

## Introduction

Seated and wheeled mobility is designed to support a person in an optimal position within a dependent or independent mobility base. Optimal positioning may be defined as orthopedic alignment, body symmetry in multiple planes, pressure distribution and mitigation, and/or increased function. Another measure of optimal positioning within a wheelchair is **comfort – otherwise referred to as the lack or reduction of pain**. Prolonged sitting can lead to pain, particularly in certain populations. This brief paper is designed to summarize current research related to pain in people using wheelchairs.

Much of the research on pain in wheelchair users focuses on people with spinal cord injuries who self-propel a manual wheelchair and subsequently develop shoulder pain (which can also involve pain in other areas). In this document, we will focus on pain experienced by people using wheelchairs, separate from self-propulsion.

Pain mitigation is very important to caregivers. In a study by Heydenrijk-Kikkert, et al., 2023, 79% of caregivers indicated that addressing pain was “very important.”

## Pain Prevalence

People with conditions which include increased muscle tone, spasticity, and/or large uncontrolled movement (i.e., dystonia) are likely to experience pain in their wheelchair seating system.

- 3 in 4 children with cerebral palsy experience pain (CPARF, 2023).
- 75% of adults with cerebral palsy experience chronic pain according to the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM, 2023).
- According to a 2020 study from BMC Neurology involving 3,545 children and adolescents with cerebral palsy, 42.5% of patients reported experiencing some type of pain (Eriksson, et al., 2020).
- Frank and De Souza (2017) conducted a study which looked at individuals with cerebral palsy (GMFCS levels IV and V) who use power wheelchairs. Of the 102 participants, 20 reported problematic pain (20%) with 18 of the 20 participants requiring medical management of significant pain (90%).
- A study of 252 participants, aged 3 to 19 years, across all levels of severity of cerebral palsy found that 54.8% of participants reported some pain (Penner, et al., 2013). Further, 24.4% of caregivers reported participant pain that affected level of activity, and 38.7% of physicians reported participant pain.
- Novak, et al. (2012) performed a systematic review with meta-analysis of 30 studies on cerebral palsy and found that 3 out of 4 children with cerebral palsy were in pain.
- Another group of researchers (Kembhavi, et al., 2011) reviewed 12 studies on pain in adults with cerebral palsy and found the three most common themes were 1) prevalence of pain, 2) the effect of pain on functional activities, and 3) coping or intervention strategies for pain.

Research has shown that up to 75% of people with cerebral palsy experience pain.

## Pain Etiology

- Pain is often a result of the impairments that are associated with cerebral palsy, i.e., contractures, abnormal postures, dystonia, skin breakdown, hip subluxation or dislocation, and scoliosis. This pain can affect a child’s behavior, their ability to do things for themselves and their social relationships.

Children might avoid day-to-day tasks that are important for independence, such as attending school and social events (CPARF, 2023).

- A 2020 study (Eriksson, et. al) examined pain levels of cerebral palsy clients from ages 4 to 18 and found:
  - About two-thirds of clients said their pain affected the performance of daily activities.
  - Female clients had a higher risk of experiencing cerebral palsy pain.
  - Clients with higher level Gross Motor Function Classification System scores (which tests overall mobility) had a higher risk of pain.
  - The feet and lower leg area was the most common region for pain, followed by the hip and thigh area.
- Lyons (2017) found that discomfort increases over the time an individual is unable to change their position in the wheelchair.
- Frank and De Souza (2017) found that pain in individuals with cerebral palsy using power wheelchairs was caused by spasticity, spinal curvatures, and/or back and hip pain.
  - Penner, et al. (2013) stated that physicians identified hip dislocation/subluxation, dystonia, and constipation as the most frequent causes of pain in wheelchair users in their study.

Pain may be caused by lack of movement or be related to the wheelchair itself.

- Over half of the participants in the Frank and De Souza 2012 study reportedly believed that their pain was related to the wheelchair itself.

### **Pain Interventions**

Typically, we respond to discomfort in sitting by changing our position.

- Movement within the wheelchair, such as Dynamic Seating, can reduce client pain (Lange, 2021; Lange, et al., 2021).
- If a wheelchair user is unable to change their position, discomfort increases over time (Lyons, 2017).
- Many wheelchair users must rely on caregivers to note and intervene to alleviate their pain, particularly if the user is non-verbal and/or has intellectual disabilities (Lyons, 2017).
- Dicianno, et al. (2015) reported that use of the tilt feature on wheelchairs can reduce pain.
- Frank and De Souza (2012) indicated that changing position relieves discomfort.
- Use of appropriate seating interventions, as well as competent seating assessment, may also reduce pain (Frank and De Souza, 2012).

Movement and changing position can reduce pain.

### **Conclusions**

Research has demonstrated a strong prevalence of pain among wheelchair users, up to 75%. Most of the studies focused on wheelchair users who have cerebral palsy, though pain may occur in anyone who is unable to change their position (Lyons, 2017).

These studies found that the following factors may contribute to pain: contractures, abnormal postures, dystonia, skin breakdown, hip subluxation (partial dislocation of the hip) and scoliosis (CPARF, 2023; Frank and De Souza, 2017; Penner, et al., 2013) spasticity (Frank and De Souza, 2017), and constipation (Penner,

et al., 2013). Pain, or the relief of pain, was also linked to seating and wheeled mobility equipment (Frank and De Souza, 2012).

Several sources concurred that movement and/or a change in position can alleviate pain (Lange, 2021; Lange, et al., 2021; Lyons, 2017; Frank and De Souza, 2012). Several sources specifically found that dynamic seating can reduce client pain (Lange, 2021; Lange, et al., 2021).

Pain is common in wheelchair users. Wheelchair seating strategies to reduce that pain certainly include traditional seating interventions. Another important factor which can alleviate pain is **movement**. For wheelchair users unable to move within their wheelchair seating system (perhaps due to inability or required postural supports), movement can be provided through other technologies, including **dynamic**

Movement can be provided though other technologies, including Dynamic Seating.

**seating**. Dynamic seating is movement which occurs within the seat and/or wheelchair frame in response to force from the user. Dynamic components absorb force which, in turn, assists the user back to a starting position. Movement can be provided at the hips, knees and head.

A critical goal of wheelchair seating and mobility evaluation is to alleviate user pain.

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### ***About the Author***

Michelle is an occupational therapist with 35 years of experience and has been in private practice, Access to Independence, for over 15 years. She is a well-respected lecturer, both nationally and internationally and has authored numerous texts, chapters, and articles. She is the co-editor of *Seating and Wheeled Mobility: a clinical resource guide* and former NRRTS Continuing Education Curriculum Coordinator and Clinical Editor of *Directions* magazine. Michelle is a member of the Clinician Task Force. Michelle is a certified ATP and SMS.

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