilitative services, mental status may stabilize or improve even with worsening physical condition (Stanghelle and Festvåg, 1997; Davidson et al., 2009).

Compounding this is stigma and prejudice towards persons with disabilities in some societies where many members of the general public view persons with disabilities (or parents of children with disabilities) as responsible for their own disability through having sinned, engaged in incest or as victims of magic or witchcraft. (WHO/World Bank, 2011; UNICEF, 2013; Yeo, 2005; Groce, 2013) No less limiting is the common view of people with disabilities as objects of charity, rather than persons with the same entitlement to rights and equal access to resources. (Groce et al., 2013).

The vast majority of physicians and other healthcare professionals working in developed countries in the post-vaccine era have never encountered a case of polio and thus often lack experience and understanding of the treatment and long-term pathology of the disease (Becker and Stuijbergen, 2004; Atwal et al., 2013). Since PPS is a relatively newly recognized disorder, with an unknown etiology and a wide range of possible presenting symptoms, diagnosing and managing is challenging (Trojan and Cashman, 2005). Current recommendations call for individual symptom management plans, requiring a multi-disciplinary approach involving a range of professionals including physiotherapists, orthopedic surgeons, rehabilitation experts, neurologists, psychologists and respiratory consultants (Pountney, 2009). Barriers such as inaccessibility of treatment centers, financial constraints, and lack of education of patients and practitioners present additional difficulties for treatment (Foster et al., 1993; Becker and Stuijbergen, 2004; Iezzoni et al., 2006).

On a more positive note, polio survivors are one of the largest and most recognizable disabled groups, and have been leaders in disabled people's organizations (DPOs) and the global disability rights movement (Fleischer and Zames, 2011). Further, many of the challenges faced by polio survivors—equal access to health, education and employment opportunities, poverty eradication, and personal mobility, for example—fall within the mandates of the CRPD. Thus, the status of polio survivors stands them in good stead when advocating for State responses to their needs.

#### 3.2. Developing countries

Over the past two decades, major global health initiatives against polio led by WHO, with crucial financial and technical contributions from groups such as Rotary International, UNICEF, the United States' Centers for Disease Control, and, more recently, the Gates Foundation, have coordinated one of the largest and most successful public health campaigns in history. With such a strong focus on eradicating polio, however, insufficient attention has been paid to those who do contract the disease and their subsequent health and rehabilitation, as well as social, financial and psychological needs throughout their lifetime.

Today, the largest, youngest populations of polio survivors live in developing countries (Rekand et al., 2003). However, little research has been conducted to assess their current situation. In developed countries, polio survivors tend to be older and middle to upper class, as the majority of infections occurred before a vaccine was available (Oshinsky, 2010). In contrast, due to the later introduction of wide-spread vaccination, survivors in developing countries are often younger, many still children or of prime working age (Halder, 2008; Gonzalez et al., 2010). Furthermore, polio occurs disproportionately amongst the poorest, most marginalized

populations; those least likely to have received vaccine protection (Pinto and Sahu, 2001; Yeo and Moore, 2003; Halder, 2008). This younger cohort presents different needs and challenges to health-care and rehabilitation, as well as education, social integration and economic self-sufficiency, than their older counterparts in resource-abundant environments.

In developing countries, what little research exists concerning polio survivors has focused on individuals immediately disabled after the initial polio infection. In most countries, the numbers disabled by polio far outstrips the medical and rehabilitative services available (Parnes et al., 2009). Moreover, available services tend to be expensive, limited in scope and/or available only in urban medical centers or specialized facilities that can accommodate only small numbers of patients (Boyce, 2000; Halder, 2008; Parnes et al., 2009; Groce et al., 2013). There are limited options for education, employment, social integration or civic participation.

