

## Purpose

The purpose of this study is to generate a synthesis of narrative research in the area of spinal cord injury (SCI) rehabilitation in order to determine how existing qualitative studies can inform research and rehabilitation practices for SCI survivors.

## Background

Approximately 12,000 people experience a new SCI each year in the United States. The average life expectancy for this population continues to increase, but among survivors, more than 99% of people experience chronic conditions<sup>1</sup>. Rehabilitation needs are extensive, yet the duration of services is decreasing<sup>1</sup> under restrictions of medical payment systems<sup>2</sup>. As a result, **it is critical to identify how real life experiences can support rehabilitation services and inform therapeutic goals.**

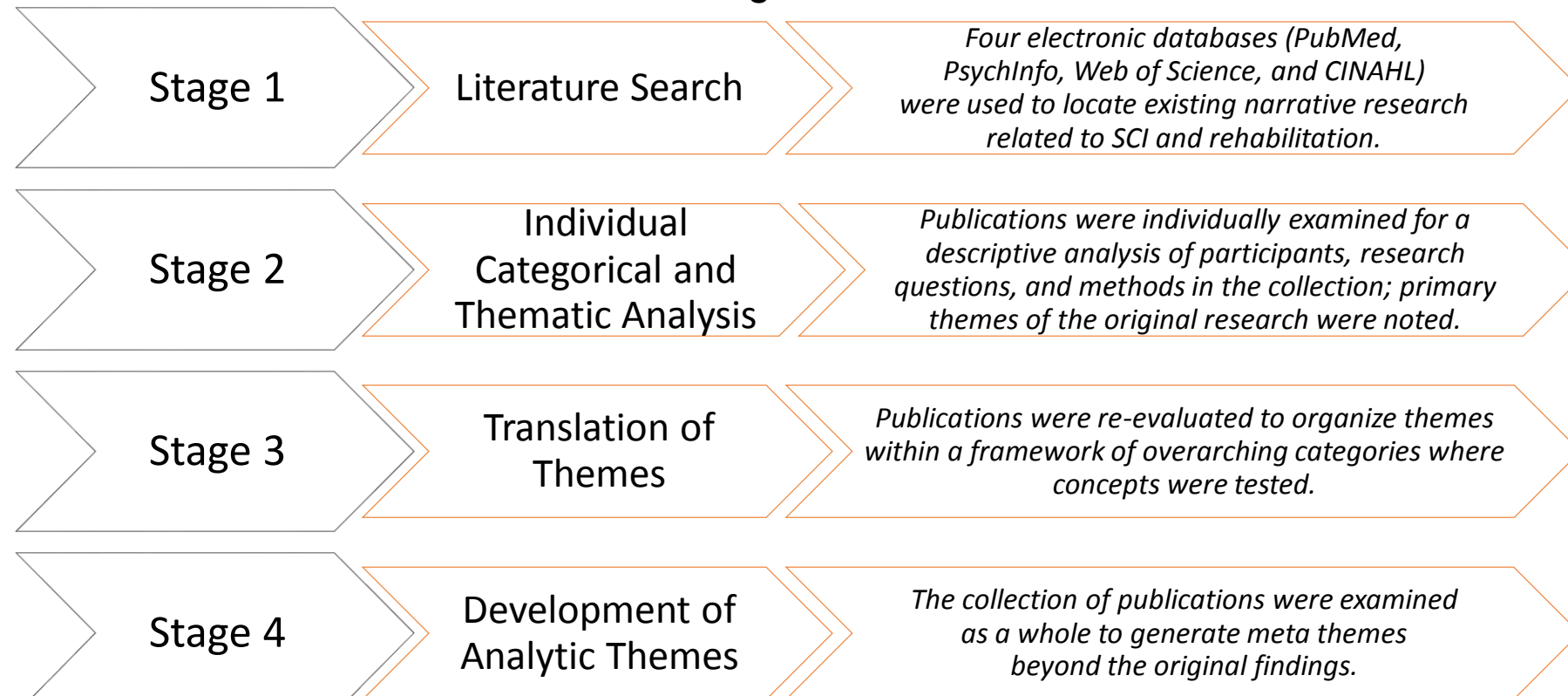
A ubiquitous challenge in rehabilitation and disability research is rooted in the methods by which experiences are defined. With quantitative measures dominating the gold standards of rehabilitation research<sup>3</sup>, individuals' functions, experiences, and feelings are typically outlined in uniform surveys or assessment scales<sup>4</sup>. By default, this means that a person is limited to reporting only within the range of values<sup>5</sup> provided. Scales can bias results<sup>6</sup> and also neglect heuristic perspectives.

