# Late effects of polio

Interviewing general practitioners and health professionals about the need for and the means of promoting continuing professional development

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#### Background and objective

Polio Australia estimates tens of thousands of polio survivors are experiencing late effects of polio (LEoP), including increased cases among young women of childbearing age in some migrant communities. Because polio has been declared eradicated in Australia, the provision and uptake of education by general practitioners (GPs) and healthcare professionals (HCPs) is minimal. We explored the awareness of LEoP among HCPs and ways to enhance knowledge dissemination to improve clinical practice.

#### Methods

A qualitative study was undertaken, informed by a descriptive (transcendental) phenomenological approach. Semistructured interviews were audio recorded, transcribed and analysed inductively, with a conciliation among the research team used to finalise the themes.

#### Results

HCPs expressed the importance of learning about LEoP and how this may help build supportive patientpractitioner relationships and contribute to patient outcomes. Factors influencing the uptake of professional development included motivation, possibly stemming from a lack of awareness of LEoP, together with the time and logistical limitations of practice generally.

#### Discussion

Online learning activities followed by an assessment may be attractive for some HCPs, but peer-based and multidisciplinary continuing professional development activities remain preferred. AUSTRALIA AND NEW ZEALAND were declared poliomyelitis-free during the early 2000s, with the last Australian poliomyelitis epidemics occurring between 1955 and 1962.<sup>1</sup> This has been attributed to the success of childhood vaccination. However, Polio Australia estimates that 'there are tens of thousands of polio survivors experiencing the late effects of polio'.<sup>2</sup> In 1993, Polio New Zealand estimated that there were between 3000 and 5000 people living in New Zealand who had post-polio syndrome (PPS).<sup>3</sup> Overall these figures include an estimated high prevalence among migrant populations, including women of childbearing age.<sup>4</sup> Here it is important to note that although polio was eradicated in Australia and New Zealand, this was not the case in many parts of the world. Consequently, the age range of potential patients experiencing the side effects of polio can include many relatively young people in migrant communities.<sup>5</sup>

Although poliomyelitis was highly contagious and led to paralysis, disability and death during epidemic times, its serious sequelae, known as the late effects of polio (LEoP), continue as chronic neurological and/or musculoskeletal changes or weaknesses. PPS refers to a new onset or worsening of poliomyelitis-related symptoms, such as muscle weakness, reduced respiratory function and fatigue. PPS typically occurs after a period of many years without new symptoms, and it is estimated to affect 20–75% of polio survivors.<sup>6</sup> These symptoms can be severely disabling, complicate surgery and childbirth and reduce quality of life, and require holistic management using a multidisciplinary approach.<sup>7,8</sup>

Yet, there is a widespread lack of awareness about LEoP and PPS among general practitioners (GPs) and healthcare professionals (HCPs).<sup>8-11</sup> Although there is an LEoP module in HealthPathways, its uptake is relatively low.<sup>12</sup> Furthermore, existing literature has repeatedly called for improved training on polio and PPS for HCPs.<sup>9,10</sup> Consequently, this study explored the perspectives of Australian and New Zealand GPs and other HCPs on learning about polio and its sequelae, and how this could be best achieved.

# **Methods**

This study was approved by The University of Melbourne Human Research Ethics Committee (Reference no. 1955587). The study addressed two questions: (1) what are Australian and New Zealand HCPs' views on learning about polio and its sequelae; and (2) how can knowledge translation about LEoP be enhanced for Australian and New Zealand health practitioners to better inform clinical practice?

A constructivist paradigm and descriptive (transcendental) phenomenological approach was adopted, and semistructured interviews deployed with experienced HCPs. A descriptive (transcendental) phenomenological approach is used when the researcher wants to describe the phenomenon under study and brackets their views, in contrast to an interpretive (hermeneutic) phenomenological approach, which is used when the research question asks for the meaning of the phenomenon and the researcher does not bracket their experience and prior engagement with the issues under study.13 The project, including the development of the interview questions and data interpretation, was supported by a reference group from the membership of a post-polio association.

Eleven participants (Table 1) were recruited purposively for their professional expertise with the assistance of the post-polio association reference group, which circulated recruitment information, and included four GPs, three physiotherapists, one anaesthetist, one orthotist, one occupational therapist and one social worker. All were practicing in Australia or New Zealand.