Even less is known about individuals who survive polio without residual disability but who subsequently find themselves with PPS. There is little research or understanding of how PPS manifests itself in individuals who did not suffer from residual paralysis after acute infection or how the condition of persons disabled by polio deteriorates over time with the onset of additional PPS complications in developing world settings. Specifically, how PPS-related health issues might be compounded by factors found among poor populations in developing countries: lack of access to rehabilitation or assistive devices (wheelchairs, crutches), poor nutrition, hard labor or exposure to diseases such as malaria or HIV which might further compromise the health of millions of polio survivors. Nor has there been much attention to low-cost, low-tech interventions to address these needs. Furthermore, chronic underreporting on prevalence of polio survivors and competition for resources and attention from individuals with other diseases and social problems has led to the significant lack of attention towards this population (Zhang, 1991; Andrus et al., 1997; Nathanson and Kew, 2010). Nor has there been discussion on the potential impact that their needs will have on local medical and rehabilitation systems as PPS begins to appear among aging populations in coming decades.

Evidence from the few existing developing countries studies also finds that disability from polio has profound social and economic consequences. Halder, studying women disabled by polio in India found they were disproportionately under-educated and unemployed, with only 32% working, despite unfilled government quotas for women with disabilities (Halder, 2008). Similarly, in a Chinese study 85% of disabled polio survivors over age 15 were either unemployed or underemployed and their marriage rates were markedly lower than for non-disabled individuals (Dai and Zhang, 1996b). A paired-sibling study in Lebanon noted significant differences in employment, social class, income and marital status between individuals disabled by polio and non-affected sex-matched siblings (Shaar and McCarthy, 1992). A recent Nigerian study reported adolescent disabled polio survivors scored significantly lower than age- and sex-matched peers on quality of life measurements, particularly concerning productivity, community participation and emotional/physical health (Adegoke et al., 2012).

It is estimated each case of paralytic polio results in the loss 13–14 disability-adjusted life years (DALYs) in low- and middle-income countries (Duintjer Tebbens et al., 2010). In addition, long-term polio survivors also experience significant economic consequences. Medical treatment for polio in low- and middle-income countries averages US\$600–6000/case, with additional costs through lost productivity (Duintjer Tebbens et al., 2010). Given average GNI/capita between US\$930–3200 in these countries, these costs pose a substantial burden (Duintjer Tebbens et al., 2010).

Polio also results in significant economic losses at the country level. Balancing the gains of averted medical costs and lost

productivity due to polio with the expenses of eradication efforts, it is estimated that eradication leads to net saving of US\$40–50 billion through 2035 (GPEI, 2010). Low-income countries stand to benefit most, as they will accrue about 85% of these gains (GPEI, 2010). These predictions are based on the current relatively low incidence of polio; when looking at historical savings given pre-vaccination rates of polio, the US alone has saved US\$180 billion (Thompson and Tebbens, 2006).

In developed countries, rehabilitation services, availability of assistive devices and an accessible physical and social environment have been shown to mitigate many of the negative outcomes associated with both the original disability and complications arising from PPS. Much of the research on interventions and supports for polio survivors has been based on interventions from developed countries which assume the availability of whole teams of specialists. However, many developing countries lack these clinical resources, as well as the infrastructure, information and political will to tackle these challenges. An exception is found among some community-based rehabilitation (CBR) services, which provide coordinated services in areas that are often resource-poor. However, such services still reach only a small proportion of those who need support and have yet to be brought 'to scale' (WHO, 2011).

Provision of rehabilitation services and assistive devices can also be costly. In one older analysis, the cost of rehabilitation per polio patient with paralysis in China averaged 1112 Yuan (approximately 180 USD) (Dai and Zhang, 1996a), which is more than the entire per capita healthcare spending in many developing countries (UC Atlas of Global Inequality, 2006). Given rising prices, inflation, and the additional costs associated with PPS management, this figure is likely considerably higher today.

