

Fakultät für  
**Psychologie**

Christina Weckwerth

# **Using Eyetracking to Enable Cervical Spinal Cord Injured Mechanically Ventilated Patients to Report on Pain, Needs, and Appraisals**

Dissertation

# **Using Eyetracking to Enable Cervical Spinal Cord Injured Mechanically Ventilated Patients to Report on Pain, Needs, and Appraisals**

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Christina Weckwerth, M.Sc.

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*Meinen Eltern und meiner Schwester gewidmet*

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## Publications

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In addition to the manuscripts that are part this thesis, the author contributed to the following articles related to the topics of the thesis:

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Weckwerth, C. (2023). Wege der Kommunikation bei querschnittgelähmten und invasiv beatmeten Patient:innen auf der Intensivstation. *Unterstützte Kommunikation*, pp. 36-39. VanLoeper.

### **Abstract**

Cervical spinal cord injury (CSCI) resulting in tetraplegia and subsequent permanent artificial ventilation leads to an inability to communicate orally and often also inhibits gestures and mimics. This is due to level of injury, which leads to immobility of all extremities and the destruction of the phrenic nerve, which innervates the diaphragm. The autonomous respiratory activity (also very important for verbal communication) is suspended. Patients with CSCI have been a neglected group within research. This thesis investigates the use of eyetracking (ET) technology as an option for CSCI patients to effectively report their subjective pain perception, needs and appraisals during acute critical illness in the intensive care unit. After familiarizing themselves with the use of the ET (in a practice phase), the device was calibrated and the actual test phase began. Questions about basic needs or the subjective perception of pain were shown on the display of the ET and also read aloud by the ET device. The patients answered the questions by keeping their gaze fixed on one of the proposed answer options (e.g. "Yes"/"No"). In three journal manuscripts the effectiveness of the ET could be demonstrated. The first study examined how people with CSCI cope with the current condition and future limitations. Patients were able to give multifaceted reports of their current state, such as feeling trapped or unsafe. The second study evaluated the perceptions of wearing a tracheostomy tube in critically ill individuals with acute and chronic spinal cord injury (aCSCI, cSCI). It emphasized the importance of regularly assessing the subjective perception of critically ill tracheotomized individuals in the daily routine of an intensive care unit (ICU). The third study examined the relationship of pain and pain perception in CSCI patients with reported needs and appraisals. Contrary to previous research, results suggest that pain is not a dominating factor in needs and appraisals. This thesis shows that it is possible to support communication of ICU patients who cannot communicate orally, and how. The

faceted reports on pain, needs and appraisals furthermore underline the relevance of ET usage as well as potential benefits of further research on ET-based communication in ICU patients.

*Keywords:* Cervical Spinal Cord Injury, Eyetracking Technology, Intensive Care Unit, Pain, Needs, Appraisals



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### List of Abbreviations

AAC	Augmentative and Alternative Communication
ALS	Amyotrophic Lateral Sclerosis
<i>a</i> SCI	Acute Spinal Cord Injury
ASIA	American Spinal Injury Association
CSCI	Cervical Spinal Cord Injury
<i>c</i> SCI	Chronic Spinal Cord Injury
CNS	Central Nervous System
CT	Computed Tomography
DMGP	Deutschsprachige Medizinische Gesellschaft für Paraplegiologie
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders
EMT	Eye-Mind-Theory
ET	Eyetracking Technology
FiO <sub>2</sub>	Inspiratory Oxygen Concentration
HIV	Human Immunodeficiency Virus
IASP	International Association for the Study of Pain
ICU	Intensive Care Unit
IL-1 $\beta$	Interleukin- 1 $\beta$
ISNCSCI	International Standards for Neurological Classification of Spinal Cord Injury
ISS	Injury Severity Score

MDD	Major Depressive Disorder
MLE	Major Life Event
MRI	Magnetic Resonance Imaging
NA	Negative Affect
PA	Positive Affect
paO <sub>2</sub>	Arterial Oxygen Partial Pressure
PNS	Phrenic Nerve Stimulation
POR	Point of Regard
PWB	Psychological Well-Being
QOL	Quality of Life
SCI	Spinal Cord Injury
SCIAM	SCI-Adaption Model
SES	(Theory of) Socio-Emotional Selectivity
SWB	Subjective Well-Being
TBI	Traumatic Brain Injury
TNF	Tumor Necrosis Factor
TWBS	Tracheostoma Well-Being Score
VAITS	Ventilator Assisted Individuals with Tetraplegia
WHO	World Health Organisation

## **1 Overview of Topic and Contribution**

This dissertation explores the use of eyetracking technology (ET) as a means by which mechanically ventilated patients with cervical spine injuries (injury level above the third cervical vertebra) can report their pain, needs, and appraisals. The aim is to investigate the feasibility and effectiveness of using ET as an alternative method of communication for patients with extremely impaired mobility and an inability to communicate verbally or by using their hands for writing or pointing due to cervical spine injury and mechanical ventilation. Using the ET-system, I conducted three studies to answer open questions about cervical spinal cord injured patients' pain, needs, and appraisals. In these manuscripts, fundamental psychological studies are embedded, which will be highlighted after this short introduction. Afterward, a medical overview of the spinal cord injury will be presented, including why mechanical ventilation is necessary, including a short introduction to the orotracheal and endotracheal ventilation mode, and what the important psychological outcomes resulting from a spinal cord injury are. After this theoretical introduction, an interim summary, a short overview of each research paper will be given, followed by a summary and discussion.

## **2 Fundamental Psychological Considerations**

### *2.1 Pain and Pain Transmission in Spinal Cord Injured People*

Pain, as a negative reaction to a stimulus, plays a fundamental role in the generation of emotions, often pain is also equated with emotions (c.f. Ellsworth & Scherer, 2003), which are controlled by the brain (c.f. Price, 2000). The International Association for the Study of Pain (IASP) has defined pain as “an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage” (International Association for the Study of Pain, 2023). Three

significant features of the experience of pain are acknowledged in this definition (Eccleston & Crombez, 1999):

1. Pain possesses distinctive sensory and perceptual qualities.
2. There is no definite association between pain and damage to bodily tissues.
3. Pain is an unpleasant emotional encounter.

Pain elicits avoidance and withdrawal behaviors, and we make every effort to evade this distressing and exceedingly unpleasant sensation. Our brain even has a mechanism for pain reduction through the release of the body's own opioids (Navratilova et al., 2015). Early works on pain describe the meaningfulness of experiencing pain as something constructive (Sternbach, 1969). According to Price (2000), pain can be divided into three components; (a) sensory - the raw sensation of the intensity of pain, (b) immediate emotional consequences of pain, and (c) possible long-term emotional consequences of pain (chronic pain). A different brain region is associated with all three of the above components. On the one hand, the raw sensory components of pain are conveyed via the spino-thalamic tract (ascending fiber pathway in the lateral spinal cord) to the thalamus (ventral postero-lateral part) and from there on to the primary and secondary somatosensory cortex of the brain. The emotional staining of pain is accomplished via pathways targeting the cingulate gyrus and the cortex of the insula. In contrast, the long-term emotional consequences are mediated via fiber pathways to the prefrontal cortex.

The perception and transmission of pain in patients with spinal cord injury (SCI) is unique due to the severity of the injury to the spinal cord, which disrupts the reliable transmission of sensory information from the body to the central nervous system and back. Nevertheless, patients with SCI are still able to experience pain.

Chronic pain is a common comorbidity in individuals with SCI, with Finnerup (2013) reporting that approximately 70% of SCI patients suffer from pain, and one third of them experience severe pain that significantly impacts mood and perceived quality of life. Pain experienced by individuals with SCI can be categorized into three classifications as defined by the International Spinal Cord Injury Pain Group. These classifications include: (a) nociceptive pain, further subcategorized into musculoskeletal, visceral, and other types of pain; (b) neuropathic pain, which can occur above or below the level of injury and (c) pain caused by other factors such as (e. g.) osteoarthritis in the shoulder or bladder spasms. Nociceptive pain transmission and perception in SCI patients are believed to occur in a similar manner as in individuals with intact spinal cords (Hadjipavlou et al., 2016). However, neuropathic pain transmission is different. At the level of injury, neuropathic pain is thought to result from hyper-excited neurons due to altered expression of N-methyl-D-aspartate and glutamate receptors, as well as sodium and calcium channels, increased activity of glial cells, and/or underfunction of endogenous inhibitory neurons (Hadjipavlou et al., 2016). Below the level of injury, the origin of pain is less clear. If the spinal cord is completely severed, the source of pain may be in the intact part of the central nervous system (CNS) above the injury, possibly due to spontaneous activity of disinhibiting pathways, sensitization of the spino-thalamic tract, or changes at the level of the thalamus or cortex in the brain (Hadjipavlou et al., 2016). Alternatively, the authors propose that the origin of pain may be below the level of injury, resulting from a dysfunctional relationship between the fast lateral spino-thalamic tract and the slower medial polysynaptic pathway, which may dominate after injury and cause late onset pain as well as a diffuse spread of pain perception.

This thesis also deals with needs, appraisals and well-being in patients with SCI. The following sections will present these aspects in more detail.

## *2.2 Appraisals, Needs and Well-Being of Spinal Cord Injured People*

A SCI-Injury is a life changing and emotionally overwhelming experience with a high psychological impact. Le and Dorstyn (2016) demonstrated that people with a SCI have a higher probability to develop mental health issues. Dealing with this severe injury requires coping and adaption processes.

Diverse models try to explain the complex mechanism of psychological adaption to illness and disabilities (Livneh & Martz, 2012). One is the SCI-Adaption Model (SCIAM; Craig & Tran, 2008). The SCIAM is defined as a complex multidimensional and temporal process, which also combines elements from the Biopsychosocial Model (Engel, 1977), the Stress Appraisal and Coping Model by Galvin and Godfrey (2001) and the Transactional Model of Stress and Coping by Lazarus and Folkman (1984) and therefore unites psychological, biomedical and social factors (Craig et al., 2017). These combined factors influence the adaption outcomes, which are also mediated by primary appraisal and coping strategies (Galvis Aparicio et al., 2021). Primary appraisals in relation to adaption following SCI have been widely studied (c.f. Post & van Leeuwen, 2012). Bonanno et al. (2012) pointed out that challenging appraisals as opposed to threat appraisals can lead to greater life satisfaction and lower depression symptoms. In 2010, Kennedy et al. examined the connection between psychological health, coping and appraisals. The authors stated, that appraisals and coping strategies are close related to psychological distress and also are significant predictors of depression, even 21 years post-injury (Kennedy et al., 2016). This implies, that cognitive appraisals in the early phase of injury influences future psychological outcomes (Kennedy et al., 2009).

The patients' lack of ability to speak naturally leads to the inability to express their needs. It should not be forgotten that these patients still have needs and want to



experience their fulfilment. Previous research reports little to nothing on the needs of mechanically ventilated patients with cervical spinal cord injury (CSCI). In a pilot study by Duffy et al. (2018), basic needs were assessed in  $n = 12$  mechanically ventilated patients using ET and communication boards. The authors asked the patients about pain experiences, satisfactory positioning, room temperature, and whether there was a need for suctioning. Additionally, they were asked if there was anything else they needed. The answers by the patients were given via head nodding as the primary communication form, although five patients were able to write. Important to mention is that none of the patients had a cervical spinal cord injury. It turned out that 83% of the patients had needs beyond basic needs. These needs included spiritual, physical and environmental (e. g. television), as well as physiological aspects, like hunger or thirst. It should be noted that the sample size was very small and none of the patients had a diagnosis of CSCI.

In addition to the severity of the injury and the resulting physical and psychological consequences, experiencing pain and unmet needs can further negatively impact the well-being of patients with CSCI.

### *2.3 The Concept of Well-Being*

In this dissertation, the focus is on the *well-being* of SCI patients in the intensive care unit. Well-being is a multifaceted concept that encompasses both physical and mental health, as well as a sense of purpose, happiness, and contentment in life (c.f. Eid & Larsen, 2008; Kahneman, 2003; Ryff, 1989). First, a short historical overview of the well-being concept will be given.

