

Module 10 – Quality of Life Research

Who Defines “Quality”?

One of the things that is unique about quality-of-life research is that it can examine a study participant’s own perceptions of how they live and how they feel, instead of only asking physicians, social workers, or other professionals to evaluate the participant.

Studies that ask participants to report how they feel use special endpoints, or measurement tools. These tools are called self-reported outcomes, or patient-reported outcomes (also known as “PROs”).

Most PROs are questionnaires that ask participants to rate various aspects of their lives, such as how they feel physically, mentally, and emotionally, or how easily they can accomplish daily activities. By asking participants to rate how they feel or function, PROs can provide a picture of how an intervention—like a product or service—actually affects day-to-day life.

But just because a study uses PROs does not guarantee that the research measures things that are important or even relevant to people with an SCI. PROs that are designed without input from people with lived experience may leave out important aspects of quality of life, or may include questions that aren’t relevant to people living with an SCI. Research that uses endpoints like this are less likely to lead to guidelines that are effective, or programs, services, and treatments that really help.

Here’s a real-life example. Some SCI clinical trials have used PROs that were originally developed for the general population. The reason these PROs were used is that there weren’t tools specifically developed for SCI that had been thoroughly tested, or “validated,” to ensure they were accurate and reliable.

The existing PROs were well validated in the general population. But they contain material that may be irrelevant or inappropriate in SCI. For example, one asks about running or climbing several flights of stairs, and another asks participants if they are so content with life that they would not change anything. These PROs leave out other areas of health and functioning that would be relevant for an individual with an SCI. Because of these shortcomings, these general PROs might not be sensitive enough to detect changes in functioning or overall health for individuals living with an SCI.

Some PROs have been developed specifically for SCI. But they often have a narrow focus that makes them inappropriate for use in studies that enroll a diverse population of participants. For instance, the Quadriplegia Index Function is not applicable to individuals with paraplegia.

As we've learned in the modules on SCI Biology and Aging with an SCI, a spinal cord injury can lead to a broad constellation of physical and psychosocial secondary complications, in addition to impaired sensory and motor function. Many of these have profound effects on quality of life that could lead to new topics for research, or new PRO measures that could help detect changes that would improve the lives of people with an SCI.

SCI research advocates can help design PROs that are more relevant and meaningful to different populations of people with spinal cord injuries so that quality of life studies in SCI are more useful to the community. Advocates also can suggest ways to test or validate new PROs that might be more appropriate.

Next we'll talk about some important things to consider when developing new ways to measure quality of life.