Moreover, even when rehabilitation services and assistive devices are available, utilization by polio survivors may be poor due to lack of information about benefits, financial constraints, and inaccessibility of clinics (Green-Abate et al., 1989; François et al., 1998; Wyatt, 1998; Halder, 2008). For example, in many countries, services are located in urban areas, while the majority of polio survivors live in rural areas without adequate transportation (Huang, 1999; Souphan Inthirat and Sihabandith Thonglith, 1999; Boyce, 2000; Halder, 2008; Groce et al., 2011). Furthermore, in countries where civil unrest, armed conflict, political instability and economic problems presented barriers to effective vaccination campaigns, substantial polio survivor populations exist, but rehabilitation programs and disability support services continue to be limited in the aftermath of the unrest that blocked effective vaccination campaigns in the first place (Black, 1996; Boyce, 2000; Groce, 2013). Additional barriers may also exist, for example, in Afghanistan, the lack of female staff greatly decreased attendance rates of young, polio-paralyzed girls at orthopedic centers (François et al., 1998).

CBR, first promoted by WHO in the 1970s in response to a lack of rehabilitation services, offers a low-cost, effective strategy for rehabilitation, education, poverty reduction, and social inclusion for polio survivors in resource-poor settings (Lagerkvist, 1992; Lundgren-Lindquist and Nordholm, 1993; WHO, 2004; Hartley et al., 2009; WHO, 2011). The use of local resources and leadership makes CBR attractive as an international development approach; however, concerns about the inability of CBR to be brought to scale, inconsistent implementation, limited integration with national health services and policy-making, and failure to maximize participation of people with disabilities (particularly women), have been raised (Hartley et al., 2009).

Additionally, DPOs play important roles in advancing disability rights and advocating for the needs of polio survivors (Yeo and Moore, 2003). Both polio-specific and more broad-based DPOs

have been instrumental in increasing economic opportunities, social inclusion and participation for survivors. Examples of polio-specific programs include: the Polio Victims Association in Nigeria, which holds skills acquisition workshops in fields such as carpentry, metalwork and tailoring (Renne, 2006); Socieda Peruana de Polio [Peruvian Society of Polio], which disseminates information on the late-effects of polio to members and healthcare providers (Graña, 2002); and Mukti, in India, Pakistan, Bangladesh and Sri Lanka, providing assistive devices to polio survivors (Mukti, 2012). The expertise, networks and support base of such groups will be vital tools in designing and implementing future programs for polio survivors. However, these groups often reach only a small number of all polio survivors in a region.

#### 4. Future needs

Although the situation of polio survivors in high-income countries is relatively well-documented, a dearth of information in low- and middle-income countries continues. The lack of knowledge has profound political, economic and social implications for local, national and international policy-making; this need for accurate data on persons with disabilities generally is reflected in a separate article (Article 31) of the CRPD (UN, 2006).

Without question, the largest knowledge gap concerns survivors disabled by polio in developing countries. While the number of individuals disabled by polio will begin to disappear in the next few decades in developed world, such individuals will continue to be a major concern in much of the developing world for at least another generation (Gonzalez et al., 2010). And as the population of younger polio survivors reaches middle and old age, a new wave of individuals with PPS will begin to make additional demands on developing countries' health systems.

Current care strategies for polio survivors in developed countries, typically involving coordination of multiple skilled professionals, may not be transferable to limited resource settings, particularly given the complexity and high cost of PPS-case diagnosis and management. Furthermore, anecdotal evidence suggests that healthcare workers in developing countries are largely unaware of PPS.

Preventing and reducing negative health outcomes associated with polio pathology, and addressing the social and environmental barriers to rehabilitation and participation, affects individuals' quality of life and may avert issues such as loss of productive workers, high rates of poverty and dependency on family or public assistance. There are concomitant issues in terms of life-long and intergenerational poverty as individuals disabled by polio attempt to support themselves and their families, often with limited access to the healthcare, education, skills and social support networks available to their non-disabled peers.