#### *2.3.1 Historical Classification of Well-Being*

The question of what makes a life worth living has been contemplated since antiquity (McMahon, 2008). In the following, the concept of well-being will be

historically classified. In 440 BC Herodotus wrote about King Croesus of Lydia, who was convinced that he was the most fortunate person in the world, until he met the wise man Solon and his attendant. Solon suggested to King Croesus that many people without great possessions or wealth were more blissful (McMahon, 2008; Oman, 2021). Herodotus (440 BC) used several terms to describe what King Croesus was looking for, or rather what he was convinced he already possessed. These were, on the one hand, the ancient Greek terms *albios*, *eutychia* and *eudaimonia*, which meant happiness or bliss. The most significant term, however, is *eudaimonia*, which became increasingly important in subsequent years and is still significant today (McMahon, 2008).

### *2.3.2 Hedonistic and Eudaimonic Well-Being*

Hedonistic and eudaimonic well-being are subjectively perceived components of well-being (Omann et al., 2017). Like the term *eudaimonia*, the term *hedonia* dates back to ancient times. In classical view, these two concepts were considered opposites and independent of each other (Omann et al., 2017). Hedonistic well-being is the result of maximizing pleasure and joy while minimizing pain and suffering. It includes the cognitive pleasure we felt, for example, when we achieve a goal (Ryan & Deci, 2001; Venhoeven et al., 2013). Both Ryan and Deci (2001) and Henderson and Knight (2012) postulated that pleasure and happiness arise from the totality of hedonistic moments. Accordingly, *hedonia* is considered synonymous with well-being, whereas *eudaimonia* should be clearly distinguished from this perspective (Oman, 2021; Omann et al., 2017). Focus of the eudaimonic concept captures the experience of meaning, purpose, and significance (Omann et al., 2017). Henderson and Knight (2012) postulate that *eudaimonia*, based on Aristotle's ideas, should be viewed as an expression of virtue and the pursuit of purpose. Ryan and Deci (2001) expand this notion a bit further, describing *eudaimonia* as realizing the potential that lies within

oneself and living in harmony with one's true self. Thus, well-being in the eudaimonic sense can be achieved through the pursuit of personally meaningful goals that arise from intrinsic motivation (Ryan & Deci, 2001; Ryff & Keyes, 1995). Nevertheless, it must be noted that a life focused on eudaimonia, can also have negative consequences, for example, when personal sacrifices must be made in order to achieve future goals (Spillemaeckers et al. 2011). Also, focusing purely on hedonistic goals can lead to neglecting well-being that lies in the future (Ryan & Deci, 2001; Spillemaeckers et al. 2011). The construct of subjective well-being (SWB; Diener et al., 1999) is central to capturing hedonistic well-being and the concept of psychological well-being (PWB; Ryff, 1989) represents the most significant conceptualization within the eudaimonic approach.

Ryff and Keyes (1995) described six dimensions of psychological well-being, which they termed (a) autonomy, (b) environmental mastery, (c) positive relationships with others, (d) personal growth, (e) purpose in life, and (f) self-acceptance. These dimensions later became known as Ryff's six factor model of well-being and are among the most important approaches in research on well-being.

Increasingly, interrelationships of eudaimonic and hedonic well-being are being discussed (Henderson & Knight, 2012), in which the two concepts are no longer viewed as distinct categories but as perspectives that interact with each other. As an extension to the common approach, coming from positive psychology, the concept of flourishing has been established. Here, both hedonistic and eudaimonic aspects of well-being are considered (Huppert & So, 2013; Seligmann, 2011). In the context of research on well-being, further concepts have been developed that now consider both aspects together (Diener et al., 2010; Huppert & So, 2013)

### 2.3.3 Subjective Well-Being and the Set-Point-Theory

The well-being literature examines the mechanisms and reasons behind individuals' positive life experiences, encompassing their cognitive assessments and affective reactions (Diener, 1984). Many different words have been used to describe SWB, which has initiated discussions about the precision of the SWB-term. Happiness, for example, was often used to evaluate ones overall life (Stone et al., 2013). According to Diener (1984), SWB consists of three distinct dimensions: (a) life satisfaction (LS); (b) positive affect (PA); and (c) negative affect (NA). In relation to a major life event (MLE), research about SWB has demonstrated, that MLEs can have a short- and a long-term effect on SWB (Luhmann et al., 2012). Early research about SWB proclaimed that MLEs, such as getting married or being unemployed, do not affect the level of SWB for more than a few months, because people adapt to the given live circumstances quickly (Luhmann et al., 2012). In one of the early studies about SWB, Brickman et al. (1978), compared average SWB-level of lottery winners with the SWB-level of paraplegic persons. Only weak mean level differences were found by the authors, comparing the two groups. So, their conclusion was that both groups had adapted to their specific MLE. Brickman (1971) labelled the described phenomenon as the *hedonic treadmill*, which became fundamental in various psychological theories, such as the set-point theory (Lykken & Tellegen, 1996) or the dynamic equilibrium theory (Headey & Wearing, 1989). The set-point theory (Lykken & Tellegen, 1996) states that each person's SWB has a baseline to which it returns after an MLE, for example. Using twin data, the authors estimated that 80% of the stable component of SWB consists of a heritable component. Similarly, the authors emphasized that the individual SWB level is better predicted by the SWB level of the twin than it would be by sociodemographic data, for example. This led the authors to conclude that life circumstances are negligible for the SWB level and the genetic

factor is in the foreground. Contrary to the described results, Lucas (2007a) demonstrated, that effects of MLE can persist up to many years. To this, it must be mentioned that the adaption rate to negative experiences (Lucas, 2007b) was slower than to positive experiences (Lucas et al., 2003). To sum up these results, MLEs can have a major impact on ones live, but the strength varies, depending on the life event (Luhmann et al., 2012).

#### *2.3.4 Well-being and Quality of life in Spinal Cord Injured People*

SCI, especially at the level of the cervical vertebrae, has a significant impact on an individual's physical functioning, but likewise affects their subjective well-being. Quality of life (QOL) and well-being are closely related and to some extent mutually dependent. Gaspar et al. (2012) describes these two constructs as overarching concepts that cover many different aspects. Quality of life describes a person's perception of happiness and what a good life means to them. Quality of life plays an important role in SCI patients, especially in the phase of rehabilitation (Migliorini & Tonge, 2009). Measures of objective quality of life in persons with disabilities are significantly lower than in persons without disabilities, but this is not evident for SWB (Migliorini & Tonge, 2009). Similarly, this phenomenon has been observed in patients with SCI, including those with tetraplegia and permanent mechanical ventilation (Albrecht & Devlieger, 1999; Bach & Tilton, 1994). The authors found that so-called VAITs (Ventilator Assisted Individuals with Tetraplegia) are significantly more satisfied with regard to housing and family life than tetraplegics who are not dependent on ventilation.

One approach to the above mentioned, partly contradictory, statements is offered by the disability paradox (Albrecht & Devlieger, 1999). It is derived from the salutogenetic approach by Antonovsky (1987, cited by Blättner, 2007) which attempts

to explain why people can be positive despite negative experiences. The disability paradox highlights the importance of the experiences of individuals with disabilities and their view of the world, in relation to their social context and social relationships (Albrecht & Devlieger, 1999). The paradox is that people with severe and serious and persistent illnesses report that they have a good and sometimes excellent quality of life, although some outsiders think that these people lead an apparently undignified life. To explain this phenomenon and possible contributing factors, Albrecht and Devlieger (1999) conducted semi-structured interviews with 153 individuals with disabilities. Albrecht and Devlieger (1999) provide an explanation for the phenomenon wherein severely ill individuals still report a favorable quality of life. They attribute this to the harmonious interplay and preservation of the physical, mental, and spiritual aspects of well-being, combined with the social interconnectedness of each person. Similarly, the authors discuss that the perceived high quality of life of the severely ill individuals may be due to a secondary gain that results from the condition causing individuals to re-evaluate their lives and social environment.

The findings lead to another established theory that offers an approach to explain the perceived well-being of patients with CSCI.

#### *2.4 Theory of Socio-Emotional Selectivity*

Perceiving time is fundamental in human experience and behaviour, relevant even for the evolution of human cognition (Suddendorf et al., 2009). In the theory of socio-emotional selectivity (SES; Carstensen et al., 1999), (perceiving) time as a factor is accompanied by a motivational component, contrary to other life span theories. The theory is less traditional and does not concentrate on changes over a life span in relation to the chronological age. Rather, it focuses more on the effects, which result from an alteration of the future time horizon of an individual's life (Carstensen & Lang, 2007).

So, the central message of the SES is as follows: Individuals, who experience their life as unlimited, as it is in case of youth for example, are motivated to face new information (e. g. going to a secondary school or making friends who share the same interests or even serve as role models). Contrary to that, individuals, who perceive their lifetime as limited (aged or ill persons) are motivated to achieve more emotional goals. These people distance themselves from perfunctory social relationships more often, but intensify or deepen other contacts, especially those that have existed for a longer time (Carstensen & Lang, 2007).

The SES does not state that the change in motivation to a preference towards emotional goals proceeds consciously. Such goals can have an influence on subliminal cognitive processes, such as attention control (Carstensen & Lang, 2007). If people prefer emotional goals, they lay the focus on emotional content and experience these contents more intensely (Carstensen, 1991; Carstensen & Turk-Charles, 1994). In relation to well-being, some studies demonstrate, that well-being and life satisfaction barely differ between young and older people (c.f. Diener et al., 1999).

Motivational changes in higher adulthood also influence decisions in the context of health (Löckenhoff & Carstensen, 2004). Older people tend to rely on decisions suggested by the physician or close relatives (Carstensen & Lang, 2007). Carstensen et al. (1999) were able to apply the theory to a group of seriously ill people. In 1998, Carstensen and Fredrickson studied a group of men with human immunodeficiency virus (HIV;  $M_{age} = 37$  years). They explored, the cognitive dimensions the participants used to describe similarities with social partners. The participating individuals were at different stages of HIV disease and thus had different life expectancies. The results suggested that HIV-positive, symptomatic men represented social partners almost exclusively along an affective dimension, indicating

the prioritization of emotional goals, just as older individuals did in previous studies (Carstensen & Fredrickson, 1998; Carstensen et al., 1999). Given these findings, it can be surmised that the subjective well-being of CSCI patients on permanent mechanical ventilation can be related to the theory of socioemotional selectivity and that being embedded in an emotionally positive and stable social environment is a key contributor to well-being.

The following section takes a more detailed view of the impact that SCI can have on an individual's mental health.

### **3 Psychological Outcomes of Cervical Spinal Cord Injury**

The diagnosis of SCI can certainly be called a MLE (Monroe & Slavich, 2020). MLEs are defined as “imposing substantial acute, additive demands upon the individual and possibly having a significant implication for mental and physical health” (Monroe & Slavich, 2020). In diagnosing SCI-related comorbidities, some are at a psychological level, including depression and anxiety. These two comorbidities will be highlighted in the following section.