Open-ended questions (Table 2) were developed based on a literature review and with guidance from the post-polio association reference group. The structure took into account the research questions and the (busy) professional context in which the participants worked, and subsequently their likely availability. Interviews ranged from 10 to 35 minutes (median duration 20 minutes and 9 seconds). Interviews were initially offered face to face, but to allow for trans-Tasman interviews and due to COVID-19-related public health restrictions in Australia, only one interview was conducted in-person, with the further 10 conducted via video conferencing.

Interviews were audio recorded and transcribed for analysis using NVivo-12 (QSR International). Data were initially inductively coded to create a coding tree and themes were developed from the codes. As data were reviewed and a team consensus built, themes were also iteratively reviewed, refined collectively and grouped deductively in relation to the research questions. During this process, all three authors reviewed the data, conciliated the emerging themes and consulted the reference group. Themes were subsequently triangulated with previous research.

In the development of the interview schedule and subsequent analysis, the professional positioning of the researchers was taken into account: a Masters of Public Health candidate previously trained as a GP, a clinical psychologist involved in health promotion for people with disability and an academic medical practitioner.

**Table 1. Participants** 

### **Results**

Four key themes and six subthemes were elicited and organised into two categories in relation to the research questions. Both data saturation and theoretical saturation were determined to have been reached, based on the recurrence of data, and these data could be readily incorporated into existing codes (Table 3).

Under the first category, views on learning about LEoP, two themes were identified: competence to achieve good patient outcomes (with two subthemes: in polio-survivors in general; and in immigrant populations); and building a supportive patient-practitioner relationship.

Under the second category, factors influencing the uptake of professional development about LEoP, two themes were identified: motivating and supportive factors (with two subthemes: having a choice of education and training modalities; and interests and relevance to professional practice) and limitations and boundaries (with two subthemes: system related; and health professional related).

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Participant	Profession	Country of practice	Professional experience* (years)
HP1	Anaesthetist	Australia	>15
HP2	GP	Australia	>15
HP3	GP	Australia	>15
HP4	GP	Australia	>15
HP5	GP	Australia	>15
HP6	Physiotherapist	New Zealand	5–15
HP7	Physiotherapist	New Zealand	5-15
HP8	Orthotist	Australia	>15
HP9	Occupational therapist	Australia	>15
HP10	Physiotherapist	Australia	> 15
HP11	Social worker	Australia	5–15

\*Participant professional experience was grouped according into three categories (1–5, 5–15 and >15 years) to minimise personal intrusion and help protect identities, consistent with Human Research Ethics Committee requirements, while still providing an indication of the range of professional experience. GP, general practitioner.

#### 318 Reprinted from AJGP Vol. 52, No. 5, May 2023

# Views on the importance of learning about LEoP

Theme 1: Competence to achieve good patient outcomes

#### Subtheme 1: In polio survivors in general

Some participants, particularly the non-medical clinicians, explained how diverse needs existed among polio survivors. Hence, awareness about PPS and an individualised management approach were important:

There's a lot of variation within the group and the general blanket rules I find clinically don't tend to work for them, it really needs to be an individualised approach. [HP10]

Patient safety was a key issue, and some participants described how evidence could better inform their management of the increased risks associated with falls for patients with PPS:

An example would be that there was a group in Europe that recently, an orthopaedic group that reviewed all of their fractures with people with a history of polio and had found that most people that have a lower limb fracture don't actually return to their previous level of function ... this is ... extra information that we can provide to our patients to say that it's well detailed that people who do have a fall, if you have a horrific fall and break something, we know you're not going to get back, or the chances of you getting back to

# **Table 2. Interview questions**

- 1. Please tell me about how you keep your professional knowledge up to date.
- 2. How do you like to learn? [Probes: Mode of delivery and reasons for preference]
- What topics do you consider relevant or interesting? [Probe: Why?]
- 4. How important is it to you/your work to know about rare problems, such as late effects of polio and post-polio syndrome?
- 5. How would you find information should you come across a patient who might be affected by late effects of polio?
- 6. Thank you very much for your time. Is there anything else you would like to add?

your life at the moment are slim ... So for this reason we ... would prefer for you to start considering what gait aides or what orthotics you can use. [HP10]

#### Subtheme 2: In immigrant populations

One participant noted that a significant number of polio survivors were immigrants and much younger than the Australian-born polio survivors. This participant also explained that immigrants were less likely to declare a history of polio because of stigma and concerns regarding potential implications for their visa status:

