Chronic pain is something that many people, including many individuals with post-polio syndrome (PPS), face on a day-to-day basis. In fact, from the preliminary results of our recent survey of post-polio people, we found that 373 out of 419, or 89 percent, reported at least some daily pain. Of these individuals, more than half (227) rated their average pain as being equal to or greater than five on a scale of one to 10. While it is of little comfort to those experiencing PPS, you are not alone!

Although these results are preliminary, we previously completed a survey with a smaller number of participants (63) with post-polio syndrome. In this study we also found that pain was a very common issue for people experiencing PPS. Some 91 percent of the survey participants reported pain, and everyone who experienced pain also reported that they had not been pain-free during the previous month.

Another sign that pain is a major issue for people with PPS is that, in our surveys, those who reported pain said that they have experienced pain for an average of 20 years. We also asked people about where they experience pain most frequently. People responded that they most frequently felt pain in the shoulders, lower back, legs and hips. Pain intensity was greatest in the knees, legs, wrists, lower back and head. Knowing where the most common and most severe types of pain occur is a good start to finding ways to help reduce that pain.

Another problem with pain, and why it needs to be addressed, is that it often interferes with activities that are important to people. We also asked about this in our smaller-sample survey, and found that pain interfered most with sleep and with recreational activities, mobility and normal work activities, in that order.

Finally, we found that 70 to 95 percent of those in the smaller survey had tried a number of pain treatments – heat, acetaminophen, ice, aspirin or ibuprofen, strengthening exercises – but fewer than half of the participants with pain were using any pain treatment at the time of the survey.

The next step is to investigate ways to reduce the interference of pain in important daily activities and to test what is most effective in reducing pain for most people. It’s also important to understand which coping methods are both effective and easy to use, so that people can incorporate them into their lives and continue to use them to treat their pain.

The amount of pain that people with PPS report may not surprise anyone experiencing PPS, but this is critical information to support further research about PPS pain. From such research we can determine which areas of pain are most important to target, and researchers can begin to design and test interventions to reduce the degree to which pain interferes with key activities. In future columns, we’ll discuss research findings regarding different treatment options for pain management.

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