#### *3.1 Depression and Anxiety in Cervical Spinal Cord Injured*

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) outlines the clinical aspects of depression. It states for a minor depression: two to four of the symptoms listed below must be present for  $\geq 2$  weeks (five or more symptoms are required for major depression). A depressed mood, characterized, among other things, by the withdrawal of the person or a decline in interest in activities or social contacts, must be present to fulfill diagnosis criteria. Furthermore, the symptoms must cause the person significant distress or impairment, and there should be no manic or hypomanic behavior. The following symptoms for determining minor/major depression are listed in the DSM-IV:



- Depressive mood
- Significantly decreased interest or pleasure in all/most activities
- Significant weight loss (or poor appetite) or weight gain
- Insomnia or hypersomnia
- Psychomotor retardation
- Fatigue or energy loss
- Feelings of worthlessness or excessive or inappropriate guilt
- Decreased ability to think or concentrate, or indecisiveness
- Recurrent thoughts of death (not just fear of dying), or suicidal ideation, plan or attempt

The occurrence of depression in SCI patients has been well studied to this point, however the course of depression after SCI remains unclear. Depressive symptoms, including major depressive disorder (MDD) are very common in people with SCI, and are associated with negative outcomes for the individual, therefore the Consortium for Spinal Cord Medicine recommended a clinical practice guideline for screening, diagnosis and treatment of MDD in SCI patients (Bombardier et al., 2004). Factors such as pain appear to coexist with depression, with a probability of co-occurrence of approximately 60% (Hoffman et al., 2011). Craig et al. (2017) pointed out, that nearly 30% of SCI patients showed depressive mood in the short- and long-term. However, there are some barriers, to implementation of the recommended guidelines, e. g. screening for MDD in SCI patients takes too much time and is awkward (Kroenke et al., 2001). Nevertheless, it seems essential, because as early as 2004, Bombardier and colleagues highlighted that they observed no improvement with regard to the treatment of MDD in SCI. Several authors (Khandelwal et al., 2022; Pretz et al., 2016) revealed, that no significant differences were seen between patients with paraplegia and

tetraplegia in the severity of depression and anxiety. Surprisingly, individuals with tetraplegia did not have (significantly) higher mean scores for depression and anxiety than patients with paraplegia or incomplete SCIs. Other studies, in turn, came to a contrary conclusion. Pain, as well as depression, are very present challenges for a person with SCI. The severity of the injury not only affects quality of life, but can also have biopsychosocial consequences (Hough, 2014). Depressive symptoms are sometimes associated with other conditions of the body, such as pressure ulcers (the motivation for preventive skin care is sometimes less pronounced (Smith et al., 2008), which may lead to increased medication (Elliott & Frank, 1996). In addition, Matsuda et al. (2016) stated that artificial ventilation, among other factors, is highly correlated with depressive disorder, with men having a 36% lower risk of developing depressive symptoms.

Beside depression, anxiety is a common problem in patients with SCI (Le & Dorstyn, 2016). Up to 45% of patients report fear or panic as well as excessive anxiety, symptoms that may extend to generalized anxiety disorder (Craig et al., 2017; Mitchell et al., 2008). Increased suffering and fear of secondary consequences, which can sometimes also be life-threatening (e. g. malfunctioning of the ventilator, delayed suctioning of tracheal secretions that obstruct the airways), play an important role. Additionally, mental illness before the injury also contributes significantly to the overall impact (Agar et al., 2006; Kennedy & Duff, 2001).

Prevalence data for anxiety in the context of SCI are also subject to discrepancies (Le & Dorstyn, 2016). These discrepancies may be explained by different definitions for anxiety disorder (specifically cognitive, affective and behavioral symptoms as well as physical symptoms) or subsequently the measuring instruments used. Additionally, the effects of individual factors (e. g. personality) on

psychological outcomes are discussed as well as the extent to which these factors may influence the patients' adaptation to the diagnosis of SCI. In this context, Eroğlu et al. (2022) revealed, that the Type D personality, which is characterized by negative affect, social inhibition and a high association with anxiety and depression (Dubayova et al., 2013), was associated with significantly lower scores in mental health.

In addition to the psychological impact of SCI on mental health, the severity of the injury and permanent artificial ventilation lead to another challenge: By which means can CSCI injured individuals communicate with their environment? This challenge will be highlighted in the following section.

#### **4 Communication and Communication Difficulties in Patients with CSCI**

##### *4.1 Augmentative and Alternative Communication*

For all of us, language is enormously important on a daily basis. Language is one way we express our personality. People who are dependent on mechanical ventilation lose their ability to speak and thus also a large part of how they express their personality. If the reason for the need for mechanical ventilation is a cervical spinal cord injury, many non-verbal ways of communication are also no longer available. For people with invasive ventilation, the most frustrating experience is the loss of oral communication (Yang, 2016). Some people even consider this circumstance to be dehumanizing (c.f. Baumgarten & Poulsen, 2015; Guttormson et al., 2015). Carroll (2007) conducted interviews with people who had been dependent on mechanical ventilation for a number of different reasons. One patient's statement clearly underlines the feelings of the patients described above: "Being trapped in a silent world makes me feel frustrated and incomplete" (Carroll, 2007). If this statement is applied to patients with CSCI, it becomes even more significant. Happ et al. (2015) estimate that approximately 50% of the patients on the intensive care unit (ICU) are

awake enough to communicate, for example, with the nursing staff, but are not properly understood due to the existing invasive ventilation. In a conference contribution, Jansen (2020) summarizes the main emotions that non-speaking patients primarily express. These include:

- Helplessness
- Frustration
- Isolation
- Misunderstanding
- Loss of control
- and fear

Communication with nonverbal patients in the ICU can be supported or improved by augmentative and alternative communication (AAC; c.f. Elsahar et al., 2019; Hoorn et al., 2016). AAC refers to all forms of communication apart from oral speech (American Speech-Language-Hearing Association, o. D.).

The most common form of communication with non-verbal critically ill patients is lip reading or nodding. This form of communication is one of the non-tech forms within the AAC (c.f. Khalaila et al., 2011; Menzel, 1998). However, non-tech AACs are time-consuming and inefficient in terms of comprehensibility (Wojnicki-Johansson, 2001). In addition to non-tech, AAC technologies are further subcategorized into low-tech AAC (e. g. paper-pencil or writing boards) and high-tech AAC (e. g. communication via tablets or smartphones or via applications installed on them such as ET). In a pilot study with a so-called LifeVoice System in intubated patients in the ICU, Miglietta et al. (2004) showed that there was an improvement in well-being of the patients due to sharing their thoughts and emotions with the means of that system. It is important to note that tetraplegics, due to the type of injury and

the need for permanent artificial ventilation, are also unable to use picture, letter or writing boards, for example and therefore rely on alternatives. The application of ET devices offers a good opportunity to overcome this communication barrier (c.f. Duffy et al., 2018). In addition to Duffy et al. (2018), some other studies have already shown that the use of ET in invasively ventilated patients can contribute to improved communication (c.f. Ull et al., 2020, 2021). So far, the focus has primarily been on patients with neurodegenerative diseases, such as amyotrophic lateral sclerosis (ALS; c.f. Caligari et al., 2013). So far, the current state of studies on the communication possibilities of patients in the ICU with mechanical ventilation and a high CSCI is weak.

In this thesis, ET plays a central role. The following chapter will introduce the history and development of ET technology and its importance to the means of communication.

#### *4.2 The Eyetracking-Method*

This brief historical background of the ET development was taken from: Pluzyczka (2018) and Richardson and Spivey (2004). The history of eye movement recordings can be traced back to the late 19<sup>th</sup> century. Some milestones should be mentioned here: Ahrens (1891) and Delabarre (1898). Delabarre (1898) used a lever attached to a cornea with *Plaster of Paris*, which was improved by Huey in 1908 by recording lever movement on a surface covered with soot on a rotating drum. Delabarre (1898) also used a moulded cap on a *cocainized eye* with a wire attached to a lever to record horizontal eye movements on a smoked surface of a kymograph cylinder<sup>1</sup>. However, these mechanical methods faced criticism for motion impediment and eye staining. In 1901, Dodge and Cline developed a non-invasive technique using

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<sup>1</sup> A kymograph is a scientific instrument used to monitor and record changes in a variable over time.

light reflection from the cornea to record horizontal eye position on a photographic plate. This was followed by Judd et al. in 1905 who introduced motion picture photography to record eye movement in two dimensions by inserting a small white speck of material into the eye. Gilliland (1921) recorded the horizontal movement of one eye with the vertical movement of the other eye. In 1925, the first two-dimensional eye movement recording was achieved. By reflecting a light from a pearl on a pair of glasses, Miles and Shen (1925) were able to record the head position. Advancements in technology in 1930 allowed for improvements in ET systems, with the use of monocularly reflected beams and film reels to record fixation dots for two-dimensional scan paths. In 1937, Buswell refined the head tracking method using the photochronograph method. In 1948, the first head-mounted eye tracker was invented by Hartridge and Thomson, which allowed for more freedom in head movement for participants. ET was applied in usability engineering in 1950, where Fitts et al. used motion picture cameras to study pilot's eye movement during airplane landing. In 1958, the technique was further advanced with less obtrusive objects, allowing for recording of eye movements in response to visual scenes.

The initial aim of using ET was to observe the processing of cognitive tasks and attention processes (Bartl-Pokorny et al., 2013). In this context, the Eye-Mind-Assumption (Just & Carpenter, 1980) should be mentioned. The core statement of this assumption is that as soon as individuals fixate an object (e.g., text), they think about it (process it) in the same moment. Wu and Liu (2022) challenged this assumption in the context of multiple representation. In this study, referring to two or three types of representations (identification task, correlation task, prediction task, and generation task) was considered as multiple representations. The authors were able to show that there are indeed temporal deviations between the collected eye movement data and the verbal protocols. They justified the results by considering both the margin of

interpretation in argumentation tasks and the complexity of information in certain representations.

The explanation given so far on the development of the ET method primarily points to a pure tool for information gathering. However, ET has also increasingly developed into a user-friendly communication tool over the years. Especially in the application in medicine ET gets more and more meaning and importance, as this thesis confirms. Moreover, ET is a user-friendly and natural way of communication (c.f. Ull et al., 2020). ET has become increasingly important in a wide range of other disciplines, such as biometrics (e. g. Galdi et al., 2016), health services (e.g. Gold et al., 2016) and cognitive and neuroscience (e.g. Starr & Rayner, 2001).

Authors suggest, that we absorb 80-90% of information from our environment via our eyes (c.f. Zhang et al., 2017). Nowadays, ET uses a non-invasive infrared-based video method (Bartl-Pokorny et al., 2013). Infrared sensors deliver data for image analysis to assess gaze position based on identifying and locating the pupil and corneal reflection of the eye (Duchowski, 2007). Corneal reflection is generally measured by the infrared source relative to the position of the pupil (Duchowski, 2007). According to Crane (1994), these reflections are called Purkinje reflections or Purkinje images. Based on the nature of the eye, four Purkinje images are formed: reflections from the (a) front and the (b) rear surface of the cornea as well as the (c) front and the (d) rear surface of the lens. ET-systems that rely on video-based technology usually detect the initial Purkinje image (Duchowski, 2007). Today's systems usually use a digital camera embedded in a screen. The focal distance of approx. 50-60 cm offers the user a good freedom of movement (Duchowski, 2007). Manual settings, such as the angle of inclination of the camera, for an optimal recording of pupillary and corneal reflection are no longer required with today's

devices (Duchowski, 2007). The newer systems also have the possibility of self-calibration by individual test subjects. This considerably simplifies and accelerates the application (Duchowski, 2007). With the correct calibration procedure, the eyetracking systems can display the viewer's so-called point of regard (POR) on the screen. To distinguish eye movements from head movements, two specific eye landmarks are required. The positional disparity between the center of the pupil and the corneal reflection alters during pure eye rotation, but it remains relatively stable when encountering slight head movements (Duchowski, 2007).

#### *4.3 ET in Critical Care Environments*

In modern healthcare settings, interactive medical devices and information systems have become ubiquitous, particularly in the ICU (Klausen et al. 2016). ET has emerged as a promising tool for gaining insights into psychological parameters such as situational awareness or cognitive processes (c. f. Klausen et al. 2016; Rogers et al., 2005). The use of ET in the ICU presents several challenges such as changing distances, varying brightness values from extreme ranges of light or rapid eye-movement (Tien et al., 2015). Despite these challenges, recent advancements in ET-Technology have resulted in improved accuracy and reliability, making it a viable option for studying human behavior and cognitive processes in medical environments (Klausen et al., 2016). ET-Systems can provide quantitative data on perception, attention, and awareness, which can aid in understanding the cognitive workload and stress levels (Atkins et al., 2013). Klausen et al. (2016) summarized in their review on the applicability of ET-systems in critical care environments that an ET-system can be used for individuals with disabilities and also as a diagnostic tool for depression, for example.



In the past, the use of ET was mainly limited to laboratory experiments (Jacob & Karn, 2003). In the course of development, ET-Systems found diverse and interdisciplinary applications. In severe diseases, the technology was primarily used in patients with neurodegenerative diseases (especially ALS patients) to improve communication (Ball et al., 2010; Spataro et al., 2012). Some studies have shown that the acceptance in ALS, especially those with very bad health condition, was high (Ball et al., 2010; Calvo et al., 2014). A few first cases about applications of ET-Systems in the intensive care unit have been recently reported (Garry et al., 2016).