So therefore, we've got ... as many people coming in under 66 as over 66. What is also interesting, and the ones under 66 they're coming from countries that may have had poorer health. ... It's also a disease of shame, so families may not want, they may be isolated from their community, and it may not be in their interest to get a diagnosis. Then to migrate here it's not going to be in your interest to be declaring that as part of migration. So, we expect amongst the younger population of people, that there is likely to be a whole lot of people that actually do not have a diagnosis. [HP9]

This participant also explained that it was important to be aware of the increased risks that PPS posed to anaesthesia, pregnancy and childbirth in female polio survivors of childbearing age:

... if you've got even women of childbearing age and we have a number of clients that come to us now, that are having children, they're going to public hospitals, they may even require an anaesthetic. So, you know ... staff at large maternity hospitals, this will not even be on their radar. [HP9]

# Theme 2: Building a supportive patientpractitioner relationship

Some participants felt that listening to and a willingness to learn from their patients were the best ways to build positive patient-practitioner relationships:

I would always read things that my patients bring to show me if they thought it was important to how I managed them. [HP3] Conversely, a participant remarked that some polio survivors had reservations about educating their GPs and they expected their GPs to know about LEoP:

And most patients that we see will say that there's a lot of GPs who don't know much about it. ... When you go to a doctor you expect that doctors know something, rather than you having to educate them around a condition. [HP11]

## Second category: Factors influencing the uptake of professional development about LEoP

Theme 3: Limitations and boundaries Subtheme 3: Health professional related GP participants particularly felt that their priority is to keep up with knowledge on common conditions:

We tend to go for things that we see a lot of because we want to be up to date. ... so, things that are changing constantly, keeping up is more important than learning something new ... [HP4]

Other participants observed that time constraints are a barrier to learning:

I think ... it's that they [HCPs] can't afford to be interested unless that piques their interest and they choose to look further into that in their own time. I think that unfortunately people are time poor. [HP10]

#### Subtheme 4: System related

Some participants commented on how the lack of research funding and reliable statistics about polio survivors and LEoP (specifically PPS) in Australia and New Zealand have contributed to the belief that learning about LEoP is not relevant to clinical practice:

I think it would be really helpful if we had stats. We ... need to know that this is a real problem in our practice. We think it's someone else's problem somewhere else ... because we haven't had polio in Australia for years. [HP4]

If we were in a different field like stroke with lots of money, then there would be

researchers that would be dedicated to actually doing the research that would help us develop clinically. And we really lack that with polio. [HP10]

## **Theme 4: Motivating and supportive factors** Subtheme 5: Having a choice of education and training modalities

Participants generally undertook their continuing professional development (CPD) through a combination of modalities:

I think a mix is important. I like to do my own reading and learning to start with ... I think that then going on to either lecture style or workshop based is, I suppose tutorials, is a good way for me to solidify that knowledge and being able to discuss and maybe evolve the ideas that I have with others. [HP10]

Many participants would commonly use an online search engine to immediately fill knowledge gaps or refer to a known reputable online source for information about disease management:

I do use that [an online primary healthcare resource] from time to time when I come across something that I haven't dealt with recently, to look up the recommended referral pathways ... At the moment, well I do have one patient with post-polio, but yes, I haven't looked that up. And I think [an online primary

# healthcare resource] *is a good option for GPs*. [HP5]

Choice and flexibility to fit around other commitments were important features of CPD opportunities for most participants, particularly the GPs:

So, I think flexibility and probably trying to make it GP friendly rather than organisation friendly. [HP4]

Well, probably a lot of that will be on the convenience of it, as in, it sort of fits in with other things and you've got time to do something and that's available, then go to that. [HP5]

Work-life balance was especially important to some participants in the context of having time to dedicate to activities other than those associated with their professional practice. In some instances, the time required for professional development was reported to compete with life outside professional practice:

My quality of life away from medicine is important to me and I don't like to spend a lot of time still doing medical things. I do have to go to some all-day seminars for some education requirements for being a [GP] teacher but other than that I would choose to go to evening things that are lectures that may be a couple of hours long and then I would do online. [HP3] Most participants preferred interactive learning. However, increased experience with virtual delivery as a result of the COVID-19 pandemic had made some GPs more receptive of webinars:

Yeah. I often prefer it live, but lately I've been doing more webinars because of COVID. And actually, I've started to quite like the webinars. [HP5]

I think if this crisis has taught us anything it's the fact that we can actually meet virtually a lot more easily, we're better set up for that. [HP4]

Most participants were in favour of some form of peer-supported learning: We have clinical meetings in the practice, twice a month, where the doctors and the nurses talk about current issues and patients and complex patients, that's also a major source of learning. [HP2]