**Narrative research** is a qualitative method, which often draws on interviews to collect rich data about lived experiences specific to a given phenomenon<sup>7-8</sup>. Analyses of individual narratives within- and across cases are used to understand particularities of experiences and to reveal unique dimensions of a given problem.

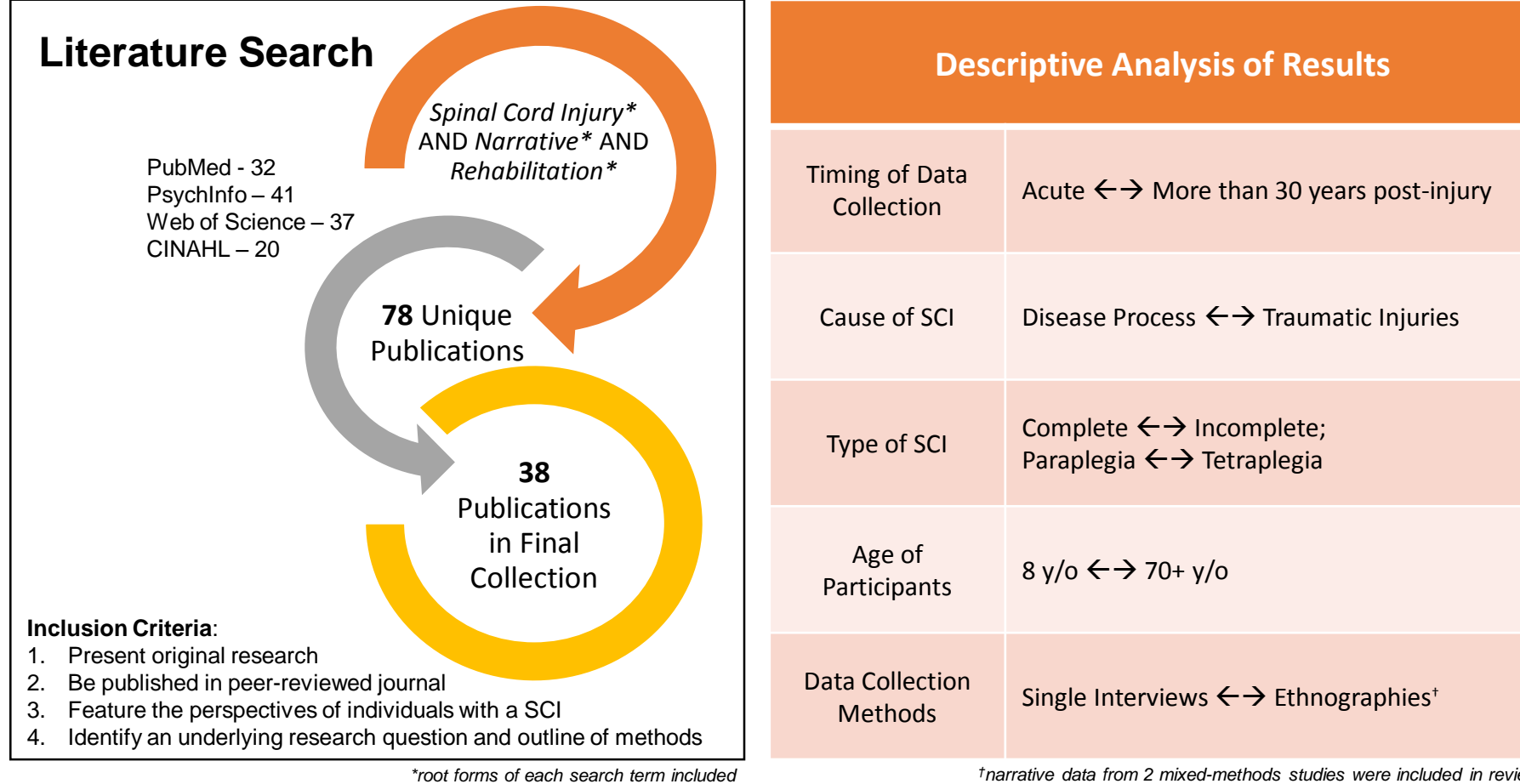
## Methods

To facilitate an informed and nuanced description of individual experiences after a SCI, and to understand how personal experiences can guide the organization, usability, and acceptability of rehabilitation services, a qualitative synthesis of narrative research in SCI rehabilitation was completed with a method informed by the work of Thomas and Harden<sup>9</sup>, as well as by Walsh and Downe<sup>10</sup>.

The methods were divided into four stages:



## Results



The collection of results generated strong evidence for implications of SCIs, which extend beyond traditional models of rehabilitative care to affect identity and engagement in daily life. Although individual experiences after a SCI were variably described, **this synthesis revealed the potential of a SCI to significantly shift one's position, perspectives, and priorities in life.**

Through iterative analysis within- and across studies, themes were developed and organized into the categories below.

- **Changed Selves:** After a SCI, changes in physical function, roles, relationships, and community participation can lead to a survivor feeling differently about him/herself and needing to "restore" or "reestablish" his or her life. (e.g. 11-14)
- **Priorities and Engagement, Redefined:** Changes in function and energy after a SCI can cause reappraisal of a survivor's priorities and engagements. (e.g. 15-17)
- **Relativity of Experiences:** A SCI is individually and relatively experienced; it marks a significant event in one's life, against which other experiences come to be referenced. (e.g. 14,18-19)
- **Secondary Health Conditions:** Secondary health conditions associated with a SCI present complex challenges, and they are common sources of frustration. (e.g. 20-22)