Effective communication between doctors, caregivers, and patients is essential during severe illness (Garry et al., 2016). It is important to mention that 40% of ICU patients depend on mechanical ventilation. Therefore, verbal communication is impossible (Wunsch et al., 2013). Not being able to communicate is a significant hurdle for physicians, nurses, and patients, and in addition, it leads to a high degree of anxiety, loss of control, and frustration (Carroll, 2004; Finke et al., 2008). In addition to Garry et al. (2016), Ull et al. (2020, 2021, 2022) show that applying ET in severely ill and mechanically ventilated patients can improve communication possibilities, psychosocial status, and quality of life.

A commercially available ET device (Tobii Dynavox I-15+) was used for the study (Tobii Dynavox, Danderyd, Sweden). The ET device was mounted on a movable bracket, which allowed flexible use. Equipped with integrated infrared sensors and a camera, the ET device captured images of the user's eyes. Using special algorithms, the system calculated the point of view, displayed it on the monitor and allowed patients to respond to questions by simply moving their gaze like a mouse pointer.

To conclude this overview, a brief medical introduction to SCI follows. Additionally, some physiological consequences that can result from this injury will be described briefly.

## **5 Medical Overview of the Spinal Cord Injury**

### *5.1 Epidemiology and General Considerations*

According to a World Health Organization report, 15% of the world's population suffers from a disability, and still 0.1% from SCI, with devastating consequences not only from a medical perspective (World Health Organization: WHO, 2013). It is often only a few seconds, in case of a traumatic event, that can fundamentally change one's life from one day to the next. Around 140,000 people in Germany live with SCI. This includes an annual growth rate of 2,400 to 2,500 people (FGQ [Fördergemeinschaft der Querschnittgelähmten], 2020). The average age at the onset of injury was 60.5 years in 2019 (FGQ [Fördergemeinschaft der Querschnittgelähmten], 2020). SCI may present with lesions on varying levels of the spine. Despite all the negative consequences that can result from spinal cord injury, this circumstance does not necessarily contribute to a reduced quality of life (*Querschnittlähmung - Internationale Perspektiven*, 2014).

SCIs may result either from a traumatic event (penetrating or blunt trauma) or from non-traumatic episodes. In 2018, the ratio of traumatic to non-traumatic causes of SCI was 45% to 55%. Traumatic causes include traffic accidents (33%), falls (29%), work accidents (14%), bathing accidents (1%), recreational accidents (7%), suicide attempts (3%), violent crimes (1%), other causes (2%; Hirschfeld, 2020). The lesions of the spinal cord are mostly associated with injuries of the bony or ligamentous spinal column, as the spinal column not only fulfills a supporting function but also protects the myelon located within the spinal canal. In the event of injury to the bony and

ligamentous structures surrounding the myelon, concomitant injury to the spinal cord may be significant and more important than the skeletal injuries (Högel et al., 2016). The severity of the SCI depends indeed also on the injury to the bony structures or the compression of the spinal cord but much more on the extent of the neurological deficit.

Atraumatic causes include inflammation (38%), vascular and intraoperative complications (32%), tumor disease (19%), degenerative processes (9%), or others (2%). The proportion of traumatic spinal cord injury was 84.5% in the past (Högel et al., 2016). However, due to the increasing age of the population, atraumatic causes of SCIs are becoming more frequent. At the level of the cervical spine, for example, retrospondylarthrosis (degenerative alterations of the vertebral articulations) can lead to compression of the spinal cord in older people (Högel et al., 2016). In addition, a number of comorbidities (which are more frequent in the elderly population) prevail in individuals suffering of spinal cord injury, including mental health disorders (primarily depression), as well as cardiovascular or metabolic dysfunctions (Lavis & Goetz, 2019). Thus, the proportion of atraumatic spinal cord injury recently increased to 51% (Hirschfeld, 2020). The consequences of a SCI on a person depends on many factors, including the type and severity of the injury, the age of the person, comorbidity, or activities before the accident (c.f. WHO, 2013). A SCI can be classified in two types: incomplete and complete SCI. In incomplete SCI, residual spinal cord function is still present so that some information can be transmitted through the spinal cord to the brain and back to the body periphery. In complete SCI, there is no communication between the spinal cord and the brain below the level of injury. In general, it can be said that the higher the location of the spinal lesion, the more pronounced the possible damage.

### *5.1 Pathophysiology of the Spinal Cord Injury*

Pathophysiologically, traumatic SCI can be divided into primary and secondary injuries. Further categorization can be done in phases: The acute phase is liable to a period of <48 hours, the subacute phase is 48 hours up to 14 days, the intermediate phase, begins 14 days after the event and can last up to 6 months, and the chronic phase starts after a duration of 6 months (Ahuja et al., 2017).

#### *5.1.1 Acute Phase – subacute Phase*

Vertebral fractures or ligamentous injuries (lacerations of the ligaments that hold the joints together, leading to, among other things, instability) result from the primary traumatic event. Consequently, compression, partial, or complete transection of the spinal cord occurs. In the further process of the injury, neurons and oligodendrocytes are damaged, as are the surrounding vasculature and blood-spinal cord barrier (Ahuja et al., 2017). The events described trigger another cascade of injury. Secondary injury consequences may induce cell dysfunction or cell death. Furthermore, vascular injury can cause severe hemorrhage. Due to the abolition of the blood-spinal cord barrier, increased inflammatory cells producing proinflammatory mediators (e.g. tumor necrosis factors [TNF] or interleukin-1 $\beta$  [IL-1 $\beta$ ]), can now also penetrate the spinal cord (Pineau & Lacroix, 2007). The described injury sequelae after traumatic events can lead to further swelling of the spinal cord, which can extend to other spinal cord segments (Ahuja et al., 2017). In the subacute injury phase, cell death dominates the injury event. Cytotoxic byproducts can trigger further damage to the spinal cord (Ahuja et al., 2017).

#### *5.1.2 Intermediate - Chronic Phase*

Contrary to an earlier historical view (López-Muñoz et al., 2006), it has been recognized that endogenous mechanisms (synaptic plasticity) of a partial regeneration

of the spinal cord are indeed evident, so that possible functional recoveries can be observed even years after the injuries (Lynskey et al., 2008; Raineteau & Schwab, 2001). The body attempts to remyelinate the damaged spinal cord, restore the vascular system, and renew the neural circuitry (Kwon et al., 2004). The clinical manifestation of paraplegia depends on the degree of neurological damage and the extent of preserved spine and spinal cord tissue.

SCI may result in partial or complete loss of sensorimotor function below the level of injury (Ahuja et al., 2017). It may include motor functions of the muscles, sensory functions of all types of sensory nerves, and vegetative functions of the nerves serving the internal organs. So, it is not just abnormal motor skills that pose problems. Paralysis-related complications arising from the neuronal lesion must also be treated, including hypersecretion, trophic alterations of the skin promoting ulceration of the skin (decubiti), thermal, vegetative and/or cardiac dysregulations, such as the spinal shock described below (Röhl, 2002).

Injuries at the level of the cervical spinal cord can lead to neurogenic shock (Guha & Tator, 1988). Neurogenic shock refers to a drop in blood pressure after spinal injury as a result of vasodilation due to loss of sympathetic tone, sometimes in conjunction with hypovolemia (circulating blood volume deficiency), accumulation of venous blood in atonic muscles, and bradycardia (Lehmann et al., 1987; Ploumis et al., 2010). It is estimated that approximately 20% of patients with CSCI experience neurogenic shock (Guly et al., 2008).

In addition to neurogenic shock, spinal shock, which is often confused with neurogenic shock, is also an issue. Spinal shock refers to transient flaccid paralysis following spinal injury, including loss of motor and sensory function as well as

autonomic and reflex functions below the level of injury. The symptomatology of spinal shock greatly complicates the initial neurologic examination to determine the severity of spinal injury (Ahuja et al., 2017). There is disagreement about when to consider spinal shock as concluded (Ko et al., 1999).

Further, loss of innervation of secondary lymphoid organs can lead to secondary immunodeficiency (immune paralysis), which greatly increases susceptibility to infections (often urinary tract infections or pneumonia) and is among the major causes of increased mortality in patients with paraplegia (Ahuja et al., 2017).

The areas of the spine that have a higher likelihood for spinal cord injuries are the lower cervical spine (neck region) and upper lumbar spine (lower back region). Injuries to the cervical spine account for about 15% of spinal injuries, with more than 2/3 of those affected experiencing concomitant neurological symptoms. In addition, 25% of cervical spine injuries are accompanied by traumatic brain injury (TBI; Högel et al., 2016).

### *5.1.3 The Cervical Spinal Cord Injury*

When a spinal injury is present, it is imperative to determine whether a neurological deficit is present. Initial orienting examinations provide clues to the level of injury with spinal involvement. For example, a flexed position of the arms indicates an injury to the cervical cord, and the absence of responses to painful stimuli is an indicator of spinal cord damage (Högel et al., 2016). During initial emergency treatment, the extent of the neurological deficit must be determined. To do this, degrees of strength are determined on the characteristic muscles of the upper and lower extremities to assess motor function. To check sensory function, the pointed-trunk discrimination and touch sensation are tested. A reflex status is also assessed (Högel et al., 2016). The findings are documented according to the International

Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI), which includes AIS classification (ASIA Impairment Scale; American Spinal Injury Association). According to this scale, five types of spinal cord injury are distinguished (Högel et al., 2017):

- AIS type A: complete motor and sensory failure including sacral areas S4/5
- AIS type B: complete motor and incomplete sensory failure, including sacral areas S4/S5
- AIS type C: Incomplete motor and sensory function. Preserved level of strength of motor function of less than 3 (of 5)
- AIS Type D: Incomplete preserved motor and sensory function. Preserved level of strength of motor function of equal or more than 3 (of 5)
- AIS Type E: no motor or sensory deficits <sup>2</sup>

Guided x-rays of the cervical spine are important for detecting traumatic instability. Computed tomography (CT) remains the primary imaging modality for emergency diagnosis. The duration of the examination is short, but it is of note that CT does not adequately image the surrounding soft tissues, particularly the spinal cord. Therefore, the diagnostic procedure of choice is magnetic resonance imaging (MRI; Högel et al., 2016). This is the best available imaging technique to identify the type and magnitude of the spinal cord injury.

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<sup>2</sup> Level of strength of motor function with 0 signifying no motor function and 5 signifying full strength. A level of 3 signifies active movement against gravity.

The cervical spine deserves particular considerations, because the short- and long-term effects of SCI are different and graver than as compared to injuries to the lower parts of the spinal cord. There are several specific consequences that will be discussed as they involve, among other aspects severe effects on the ability of the patients to communicate with their environment. The cervical spine is divided into an upper section from C0-C3 and a lower section from C3-Th1. At the upper section the rotation of the head takes place.

The incidence of cervical spine injuries accompanied by clinically apparent neurological deficits stands at 12% (Högel et al., 2016). The injury is often fatal because the area of origin of the phrenic nerve (innervates the diaphragm) is destroyed. The phrenicus nerve originates from the cervical plexus, with fiber fractions of C3, C4 and fractions of C5 (Trepel, 2022). Due to the destruction of the origin area of the phrenicus nerve, motor innervation of the diaphragm (most important respiratory muscle) is no longer given. This may result in respiratory arrest and due to the consecutive hypoxemia in cardiac arrest. However, if the initial care at the site of the accident is excellent and respiration is secured early by the emergency medical personal, more and more patients can survive (Högel et al., 2016; Kamp et al., 2021). A failure of the respiratory muscles also results in a reduced ability to speak (Johansson et al., 2018). Due to the invasive mechanical ventilation required, depending on the level of the injury, verbal communication is almost impossible for many patients.

The goals of the acute treatment are an improvement of the neurological deficits and the prevention of an additional neurological loss of function – mainly by prompt surgical treatment (preferably within a 6-hour window). A partial to complete neurological recovery is possible in some patients. In the cervical spine, for example, the improvement of the neurological level by one segment leads to significant increase



in independence and quality of life for the patient (Högel et al., 2016). Nevertheless, depending on the level and severity of the injury, insufficiencies of the respiratory system can occur and persist, which makes mechanical ventilation necessary (Kang et al., 2006).