Having a specialist multidisciplinary team, we've always got someone on the team who knows more about other stuff than what I do. So, I find that it's easier to ask someone else. [HP8]

# Subtheme 6: Interests and relevance to professional practice

Most participants would be motivated to undertake professional development in topics that were directly relevant to their practice or special interests, could fill a knowledge gap or helped them keep up with knowledge:

So, there's certain areas where you're sort of motivated by things other than your immediate need, but I would think most of the reasons you go and look at a specific thing are because you've arrived at needing to look at that specific thing. I would think that the polio, post-polio thing is in that category of things that, to be honest, I'd probably not think about until I had a patient. [HP1]

It's identification of gaps in knowledge what probably motivates me at one level, and then there may be particular areas I'm interested in ... [HP9]

# Table 3. Coding structure

Categories	Themes	Subthemes
Views on learning about	Competence to achieve good	In polio survivors in general
LEOP	patient outcomes	In immigrant populations
	Building a supportive patient- practitioner relationship	
Factors influencing the uptake of professional	Motivating and supportive factors	Having a choice of education and training modalities
development about LEoP		Interests and relevance to professional practice
	Limitations and boundaries	System related
		Health professional related

In general practice, a lot of things you need to keep up to date with and in my case, well your patients tend to get older with you, so my patients are a lot of elderly patients. So, keeping up with cardiac disease, lung disease, treatments of cancer. All that stuff is really important. [HP5]

#### **Discussion**

# Why is it important to learn about LEoP?

Studies have called for better education for HCPs about LEoP,9,10 consistent with the views of polio survivors (Post Polio Victoria Inc., pers. comm., 2019). The participants in the present study, all with specialist expertise in PPS, agreed that learning about LEoP was important for the competent management of patients and fostering positive patient-practitioner relationships. Participants reported the knowledge gaps to be addressed to include falls and anaesthetic risks; the psychosocial wellbeing and quality of life for polio survivors; and a number of issues pertinent to migrant populations, especially for younger women of childbearing age.

Survivors of the Australian and New Zealand polio epidemics are now aged in their 60s and older, and the symptoms of LEoP and normal ageing can be difficult to distinguish.10 A study by Mohammad et al reported an almost doubling of the risk of falling and a greater than threefold risk of fractures in polio survivors compared with the general population aged  $\geq 65$ years.14 Similarly, that study also reports a higher prevalence of osteoporosis in polio survivors (56%) compared with the general population (10%) for those aged over 45 years, but only approximately 30% of polio survivors were taking a bisphosphonate.14 These findings are congruent with the clinical experience of participants in the present study.

Participants that provided training about PPS to regional areas described how HCPs gained confidence to consider PPS as the underlying cause for some falls after learning about PPS. Falls, especially in adults aged over 65 years, can result in morbidity requiring hospitalisation or premature admission to a nursing home, limiting independence and affecting not just physical, but also psychosocial health.<sup>15</sup> The systematic prevention of falls and fractures has proven effective and should take a high priority in polio survivors given the more challenging rehabilitation process for this cohort.

The Royal Australian College of General Practitioners' (RACGP) competency framework and the physiotherapy boards of Australia and New Zealand all recommend increased awareness of HCPs about PPS to improve the medical management and psychosocial wellbeing of polio survivors.<sup>16-18</sup> Recent studies have confirmed that a holistic and well-informed approach will increase polio survivors' confidence in HCPs and improve their overall quality of life.<sup>10</sup>

Participants in the present study observed that polio survivors expect their HCPs to know how to manage their conditions and feel they should not themselves have to educate GPs about PPS. Other studies have reported that polio survivors often felt that their health practitioners did not listen to or dismissed their health concerns.<sup>10,19</sup> Duncan and Batliwalla suggested that polio survivors' management may benefit from improved HCP communication skills.<sup>10</sup>

Internationally, research shows PPS is emerging in migrant women of childbearing age, a legacy of the low treatment levels for polio in low-income countries (LICs) and the exclusion of girls in some LICs from receiving polio vaccination or treatment.<sup>4,5,20,21</sup> The weight of this situation was recognised in a 2012 discussion paper released by the House of Representatives in Australia that identified young immigrant populations as a group at risk of developing LEOP, specifically PPS.<sup>22</sup>