- **Sexuality, Gender, and Romantic Relationships:** Numerous narratives depict ongoing struggles for SCI survivors in the areas of sexuality and gender, which influence relationships. (e.g. 17,23-24)
- **The Impact of Place:** Physical space has a significant impact on psychosocial experiences after a SCI. Many survivors depict the hospital as a safe space for exploring disability, while the community can generate more discrepancies between individual abilities and environmental demands. (e.g. 16,25-26)
- **Scope of Rehabilitation:** For some survivors, rehabilitation is a finite period immediately following their injuries, while for others, it encompasses time, experiences, and needs years after injury. (e.g. 16,27)
- **Regaining Control:** A SCI can make survivors feel as if they have lost control. Therefore, control, or autonomy, is a common goal, which requires continuous negotiation. (e.g. 13,26,28)
- **Early Experiences, Long-term Implications:** Chronic SCI survivors remarked on the importance of early experiences to build competence and confidence. (e.g. 29-31)
- **Relationships with Healthcare Providers:** Attitudes and treatment from healthcare professionals influences the ways in which people view themselves after their SCI. (e.g. 32-34)
- **Age-Related Considerations:** The timing of an injury in one's life contributes to differences in experiences and outcomes. (e.g. 28,35-36)

## Implications for Rehabilitation

The collection of narratives and overarching themes illustrate the value of narrative data for research and intervention development for individuals with a SCI.

- Beyond motor and sensory dysfunctions, rehabilitation services must address psychosocial implications that result from a SCI, including a changed sense of self and disrupted relationships.
- Rehabilitation needs for individuals with a SCI extend beyond traditional models of health care. The physical body, abilities, and psychosocial sequelae evolve with time and experiences.
- Narratives from individuals with a SCI are a powerful tool for generating new insights about real people in real lives.

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