Of the ventilated paraplegic patients, 78.2% have a complete paralysis according to AIS type A (Hirschfeld, 2020). An intact functioning diaphragm is necessary for adequate ventilation of the lungs. For a cervical spinal cord paralyzed patient, intact diaphragmatic function is essential (Hirschfeld, 2020). Therefore, permanent or partial ventilation is usually necessary when damage occurs above C4. The percentage distribution of degrees of paralysis in the cervical spine is as follows (these values are relatively consistent): 15.5% of the cases are at level 5 C0, 1% at level 5 C1, 55.3% at level 5 C2, 22.7% at level 5 C3. In 2018, there were approximately 1,500 acute cases of SCI in Germany. Of these cases, initially around 20% of the patients required ventilation support. Within this group, approximately 30% of the patients needed long-term ventilation (Hirschfeld, 2020).

One capability that is retained in patients with CSCI, is moving the eyes, which results from the location of the cranial nerve nuclei in the brainstem. For example, the cranial nerve nucleus for the oculomotor nerve (III. cranial nerve responsible for the innervation of most of the internal and external eye muscles) is located very high up in the brainstem (Schmeißer & Schumann, 2020). Thus, eye movement is not compromised by SCI.

As transient or permanent mechanical ventilation is regularly required in cervical SCI patients, the different ventilation modes will be described briefly below. Potential problems with ventilation (e.g., pain during ventilation) can be identified from self-reports on an ET basis and can be treated if required.

### *5.3 Ventilation Modes*

Paraplegic patients requiring ventilation may receive both, invasive and non-invasive ventilation (Hirschfeld, 2020).

#### *5.3.1. Invasive Ventilation*

Along with endotracheal intubation, tracheostomy is considered an invasive ventilation technique.

If acute spinal cord injury is present, invasive ventilation using an endotracheal tube is performed as part of emergency treatment (Hirschfeld, 2020). In endotracheal intubation, the ventilation tube is inserted into the trachea via the nose or mouth (Larsen & Ziegenfuß, 2013). The oral route is preferred to avoid injury within the nose. However, the method via the nose is better tolerated by patients (Larsen & Ziegenfuß, 2013). With a requirement for mechanical ventilation of longer than 7 to 10 days a tracheostomy and ventilation via a tracheal cannula should be considered (Waydhas & Hamsen, 2017). In tracheostomy, a plastic tube is directly inserted into the trachea from the middle of the neck, between the 1<sup>st</sup> and 3<sup>rd</sup> intertracheal space. Tracheostomy has several advantages for the patient compared with endotracheal intubation, including less discomfort, better mobilization of the patient and better oral care (Larsen & Ziegenfuß, 2013). Another advantage of a tracheostoma fitting is a reduction of required analgesic and sedative medication (Hirschfeld, 2020).

In the case of spinal injuries above the 5th cervical vertebra and a complete separation of the spinal cord, permanent mechanical ventilation is imperative (see also explanation above on the phrenic nerve). In paralyzed patients with cervical SCI, tracheostomy is recommended if (1) there is spinal cord injury according to type A or B on the ASIA Impairment Scale, (2) the Injury Severity Score (ISS; Baker et al., 1974) is more than 32 points, and (3) the  $\text{paO}_2 / \text{FiO}_2$  (arterial oxygen partial

pressure/inspiratory oxygen concentration) ratio is still less than 300 mmHg three days after the initiation of ventilation, 4) facial fracture and 5) thoracic trauma (Branco et al., 2011; Menaker et al., 2013). It was further demonstrated that performing a tracheostomy no later than 10 days after the onset of paralysis has a positive effect on the duration of ventilation, and shortens the length of stay in the intensive care unit (Choi et al., 2013). More than 90% of patients with chronic or persistent ventilation that is continually needed (> 12h/day) elect invasive ventilation using a tracheostoma device, although a noninvasive procedure could also be considered (Bach, 2012; Hirschfeld et al., 2008).

### *5.3.2 Non-Invasive Ventilation*

Non-invasive forms of ventilation are used primarily to avoid intubation or tracheostomy and potential complications from the invasive procedure. Likewise, long-term consequences of a tracheostomy could be circumvented (Bach, 2012). However, noninvasive procedures are subject to certain inclusion criteria, as described by Bach (2012). These include the functional preservation of the pharyngeal and facial muscles, good patient compliance, and upper airway patency. A non-invasive form of ventilation should be avoided if, among other things, the patient is not compliant, there is an increased risk of aspiration, or there are secretions that cannot be controlled by non-invasive means (via coughing or medication; Schallom et al., 2015). Non-invasive procedures include direct or indirect diaphragmatic stimulation. Both can be used in cases of damage to the spinal cord at the level of C0 to C3 and in cases of congenital or acquired disorders of the respiratory system (Hirschfeld, 2020). The diaphragm can be stimulated indirectly through Phrenic Nerve Stimulation (PNS). By implementing a diaphragmatic pacemaker the diaphragm can be stimulated directly (Hirschfeld, 2020). Possible complications, such as damage to the phrenic nerve, are reported to be < 1% for the indirect route. The likelihood of pneumothorax occurring during implantation

of a diaphragmatic pacemaker is also  $< 1\%$  (Romero et al., 2012). Both the direct and indirect routes of diaphragmatic pacing represent complete external ventilation (Hirschfeld, 2020). However, it is not useful to perform unilateral stimulation of the diaphragm without active innervation of the other half of the diaphragm. The required breath volume is insufficient in this case. In the case of only a unilateral lesion of the diaphragm, the paralyzed side can be treated with phrenic stimulation, since implantation involves separation of the two halves of the diaphragm (Hirschfeld et al., 2008; Hirschfeld, 2020).

### *Interim Summary*

A traumatic injury to the spinal cord at the level of the cervical vertebral spine has far-reaching physiological and psychological consequences. Permanent artificial respiration is necessary, which in turn can lead to complications for the patient (e.g. pneumonia). A frequently occurring comorbidity in paraplegic people is pain. Here, it must be taken into account that the way pain is transmitted and perceived differs from that of people with an intact spinal column. On a psychological level, anxiety and depression are frequent comorbidities. Due to the extent of the injury and the permanent artificial respiration, the patients are no longer able to communicate either verbally or through gestures or mimics. This is where the use of ET becomes very important. Previous research has paid little attention to patients with cervical paraplegia and the use of ET. This thesis, in particular the articles presented in the following, illustrates how ET can be used to give artificially ventilated, quadriplegic patients the opportunity to communicate about and beyond their basic needs. At the same time, we gained new insights into the subjective feelings of these patients and were able to learn more about pain perception and their emotional world.

## **6 Short Overview of the Research Papers**

The first study addressed the impact of medical conditions on the lives of patients with CSCI and who are on permanent mechanical ventilation. The study examined how these patients cope with current and anticipated future limitations and whether these limitations place a double burden. Different from previous studies that have focused on emotional evaluations of CSCI patients alone or in comparison with healthy controls, this study examined the potential impact of (a) the current negative state and (b) anticipated future limitations by comparing mechanically ventilated intensive care unit patients with and without SCI. Results suggest that patients in both groups were able to give multifaceted reports of their current state, such as feeling trapped and unsafe by using an ET. The responses provided by SCI and other ICU patients were quite similar, suggesting that present burdens dominated self-reports.

The second study evaluated how critically ill individuals with acute and chronic SCI (aSCI, cSCI) perceived having a tracheostomy also by using ET and tried to identify possible differences in perceptions between these two groups. It emphasized the importance of regularly assessing the subjective perception of critically ill tracheotomized individuals in the daily routine of ICU care and suggested the use of a questionnaire to assess patients' perception in different categories. It is also recommended that recording the perception of tracheotomized individuals with SCI in the ICU should be implemented as a routine care practice in the future.

The third study focused on the influence of pain and pain perception in people with (high) spinal cord injuries. Pain, in particular pain transmission, occupies a special position in tetraplegia. The key question of this study was the extent to which subjective pain perception in CSCI patients, compared with non-SCI patients, may influence attention and attitude.

Overall, this work using the ET method helped to reduce the lack of research regarding pain perception, needs, and appraisals of CSCI patients. On the one hand, the results of all three studies indicated that ET seems to be suitable as a survey method and communication tool in the ICU. On the other hand, it showed that SCI patients are not as pessimistic as might be assumed. Furthermore, this work contributed to transport the subjective perception of CSCI patients to the environment.

In the following, the three research papers are covered in some more detail, before a joint discussion is presented.

**Manuscript #1: Weckwerth, C., Gaschler, R., Hamsen, U., Spieckermann, A., Schildhauer, T.A., Waydhas, C., & Ull, C. (submitted). Feeling trapped and optimistic: Current rather than prospective medical conditions dominate self-reported emotions and appraisals in mechanically ventilated spinal cord injury patients**

SCI has been found to strongly affect emotions and well-being, with high variability in anxiety, depression, and coping among SCI patients (Woolrich et al., 2006). Past research has mainly focused on patients with a long temporal delay after the traumatic event and limited communication abilities, which may not fully capture patients' perspectives during the acute phase in the ICU. ET has been proposed as a means for communication and assessing patients' needs during acute treatment. Additionally, comparing SCI patients with healthy controls may not fully capture the unique perspective of SCI patients and possibly their ambivalence between adaptation processes and the wish for complete recovery.

Therefore, we compared ICU patients with and without SCI to improve our understanding of how patients' subjective prospects contribute to their well-being. The study was conducted at the University Hospital Bergmannsheil Bochum, Germany, from February, the 1st, 2020 to November 30th, 2020, in three intensive care units. The study included a total of 75 participants, with 46 classified as SCI and 29 as non-SCI patients with diagnoses such as COPD, heart failure, or acute abdomen.

The study used a commercially available ET device from Tobii Dynavox I-15+ (Tobii Dynavox I-15+; Tobii Dynavox, Danderyd, Sweden). The ET was mounted on a holder with wheels and could be used flexibly. The ET has integrated infrared sensors and a camera to create a picture of the user's eyes. Algorithms are used to calculate the gaze point, which was displayed on the monitor and used like a mouse pointer for patients to answer questions by means of their gaze.

Self-report instruments, such as the visual analogue self-esteem scale (VASES), were used to assess mood, anxiety, depression-tendency, and self-esteem in patients who have limited language ability. The VASES presents pairs of images with written descriptions, and patients choose from affirmative options (++ or +) or a neutral option (0) to categorize their state and perspective. The study also focused on questions related to basic needs and concerns, such as thoughts about the future. To assess the basic needs, an interdisciplinary team developed a questionnaire with a total of 30 questions in the categories of Disease & Nursing and Family & Future.

The results showed that overall, SCI patients' responses to the VASES, did not differ significantly from those of non-SCI patients. However, there were substantial differences among specific VASES items. Reports of feeling trapped received a high average rating in both groups of patients, through the comparison between the two groups of patients showed that the SCI-Patients felt significantly more trapped than other patients. Furthermore, reports on basic needs related to current and future

concerns, showed a differentiated profile, with high affirmation rates for both groups on some items and low affirmation rates for both groups on other items. The findings suggest that although there were some differences in specific areas, overall SCI patients and non-SCI patients on ventilators had similar-self-reported experiences and concerns.

**Manuscript #2: Weckwerth, C., Waydhas, C, Hamsen, U., Cruciger, O.,**

**Spieckermann, A., Schildhauer, T.A., Aach, M., Gaschler, R., & Ull, C.**

**(submitted). Perceptions of critically ill individuals with acute and spinal cord injury wearing a tracheostomy tube**

During weaning (withdrawing from mechanical ventilation) in individuals with aSCI in the ICU, the most important determinants are the patterns and levels of motor, sensory, and autonomic neurological impairment (Berlowitz et al., 2016; Rogers & Todd, 2016). Mechanical ventilation (MV) may be required in up to 77% of cervical ASCI cases and 5-8% of cSCI (c. f. Leelapattana et al., 2012). Tracheostomy, a common procedure in prolonged mechanically ventilated individuals (Berney et al., 2011; Yugué et al., 2012) offers benefits such as reduced airway resistance and improved comfort, but it may also have negative impacts on patients, such as anxiety and swallowing difficulties (Mussa et al., 2021; Schönhofer et al., 2020). Current guidelines for tracheostomy management in spinal cord injured individuals focus on medical factors and do not capture patient experiences and perceptions (c. f. Raimondi et al., 2017; Sun et al., 2022). To address this gap, we conducted a study evaluating the perceptions of wearing a tracheostomy tube in critically ill individuals with aSCI and cSCI, aiming to identify possible differences between acute and chronic spinal cord injured persons.