Our participants' experience corroborated the literature. Migrant polio survivors are much younger than survivors from the Australian and New Zealand polio epidemics. This has implications for HCPs when caring for migrant women of childbearing age. These women may be resistant to disclosing their history of polio to avoid stigmatisation.<sup>4,23</sup> A lack of awareness of the risk of LEoP in pregnant migrant women can be problematic considering the ante-, peri- and postnatal maternal and infant risks and complications associated with a history of polio. For example, risks of pre-eclampsia and low birth weight are higher in pregnant polio survivors and their babies, and the incidence of caesarean section is approximately 5% greater than in women without a history of polio.8 Furthermore, caesarean sections require anaesthesia, which itself carries increased risks for polio survivors, such as aspiration or abnormal respiratory function; polio survivors require special pre-, periand postoperative considerations and management.7 The participants in the present study expressed concerns about maternity wards not being aware of these increased risks. It is critical for HCPs, particularly anaesthetists, to manage polio survivors competently.

# How can knowledge translation about LEoP be enhanced to inform clinical practice?

It is evident that strategies are needed to increase HCPs' awareness of LEoP, and to dispel the misconception that polio is a problem of the last century with no relevance to contemporary health services. However, there are differences between various professions with respect to the design and delivery of professional development to address knowledge gaps in LEoP. Peer learning approaches and the availability of online information appear to have potential across the different disciplines.

This study noted a difference between what drives participants of the various professions to learn. GPs primarily chose CPD opportunities that helped them keep up with the management of frequently seen conditions, whereas physiotherapists' and occupational therapists' main motivations were knowledge gaps they had identified, independent of the frequency of presenting cases. These findings correspond to those of larger studies of CPD preferences.<sup>24,25</sup>

This study found that the key factors influencing HCPs' CPD uptake are flexibility and choice of modalities. The variations in motivating factors and preferred modalities between different HCPs can be addressed with the continuing education method called practice-based small-group learning (PBSGL), which is well established in Canada and Scotland.<sup>26</sup>

Studies in New Zealand and the UK have shown that multidisciplinary PBSGL is favoured by HCPs, who appreciate both the educational and social aspects.<sup>26,27</sup> Several participants in the present study remarked that polio survivors require interprofessional collaboration and management, which is reflected in PBSGL. This type of learning is supported by the RACGP competency framework.<sup>18</sup>

Our participants regularly used either a generic search engine to fill knowledge gaps or a discipline-specific website, such as HealthPathways, designed to be used during consultations to provide diagnostic criteria and referral pathways. HealthPathways includes a module about LEoP, but none of our participants were aware of it. A recent study evaluating GPs' and allied health professionals' use of HealthPathways showed that 80-90% of the respondents found the content useful.28 However, notably, its use in New Zealand is almost threefold that in Victoria, with one of the main barriers being a lack of awareness among HCPs.28

Our participants perceived a lack of contemporary statistics about LEoP prevalence and a lack of research assessing and guiding the management of polio survivors. The RACGP's competency framework and the Australian and New Zealand physiotherapy boards promote the provision of equitable and evidencebased care.16-18 As one participant pointed out, a combined lack of workforce and funding, plus clinical work taking priority over research, impeded the production of evidence-based information about LEoP. Dedicated research funding that will produce and share knowledge, advance management and improve the outcomes for people with PPS is required.

### **Study limitations**

The impact of COVID-19 restrictions and time constraints for participants affected the number of participants able to be recruited to the study and memberchecking with participants after the interview. Future studies should explore the views of obstetricians and midwives, as well as those of HCPs with experience in working with migrant communities.

#### Conclusions

Thousands of Australian and New Zealand polio survivors are experiencing sequelae from past polio infections, many in migrant communities and including women of childbearing age. HCPs need to be aware of LEoP and PPS and incorporate this knowledge into their assessment and management of patients. A lack of awareness of LEoP and PPS, combined with time constraints for CPD, serves to perpetuate a serious gap in clinical knowledge, with potential adverse consequences for patients at risk of not being diagnosed or poorly managed.

Professional organisations could combine to develop multidisciplinary peer learning modules on LEoP. Existing online resources, such as the LEoP module on HealthPathways, could be more widely promoted. Organising dedicated symposia, such as that co-hosted by the University of Otago and Polio New Zealand (www.otago.ac.nz/wellington/ departments/medicine/postgraduate/ rehabilitation/otago714307.html), could also help with the dissemination of knowledge. Importantly, exploring the views of polio survivors and involving them in the co-development and delivery of educational materials could improve the relevance to all stakeholders involved.

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