

Module 10 – Quality of Life Research

Introduction to Quality of Life Research

Not all SCI research is focused on developing new therapies. In fact, an enormous amount of research is focused on other ways to improve the well-being of people living with SCI. Sometimes this research is referred to as “quality-of-life research,” or QoL for short.

Quality-of-life research is important to the SCI community because it is used to develop recommendations and guidelines for every aspect of health, clinical care, and rehabilitation. It also is used to design social and support services, and to identify problems that can affect a person with an SCI. This information can then be provided to people who are newly or recently injured to help them understand and anticipate how their injury and its treatment may affect them.

Quality-of-life research may examine almost any aspect of participants’ lives. Common examples in SCI research, in no particular order, include:

- physical, mental, and spiritual health;
- nutrition and diet;
- physical activity;
- relationships;
- social belonging and support;
- education status;
- work environment;
- financial status;
- sense of security and safety;
- freedom and independence;
- autonomy in decision-making;
- accessibility;
- and physical surroundings.

Often, quality-of-life studies test the ability of a program, service, product, or treatment to improve how people live.

Sometimes, clinical trials of drugs or devices may include one or more quality-of-life endpoints as a way of evaluating a therapy's overall impact on people's well-being. As we learned in the module on Understanding the Research Process, an "endpoint" is a specific measure of safety or efficacy used in a research study.

Quality-of-life endpoints can help demonstrate a treatment's benefits by showing an improvement in how someone feels or functions in their daily lives. In post-market studies of drugs or devices that are already approved, quality-of-life data may lead to changes in the way medical products are used or the way healthcare is practiced.

Because QoL research affects every type of care and service provided to people living with SCI, it is crucial that people with lived experience are involved in designing it. In fact, the question of who decides what to study and how to measure quality of life is one of the biggest factors in determining how useful quality-of-life research will be. The other big factor is deciding who is or isn't invited to participate in studies. As we've discussed throughout this course, priorities may differ for each individual living with an SCI.

Research advocates therefore have an extremely important role to play in ensuring that quality-of-life research is focused on answering the most important questions, and studying them in ways that truly capture the lived experience of SCI. It is also important for research advocates to help interpret how the outcomes from research studies could affect quality of life.

In this module, you will learn:

- How quality-of-life research is different from other kinds of SCI research;
- Some of the unique challenges of quality-of-life research; and
- How research advocates can improve quality-of-life research.