Fifty-one patients were enrolled in the study. The study used a survey with 25 items on tracheostomy well-being developed by an interdisciplinary ICU team based on previous reviews and input from tracheostomized ICU patients. The survey allowed the differentiation of six sub-categories related to respiration, coughing, pain, speaking, swallowing, and comfort. The following evaluation of the 25-item questionnaire allowed us to differentiate the perceptions and appraisals of aSCI and cSCI self-reports. Further statistical analysis lead to a short version consisting of 12 items (TWBS – Tracheostoma well-being score).

Patients were assessed for inclusion during daily ward rounds, and their level of consciousness was assessed using standardized scales. One inclusion criterion was that patients had an indwelling tracheostomy tube for at least 48 hours and were expected to keep it for at least 7 more days. Patients could answer the survey manually, verbally, or via ET. The survey was repeated the next day.

The results of the study indicate that regular assessment of perception in critically ill patients with tracheostomies is crucial in the daily care routine of the ICU to prevent the potentially chronic pain. The 25-item questionnaire utilized in this study allowed for assessment and differentiation of subjective perception in critically ill participants with aSCI or cSCI across various categories.

**Manuscript #3: Weckwerth, C., Gaschler, R., Hamsen, U., Spieckermann, A., Schildhauer, T.A., Cruciger, O., Waydhas, C., & Ull, C. (submitted). Pain can be reliably reported by intubated spinal cord injured patients via eyetracking and does not dominate appraisals of self-esteem and anxiety**

Pain is a complex and subjective experience that is difficult to define. The International Association for the Study of Pain (IASP) defines pain as “an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage” (IASP, 2023). Pain can trigger an escape and withdrawal behavior. Our brain has mechanisms for pain reduction through releasing endogenous opioids (Navratilova et al., 2015). The perception and transmission of pain in patients with SCI is unique due to the severity of the injury. Chronic pain is a common comorbidity in people with SCI (Finnerup, 2013). Defined by the International Spinal Cord Injury Pain Group, pain is classified into three categories: nociceptive pain, neuropathic pain, and pain caused by other conditions. Attention function is influenced by pain, especially in people with chronic pain (Eccleston & Crombez, 1999; Moore et al., 2012). The Model of the Interruptive Function of Pain explains how and why pain influences attention performance in a complex environment (Eccleston & Crombez, 1999).

The study was conducted from February to November 2020. Data was collected from 75 patients. Out of these, 46 had spinal cord injuries, while 29 were in the ICU on mechanical ventilation for other reasons. Twenty patients were excluded from the study due to not meeting the inclusion criteria or withdrawing consent. The study used the EQ-5D-5L (Herdman et al., 2011), Numeric Rating Scale (NRS; Thong et al., 2018), and Visual Analogue Self-esteem Scale (VASES; Brumfitt, 1999) to measure pain, subjective attitude, and self-esteem, respectively. A questionnaire on

patients' basic needs was also used. All these questionnaires were administered using ET. The study aimed to verify the non-arbitrary response behavior of patients' regarding subjective pain perception.

The NRS and EQ-5D-5L pain scales were found to have high and significant correlations. The results indicate mild to moderate subjective pain in the patients of both groups. The study also investigated whether pain had an influence on patient response behavior on other items that depicting anxiety or self-esteem, but pain was not found to be a predictor. Overall, the results suggest that pain appears to be a less dominant factor influencing perception or appraisals.

## **7 General Discussion**

Prior research had devoted little attention to the use of ET or psychological outcomes of patients in the ICU. Focus has been on patients with neurodegenerative diseases (e.g., ALS), among others, but has neglected CSCI. The aim of the presented thesis was to utilize ET to enable artificially ventilated CSCI patients to report on pain, needs and appraisals. Overall, the results demonstrate, that (1) patients were able to apply the ET, (2) effectively reporting on pain, needs and appraisals.

Using eye tracking in the ICU for critically ill patients seems to be rather rare presently. The groups in which ET was applied in the ICU were very small. The largest reported sample size of which we are aware to date was 39 (Duffy et al., 2018; Garry et al., 2016; Maringelli et al., 2013). In my thesis, the data from 75 artificially ventilated patients with and without CSCI were analyzed. Weckwerth et al. (submitted a) addressed this issue by focusing on mechanically ventilated individuals in the intensive care unit, some of whom had a diagnosis of CSCI. Due to the fact that 2/3 of the patients saw an advantage in using ET, it can be assumed that there is a desire for communication, but also that the patients see a chance to experience their needs being

fulfilled. Additionally, as shown by Ull et al. (2020) in a pilot study with a small sample ( $n = 11$ ), there was an improvement in perceived QOL when ET devices were used. This effect was also shown in study 1 of this thesis and could be transferred to the group of CSCI patients. Of all CSCI patients 78% stated that ET can contribute to an improvement in QOL. These results are consistent with those of Caligari et al. (2013), who also reported an improvement in QOL and communication abilities in patients with ALS. Dubayova et al. (2013) investigated the influence of Type D personality, anxiety, and depression on the subjective QOL perception of multiple sclerosis patients. The authors hypothesized that current mood, in terms of feeling angst and depressiveness, is more likely to influence patients' QOL than personality traits, which are considered stable. We support this assumption with the first study presented here. Also, CSCI patients seem to give their appraisals and perceptions regarding pain and anxiety from the current perspective, in the sense that they have a moderate pain perception, are not more anxious than invasively ventilated patients without CSCI, and also give less pessimistic ratings on the VASES scale than initially assumed. Thus, it can also be surmised, analogous to the results of the work of Kennedy et al. (2009, 2010, 2016), that less negative psychological outcomes can be expected in the future, in terms of the development of depression or anxiety disorder, if assessments are made in the early stages of injury. In our patient sample, the proportion of those with acute spinal cord injury was higher than those with chronic SCI.

In all three reported studies, moderate values are reported for both anxiety and pain or values on the VASES scale. It is possible that gender also plays a modulating role in assessments. Pieretti et al. (2016) pointed out, that gender has an important modulation factor of pain, in the sense that women are more sensitive to pain than men and also experience illness as more painful. In this thesis, there was a significant

overrepresentation of men, so a possible effect of pain, anxiety, and also other appraisals and needs were suppressed.

The moderate scores on the pain scales or the lower pessimistic attitude of CSCI patients may occasionally be explained by a relativization of the attribution of responsibility. Montada et al. (1999) examined the effects of experienced injustice and attributions of responsibility on the experienced burden of SCI and its coping SCI individuals. The authors' assumption was that SCI patients who feel themselves to be, for example, victims of fallible behavior, unjust treatments, but also guilt because of their own misconduct, are additionally emotionally burdened and also have greater difficulty accepting their disability. The results of Montada et al. (1999) show parallels to the results of this work. The authors expected that negative emotions, such as guilt or anxiety, are aversive and additional burdens for the patient, so that these negative emotions are a barrier to mastering, accepting SCI. However, the results were below the authors' expectations. Weak and mostly non-significant correlations between negative emotions and "mastery indicators" were found. The authors explained the correlation pattern, among other things, by the fact that negative emotions are perceived individually and that different dispositions, views of the self and the environment, as well as external control beliefs of each individual can play a role in coping strategies. Unfortunately, the article did not answer the question of whether there are different relations between, for example, the attribution of responsibility and the level of SCI.

### *7.1 Conclusion and Future Perspectives*

As previous research has shown, ET is a valuable tool to enable seriously ill individuals to communicate, especially patients with CSCI, for which this is no longer possible due to the severity of their injury. The knowledge and insights gained in this

work should definitely be further applied and expanded. It is highly recommended, especially in the early phase of the injury (acute CSCI), to provide (1) the patients with an ET device, to (2) enable them to communicate with the environment, and communicate their needs, but also to (3) gain further insights, through measurement instruments adapted to the ET, into the subjective feelings of this patient group. Especially the last-mentioned point is important allowing health care professionals to recognize a possible depression or anxiety.

The use of the currently used ET is sometimes a bit cumbersome, so for further research and use by the patient, a simpler tool, such tablet or mobile phone-based ET should be used. With such devices and apps, etc., particularly the younger users may be already familiar, thus requiring less practice time up front. Such devices are more user-friendly, especially for the patient. In addition, this approach is much more cost-effective. As important as it is to gain further insights into the subjective perception of CSCI patients, this is an issue better addressed in for long-term surveys, which can be challenging in this population. In this work, the focus was on patients in the ICU. For future and long-term surveys, patients are sometimes no longer available as they have been relocated to rehabilitation facilities. Hence, it would be advisable to conduct cross-institutional studies in the future, encompassing the entire treatment process.

Likewise, future research is necessary to, for example, link appraisals with different responsibility attributions of the CSCI to gain insights into their subjective perception and coping strategies, in order to provide support to the patients here as well.

A further limitation should be mentioned. Although this thesis used a large sample compared to prior studies, a sample of 75 patients (of these 46 spinal cord

injured persons) is not large enough to detect small effects. Furthermore, group sizes were not balanced.

The overall goal of further research should be to enable patients with a cervical spinal cord injury to communicate and by this improve their quality of life and well-being. Following the six-dimension model of Ryff and Keyes (1995) the overarching goal of further research should be to give CSCI patients back some autonomy and help them find self-acceptance and meaning in life. Furthermore, the focus should be on stable mental health. This means, among other things, early detection and treatment of, for example, depression or anxiety disorders. Further research should also be conducted on the subjective pain perception of CSCI patients in order to (a) better understand the pain mechanism and (b) apply a more patient-oriented and individualised analgesia.

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**Manuscript #1****Feeling trapped and optimistic: Current rather than prospective medical conditions dominate self-reported emotions and appraisals in mechanically ventilated spinal cord injury patients**

Christina Weckwerth<sup>1</sup>, Robert Gaschler<sup>1</sup>, Uwe Hamsen<sup>2</sup>, Aileen Spieckermann<sup>2</sup>, Thomas Armin Schildhauer<sup>2</sup>, Oliver Cruciger<sup>2</sup>, Christian Waydhas<sup>2,3</sup>, Christopher Ull<sup>2</sup>

<sup>1</sup>Faculty of Psychology, FernUniversität of Hagen, Universitätsstraße 47, 58097 Hagen, Germany

<sup>2</sup>Department of General and Trauma Surgery, BG University Hospital Bergmannsheil, Bürkle-de-la-Camp-Platz 1, 44789 Bochum, Germany

<sup>3</sup>Medical Faculty University Duisburg-Essen, Hufelandstraße 55, 45147 Essen, Germany

**Author Note**

Christina Weckwerth, Faculty of Psychology, FernUniversität of Hagen, Universitätsstraße 33, 58097 Hagen, Germany, email: christina.weckwerth@fernuni-hagen.de, phone: +49 (2331) 987 41 03.

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Correspondence concerning this article should be addressed to Christina Weckwerth, Faculty of Psychology, FernUniversität of Hagen, Universitätsstraße 33, 58097 Hagen, Germany, email: [christina.weckwerth@fernuni-hagen.de](mailto:christina.weckwerth@fernuni-hagen.de)

### **Abstract**

Adverse medical conditions can involve present and expected future restrictions as a double burden: Mechanically ventilated patients with spinal cord injury (SCI), on the one hand, face pain, and communication restrictions. On the other hand, they are confronted with major changes in their future life perspective. While past research on emotion and appraisals has studied SCI patients alone or in comparison with healthy controls, the current work disentangles the potential impact of (a) the adverse current state and (b) expected future restrictions by comparing mechanically ventilated intensive care unit (ICU) patients with vs. without SCI in eyetracking-based self-reports on emotions and appraisals. Results suggest that patients of either group were able to provide faceted accounts of their current state, such as feeling trapped and insecure. However, the feedback that SCI and other ICU patients gave was rather similar, suggesting that current adversities dominate self-reports.

*Keywords:* Eyetracking, Emotions, Intensive Care Unit, Self-Reported Emotions, Spinal Cord Injury.