To design effective programs and policies that improve life course outcomes for polio survivors, more research is essential. To begin, more accurate estimates of regional prevalence of polio survivors and the degree of residual disability sustained will be useful for efficient planning and appropriate resource allocation.

In addition, further data on the current situation of polio survivors in developing countries is needed, particularly into adulthood when the effects of PPS may compound existing disability or appear anew in previously symptom-free individuals. Existing research is sparse and primarily focused on the impact of the initial disease and the clinical and rehabilitative needs in the immediate aftermath. Additional research should highlight areas of large unmet need and help guide priorities.

Furthermore, while much can be gained from the experience of PPS treatment in developed countries, identifying potential adaptations of those strategies for resource-poor areas is imperative.

Just as significantly, the educational, social and economic needs of these millions of children and young to middle-aged adults must be met.

Opportunities for linkages and collaboration with the broader disability community should be explored as many of the concerns and needs of polio survivors overlap with those of people with other disabilities. Recognizing areas of shared interest will help in advancing agendas. In particular, addressing the stigma and prejudice encountered by persons disabled by polio must be part of long-term strategies to address the needs of people living with PPS and must be linked to broader efforts to confront disability and stigma faced by all people with disabilities. Ratification by countries of the CRPD and progressive national legislation is not enough—inclusion of polio survivors in community awareness campaigns and increased support by DPOs is also needed. And given the disproportionate impact of polio on women, DPOs must pay particular attention to gender sensitive research agendas and interventions.

Finally, while conferences and newsletters on PPS by groups such as Post-Polio Health International make significant contributions towards educating patients and healthcare workers, a more widespread effort combining local ownership with technical and financial investments from global health and development organizations—including those now focused on eradication efforts—is needed to fill this information and resource gap. Specially, medical, nursing and allied health professionals, particularly in low- and middle-income countries would benefit greatly from pre-service and in-service training on the needs of polio survivors. Currently, education among health professionals is almost wholly on vaccination efforts. Given the number and diversity of health concerns among the millions disabled by polio and the existence or emergence of PPS, these issues realistically will be something many clinicians will regularly encounter during their professional careers. Links where CBR programs exist and have experience with polio would also benefit clinicians through shared knowledge and practice, however it is anticipated that many patients, particularly aging persons with re-emerging symptoms who have not previously lived with a disability, will be more likely to seek care from their established health providers rather than through CBR programs.

It is particularly important that the same funders and organizations that are now working so intently on eradicating polio must acknowledge that vestiges of the disease continue and resources and support must be dedicated to continuing need for policy, programs and research in this area. Currently post-polio survivors are used in campaigns for immunization drives but their own needs and circumstances are rarely addressed (Groce, 2013).

#### 5. Conclusion

It seems increasingly likely that the age-old threat of polio will soon come to an end. However, the shadow of polio will continue for decades, taking a significant toll on the health and well-being of millions. Today, as many as 20 million people worldwide are living with polio sequelae, with the youngest and largest proportion of these survivors residing in developing countries, and a disproportionate number of these being female (Gonzalez et al., 2010). Their current situation and future needs are still largely unknown. Their lives will be limited not by their disabilities, but by the medical and social ramifications of their disabilities—the stigma, social marginalization and barriers to resources, such as medical care, education and employment—that will result in poverty, lack of choice and the denial of basic human rights.

Research and advocacy, as well as programs and policies, are needed to more effectively maximize polio survivors' health and

well-being while promoting greater social participation and inclusion.

In a recent BBC interview, philanthropist Bill Gates, discussing the current global push to eradicate polio (Walsh, 2013) told the interviewer: “polio eradication is a proving ground, a test. It will reveal what human beings are capable of, and suggest how ambitious we can be about our future.” We fully agree; however, we argue that this statement is equally relevant to those confronting the disabling consequences of polio. The battle against polio will not be won until the global community can assure those who live with the disabling consequences of polio that their needs will be met and resources will be made available to enable them to function fully and freely in the societies in which they live - now and in the decades to come.

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