## Introduction

Spinal cord injury has been reported to strongly affect emotions when evaluating the current state as well as the future (Kennedy, Evans & Sandhu, 2008). Past research has reported high variability in anxiety and depression (cf. Woolrich, Kennedy, & Tasiemski, 2006) and coping in SCI patients (cf. Kennedy et al., 2000, 2003; Kennedy, Evans, & Sandhu, 2009). Furthermore, it has been documented that SCI patients take their life stage, roles, and relationships strongly into account when thinking about their impairment (Kaiser & Kennedy, 2011).

According to Lucas (2007a), individuals who acquire a severe disability report life satisfaction levels that are more than a full standard deviation below their baseline levels, and these levels do not appear to rebound over time. Early on, research stressed that people can sustain at least some happiness despite a spinal cord injury. For instance, participants with spinal cord injuries in Brickman et al. (1978) were above neutral on the happiness scale. Yet, Lucas (2007a) pointed out that they were more than three-quarters a standard deviation below the mean of the control group, implying that the average control group participant reported a higher life satisfaction than approximately 78% of participants with spinal cord injuries. In line with this, Dijkers (1997) reported large differences between individuals with spinal cord injuries and healthy participants across studies.

Two issues are still open regarding the emotions of SCI patients which are to be tackled in the current research: (1) the point in time and mode of assessment and (2) the group of comparison. Concerning the first issue, past research has mainly collected reports from patients with a long temporal delay after the traumatic event and has focused on patients who were able to provide self-report verbally or by gestures. This restriction limits our knowledge about patients' perspectives and needs particularly

during the acute phase in the first weeks after the trauma, when patients are awake but not able to verbally communicate due to artificial airways (e.g. tracheostomy) and mechanical ventilation. Furthermore, this restriction reduces options to take patients' perspectives during medical treatment into account. Investigating appraisals earlier and including participants who cannot speak might improve treatment and long-term outcomes. Tackling the difficulties involved with blocked speech due to invasive ventilation and allowing communication about pain and additional emotional strain early on in the ICU might improve the current state as well as long-term prospects. For this, an improved understanding of SCI patients' feelings and appraisals is necessary, allowing more adequate care to be provided while still in the ICU. Eyetracking can offer means for communication despite invasive ventilation. In prior studies by Ull et al. (2020, 2022a, 2022b) mechanically ventilated patients, including patients with high paraplegia, were asked about their basic needs via eyetracking. Assessing the needs of patients during acute treatment in the ICU might reduce or prevent pain and additional emotional strain due to SCI and invasive ventilation. For instance, Van Diemen et al. (2017) were able to demonstrate that patients with SCI described their bodies as alienated at the beginning of rehabilitation. Body image explains a large proportion of variance in depression and anxiety disorders, so improving the perception of the body should be a major part of the rehabilitation process after a spinal cord injury (van Diemen et al., 2017).

Concerning the second issue, past research has either studied SCI patients without a group of comparison or compared to healthy controls. Yet, this comparison is rather unspecific. Different from other patients with severe medical conditions, spinal cord injury patients might not only be aware of the fact that they have a severe medical condition, but also expect the spinal cord injury to be a lasting affliction. So far there is no data to compare how SCI compared to other ICU patients view their future. Past

studies have exclusively targeted SCI patients and indicate ambivalence between adaptation processes and the wish for complete recovery. For instance, in Krause and Edles (2014) 51.6% of the SCI patients agreed that “SCI is a serious condition that has life consequences”. Yet, notwithstanding this evaluation, a majority of patients were optimistic. Only 25.1% agreed to the statement that their SCI is likely to be permanent. Furthermore, optimism concerning long-term developments was widespread, with 86.9% reporting they maintain hope for full recovery, which in turn was positively related to reported life satisfaction.

When comparing spinal cord injury patients with healthy controls, it might be difficult to disentangle the potential impact of a severe medical condition from the potential impact on aspects of life-satisfaction and well-being. It seems relevant to compare ICU patients with vs. without spinal cord injury for an improved evaluation of the contribution a patient’s subjective prospects might have. In the current study we provide such a comparison among ICU patients with vs. without spinal cord injury. This aims to help to disentangle the future perspective from the severity of the current medical condition.

## **Method**

### **Sample**

The study took place from February 1<sup>st</sup>, 2020 to November 30<sup>th</sup>, 2020 in three intensive care units (medical and surgical intensive care units) at the University Hospital Bergmannsheil Bochum, Germany. One focus of the hospital is the treatment of spinal cord injuries. The following inclusion criteria applied for participation in this prospective study: (1) endotracheal tube or tracheostomy tube and mechanically ventilated, (2) >18 years of age, (3) RASS (Richmond Agitation Sedation Score) of -1, 0, 1 or NU-DESC (nursing delirium screening scale) score of <3 in patients without

sedation (4) mechanically ventilated >48 hours, (5) continued mechanical ventilation for at least 24 hours, (6) ability to communicate via non-technical AAC (augmentative and alternative communication; e.g. blink or lip-reading). Any patient who did not fulfill the above inclusion criteria and/or had a speaking ability of 6 hours or more was excluded from the study. Consent to participate was obtained from all patients. Patients were able to give consent to participate by nodding their heads or blinking. Alternatively, consent was given by a legal representative. The entire study was supervised by a specialist in trauma surgery and a psychologist.

An a-priori power analysis was done with G\*Power® Version 3.1 (Faul et al., 2007) and showed a sample size of  $2 \times n = 36$  for a power of 0.80 with an  $\alpha$ -error of .05 and an effect size of  $d = .6$ . Ninety-five mechanically ventilated and intubated patients fulfilled the inclusion criteria, 20 patients had to be excluded because of cognitive impairment ( $n=8$ ), extubation before accomplishment of the testing ( $n=6$ ), language barrier ( $n=3$ ), refusal ( $n=2$ ) or sudden death ( $n=1$ ). Consequently 75 patients participated in the study ( $M_{age} = 53$ ,  $SD 17.8$ ) of which 21.3% were female and 78.7% were male (further demographic data see table 1 in the Appendix)

For analysis the sample was divided into the two groups of spinal cord injured (SCI;  $n = 46$ ) and non-SCI ( $n=29$ ) patients. Non-SCI diagnoses comprised COPD (chronic obstructive pulmonary disease), heart failure or acute abdomen.

### **Eyetracking**

To allow differentiated communication with these non-verbal patients we used the same eyetracking technology (ET) used in previous studies (c.f. Ull et al., 2020), the Tobii Dynavox I-15+ system (Tobii Dynavox, Danderyd, Sweden). The system includes commercial Windows 10 software as well as an integrated infrared camera, illumination, and processing units. The integrated camera and video-analysis algorithms were used to

determine the gaze point which in turn was used like a mouse pointer. The patient was now able *to click* on a possible answer presented on the screen by means of their gaze. The eye-tracker was attached to a movable and height-adjustable arm with wheels, so that it could be positioned close to the bed and in front of the patient. The system was initially adjusted via a 9-point calibration prior to each application. The research questions and potential answers were projected on the screen. In addition to the images, audio feedback was provided for each question and response option. No time limit for answering the question was specified. The patient was forwarded to the next question if their gaze remained on the selected answer option for at least 1000ms and the corresponding audio feedback was heard. Furthermore, a back/forward button provided the possibility to return to the previous question or to proceed to the next question.

### **Self-Report Instruments**

For the current study, the answers of SCI patients and other ventilated patients were compared. There are self-report instruments that can be applied with patients who cannot speak or communicate by gestures. The visual analogue self-esteem scale (VASES) was developed to assess mood, anxiety, depression-tendency, and self-esteem in patients whose use of language is limited (Brumfitt & Sheeran, 1999). The scale offers dichotomies concerning feelings and appraisals (seeking contact vs. not seeking contact; pessimistic vs. optimistic; clear vs. chaotic thoughts; dull vs. sharp thoughts; cheerful vs. not cheerful; angry vs. relaxed, not understood vs. understood; frustrated vs. satisfied; sad vs. happy; insecure vs. secure; trapped vs. free) that can be used by ICU patients to categorize their state and perspective. In the VASES, pairs of images are shown to the patient. A written description is presented above each picture. The patient's answers are determined by choosing one of the options below the picture (++ , +) or the neutral answer option (0) between the pairs of pictures.

In addition to the VASES (e.g. reporting to feel trapped) we focused on questions on basic needs related to current and future concerns (with a binary response format): (1) Do you think a lot about the future?, (2) Are you afraid of losing your job?, (3) Are you afraid of being unable to pursue hobbies?, (4) Are you afraid of needing constant help?, (5) Are you afraid of being alone due to your disease?, (6) Are you afraid your partner could leave you?, (7) Do you think your health will improve?, (8) Do you think you could get used to the current state of health?, (9) Do you think you will need permanent mechanical ventilation?, (10) Do you think this device will improve your quality of life?

## Results

Statistical analysis was performed using Microsoft Excel and IBM SPSS Statistics Version 27.

First, on the VASES a t-test for independent samples was used to check whether SCI patients gave more negative responses than non-SCI patients. This was not the case. The SCI patients ( $M = -.37$ ,  $SD = .40$ ) did not differ from the non-SCI group ( $M = -.18$ ,  $SD = .49$ ,  $t(73) = 1.843$ ,  $p = .069$ ). However, as shown in Figure 1, there were substantial mean differences among VASES items. For instance, reports of feeling trapped received a high average rating (in both groups of patients) while on average there was no tendency to report anger. The pronounced difference in average ratings across items underlines that patients were able to read and understand the items and to express their answers via gaze point.

While SCI patients were not generally more negative in their reports on the VASES (see above), it needs to be taken into account that one of the items might specifically address the situation of SCI as compared to non-SCI patients. Accordingly, as a follow-up we tested for group differences in reports of feeling trapped. Patients with

spinal cord injury ( $M = -1.54$ ,  $SD = .50$ ) felt significantly more trapped than other patients ( $M = -1.10$ ,  $SD = 1.15$ ;  $t(73) = 2.286$ ,  $p = .025$ ). Furthermore, one VASES item addressed optimism and was hence used for item-based group comparison as well. The Spinal Cord Injury group ( $M = -0.11$ ,  $SD = .97$ ) was lower in optimism compared to the non-SCI patients ( $M = 0.45$ ,  $SD = 1.06$ ;  $t(73) = 2.339$ ,  $p = .022$ ). For the remaining VASES items, there are no significant differences between the groups (Table 3 in the appendix).

While most VASES items lead to responses on the negative side, some are on average neutral or slightly positive. On the one hand, the patients suffering a severe injury needing permanent mechanical ventilation, report high frustration and a tendency towards depression. On the other hand, many still show optimism. Next, we compared reports of SCI- and non-SCI patients on current and future concerns related to basic needs (see Table 2). In a binary format, five items asked participants whether they were afraid of specific restrictions in their life. We computed the percentage of affirmative responses per participant group. The independent-samples t-test showed that patients with spinal cord injury ( $M = 53\%$ ,  $SD = 31\%$ ) were not significantly more anxious about their future than patients from the non-SCI group ( $M = 41\%$ ,  $SD = 35\%$ ,  $t(73) = -1.443$ ,  $p = .153$ ).

Similar to the VASES, the reports on current and future concerns related to basic needs show a differentiated profile (high affirmation rates for both groups on some items and low affirmation rates for both groups on other items). This again underlines that participants were able to provide a differentiated self-report using the eyetracking setup. Only one item showed a significant difference between the two groups: *Do you think this device will improve your quality of life?* which referred to the possible impact of

eyetracking-based communication: 78.9% of the SCI-patients answered affirmatively while only 50% of the non-SCI patients did ( $\chi^2(1) = 5.87, p = .015$ ).

Table 2 shows the results of the contingency table response frequencies in percent for the questions answered “yes” and additional the results of the chi-square test detecting differences in response behavior concerning the future.



## Discussion

The current study was the first to compare self-reports on emotions and appraisals among mechanically ventilated patients with vs. without spinal cord injury. ET-based self-report was used to overcome restrictions in terms of sample, measurement timing, and group of comparison that had limited earlier studies. For instance, when comparing spinal cord injury patients with healthy controls, it had been difficult to disentangle the potential impact of a severe medical condition from the potential impact of problematic prospects on life-satisfaction and well-being. The current study provides a comparison disentangling these potential factors. Results suggest that patients of either group were able to provide faceted accounts of their current state such as feeling trapped and insecure. While emotions and appraisals showed a differentiated profile concerning the different items, this profile in general was mostly similar for SCI and other ICU patients, suggesting that current adversities dominate self-reports. The SCI- and non-SCI patients of the current study were alike in regard to being treated at an ICU for severe medical conditions while being mechanically ventilated and unable to communicate by speaking. There were specific differences due to the special condition of SCI patients. SCI patients more strongly reported feeling trapped and at the same time more frequently underlined the value of eyetracking to enable communication and by this improve life quality. Non-SCI patients reported more optimism than SCI patients. The latter were more open to the idea of getting used to their current state of health.

In the current study we used eyetracking to acquire self-reports on emotions and appraisals of mechanically ventilated patients with and without SCI. Currently it is not clear whether mechanically ventilated patients with vs. without SCI differ in emotions, appraisals, and outlook. Until recently, communication restrictions have drastically

reduced the possibility of taking subjective needs of these patients into account. Yet, apart from restricted options for discovering what patients view as their burdens, restricted communication – in and of itself – seems to be one of the major burdens from the perspective of the patients. Invasively ventilated patients in the intensive care unit experience voicelessness as particularly frustrating (Yang, 2016), some describing the communication impairment as one of the most stressful, dehumanizing, and frustrating aspects of their ICU stay (c.f. Baumgarten & Poulsen, 2015; Guttormson, et al., 2015; Karlsson et al., 2012; Patak et al., 2004). According to Happ et al., over 50% of ICU patients have sufficient alertness to communicate with their caregivers and attending physicians. Yet, they may not be understood because of communication impairments arising from an artificial airway. Interactions between patient and medical team usually focus on the content perceived as relevant by clinicians but less on the content perceived as important by patients (cf. Foster, 2010; Leung et al., 2018).

Given that mechanically ventilated ICU patients with or without SCI share this burden of impaired communication, their emotions and appraisals might be similarly dominated by these acute restrictions leading to similar reports. A potential dominance of current adversities in reports on emotion and appraisal is in line with the theory of socio-emotional selectivity (Carstensen, 1991). The theory states that over their lifespan, people shift their motivation, which is driven by their subjective future perspective rather than by calendrical age. When the remaining life span is perceived as strongly limited, positive emotions and important social partners become valued very highly. This has, for instance, been reported by people suffering from HIV. Likely, people with a high degree of paraplegia who are permanently dependent on mechanical ventilation also recognize restrictions in future perspective compared to circumstances not dominated by ICU treatment. The overall mortality of ventilated patients is 35%, of

which approximately 32% die within one year (Hirschfeld, 2020). Furthermore, socio-emotional selectivity theory suggests that when lifetime is perceived as strongly limited, people enter a current-oriented state (Carstensen et al., 1999). Patients might manage to sustain some positive emotions and appraisals by taking current supporting factors into account, such as alleviation of communication restrictions by the ET-based setup, medical treatment reducing pain, and support from the social environment while in the hospital.

According to Bach and Tilton (1994) people with a complete traumatic tetraplegia reported life satisfaction at levels nearly equal or even exceeding the level reported by people with no health impairment. Schwartz et al. (2018) suggested as an explanation that persons with spinal cord injury have presumably adapted to their circumstances and that response shift effects are not captured by standard measurement instruments. Response shift effects are observed in individuals whose health status changes drastically (Sprangers & Schwartz, 1999). Response shift theory offers an approach to why individuals with a SCI might exhibit a tendency toward optimism. The theory postulates that 1) stable characteristics of an individual (so-called antecedents) interact with 2) cognitive-affective, and behavioral strategies (mechanisms) and influence cognitive appraisals that 3) moderate the effect on one's changed health status on perceived quality of life (i.e., response shift; Rapkin & Schwartz, 2004; Sprangers & Schwartz, 1999).

The above-mentioned aspects are further supported by the disability paradox (Albrecht & Devlieger, 1999). Why do people with disabilities, including those with SCI, report optimism or good to high life satisfaction? The central point of this paradox lies in a balance of body, mind, and soul, and the maintenance thereof, combined with a stable social environment (Albrecht & Devlieger, 1999). Previous studies on basic

needs in SCI patients have shown that SCI patients indeed feel embedded in a good social environment (Ull et al., 2022b). In fact, 75% of SCI patients reported feeling understood by their family members, and 66% did not feel abandoned by their family members (Ull et al., 2022b).

It should be mentioned that the group of SCI also included persons with acute SCI, which meant that the survey took place in a relatively short period after the accident. This raises the question of how quickly adaptation occurs in individuals with an acute SCI, especially since the response shift effect has been observed in individuals with chronically ill conditions (Finkelstein et al., 2014; Schwartz & Sprangers, 2004) and the response shift effect itself is not seen as an adaptation, but rather as an effect of adaptation (Schwartz et al., 2013). According to Schwartz et al. (2018), it can be said that the response shift effect is applicable to individuals with chronic SCI. "People appeared to change their internal standard regarding physical functioning and general health over time, ..." (Schwartz et al., 2018), so it can be assumed that individuals are responding from the current time perspective. Since the number of those with an acute SCI is highly represented, it can also be assumed that the adaptation to the given circumstances takes place promptly and the response shift effect is also valid for people with an acute SCI, although the acceptance of the current health status is low. The possible adaptation process points in the direction of a hedonistic adjustment in which individuals return to their basic level of happiness after a change in their life circumstances (Lucas, 2007b). Future research should focus on the response shift in acute illness. It can be assumed that there are diagnosis-dependent differences.

Previous research has demonstrated a wide range of psychological adjustment in patients with SCI (cf. Galvin & Godfrey, 2001) – Lazarus and Folkman` (1984) stress, appraisal, and coping model being a dominant reference. The optimistic tendency

present in some SCI patients may be a form of hope. Hope is described as the expectation to achieve a goal in the future (Tong et al., 2010). In their study, Dorsett et al. (2017) dealt with the construct of hope in SCI patients and found that hope correlates positively with acceptance. The current study, however, points in a different direction – suggesting that hope can be high while acceptance is low. On the one hand, 76.3% of the SCI patients and 80.8% of the non-SCI patients reported they think their health will improve. On the other hand, acceptance was low. Only 31.6% and 11.5% of the patients indicated they think they will get used to the current state of health. The results for people with SCI are consistent with Krause and Edles (2014) who report that hoping for an improved health status predicts life satisfaction in SCI patients.

Given the overlap of VASES reports in SCI and non-SCI patients, the focus of future work might shift towards other aspects of the current treatment, which might strongly shape patients' appraisals of their current situation. The variant of ventilation used might be such a variable. For instance, Huttman et al. (2018) screened people with long-term home mechanical ventilation (HMFV) and pointed out that their life satisfaction was severely impaired despite maximal patient care and full support of technical aids. Yet, the current investigation suggests that technical aids for communication can make a difference from the patients' perspective. In our sample 78.9% of SCI patients and 50% of non-SCI patients reported they believe that using an eye tracker will improve their quality of life. Improved communication can also help to address that patients' future perspective, in part, seems to be dominated by their current treatment. For instance, while non-SCI participants are likely to be weaned from ventilation, almost 40% reported to believe that they will need permanent ventilation.

## Limitations

Some work regarding the impact of major life events on life satisfaction has used repeated measures before and after the life event, allowing to study effects over a period of time and take individual baseline levels into account (Lucas, 2007). According to Lucas (2007), individuals show drops in their level of life satisfaction and optimism of more than one standard deviation after a critical life event (for example, onset of paraplegia) and often remain on this reduced level. On the one hand, our study could not provide data from before the major life event. On the other hand, there is a specific strength that makes this study relevant despite this limitation. Different from many other studies, we could assess severely affected patients during their stay in the ICU while they were facing communication restrictions due to mechanical ventilation. Eyetracking was used to assess emotions and appraisals of SCI and non-SCI patients. The differentiated profiles indicate that gathering information directly from the patients via eyetracking is highly relevant. The current work suggests that, while being treated in the ICU, reduced life satisfaction and optimism are mainly driven by the severe current health restrictions rather than by the subjective prospects that might differ between SCI and non-SCI patients.

As a further limiting factor, it should be mentioned that the group of spinal cord injured patients included 15 participants who were not in the ICU because of high paraplegia and the permanent need for ventilation as primary diagnosis, but because of another diagnosis (for example, after visceral surgery). So for some of the patients, paraplegia was not a novel health restriction. Future research should also consider the distinction between acute and chronic spinal cord injury. Also with respect to ventilation, future studies should differentiate between the (subjective) permanent vs. temporary need for such support in detail. Previous research on coping strategies after

paraplegia takes the level of paraplegia or the ASIA (American Spinal Injury Association) classification into account (Dorsett et al, 2017). Yet, there are hardly any studies that consider whether mechanical ventilation is permanently required. At present, it can be assumed that the subjective estimations of patients with high paraplegia and continuous mechanical ventilation concerning their future are based on their present condition.

Some of the patients have been living with the diagnosis of high paraplegia and continuous mechanical ventilation for years. Barone and Waters (2012) describe the influence biopsychosocial factors have on how patients cope with SCI and highlight that relatively recently injured patients are more prone to an avoidance and repression mechanism. However, this is contradicted by a statement by Martz et al. (2005), who investigated predictors of psychosocial adjustment to spinal cord injury in a study with 313 spinal cord injured patients. The severity and duration of the existing injury provided only weak evidence for the assumption that a longer duration, even with a severe degree of spinal cord paralysis, results in a more positive adjustment. Similarly to the participants in this study, most patients had a severity of injury at level A according to the ASIA Impairment Scale. Grade A of the ASIA Scale is reflected by a complete loss of sensory and motor function below the level of injury.

## **Conclusion**

Despite the severity of the injury, the limited scope for possible improvement in health status, and the feeling of being trapped, patients with high paraplegia show optimism. This result is consistent with the findings of Brickman et al. (1978) that ICU patients with and without SCI are able to maintain some life satisfaction.

ET-based communication in the intensive care unit can be of high benefit for patients with permanent ventilation, especially for patients with high paraplegia (cf. Ull et al., 2020). The results of the current study suggest that emotions and appraisals are dominated by current adversities. It seems reasonable to repeatedly conduct eyetracker-based assessments of emotions, appraisals, and needs, allowing the information and treatment provided to the patient to be adjusted and improved as appropriate for their current state. The VASES, which records moods, anxiety, and depressive tendencies, is particularly suitable for this purpose. It allows psychotherapeutic measures to be taken more quickly if necessary or anxiety-relieving medication to be prescribed if required.

### **Declarations**

### **Ethical Approval**

This study has been approved by the local ethics committee (Ruhr- University Bochum, Germany, grant number of approval 18-6620-BR). We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during this research.

### **Competeting Interests**

We have no known conflict of interest to disclose or any competing financial and/or non-financial interests in relation to the work described.

### **Author's Contributions**

C.W.II\*, R.G., C.U. and O.J. created the concept and the design of the manuscript.

C.W.II, R.G., C.U. and C.W.I\*\* performed data analysis and evaluation.

C.W.II., R.G. and C.U. wrote the main manuscript text.



C.W.II. prepared the tables and figures.

U. H., C.W. I, R.G., C.W.II, O.J. and A.S.: critical revision

U. H., T.A.S., R.G., A.S., C.W.II, and O.J.: Approval of the article

All authors reviewed the manuscript.

\*Christina Weckwerth

\*\* Christian Waydhas

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### **Availability of data and materials**

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

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**Appendix****Table 1***Demographic data of enrolled patients (n = 75)*

	Total
Gender m:f	59 (78.7%) : 16 (21.3%)
Age (years)	58.3 ± 17.8
LOS hospital (days)	88.7 ± 81.9
<i>Reasons for ICU Admission</i>	
Acute Spinal Cord Injury	31 (41.3%)
Chronic Spinal Cord Injury	15 (20.0%)
Other Diagnoses	29 (38.7%)
CCI (points)	2 ± 2
SOFA score (points)	8.8 ± 1.9

*Note.* Data presented as absolute numbers (percentage) or mean ± standard deviation.

Abbreviations: m = male, f = female, LOS = length of stay, ICU = intensive care unit,

CCI = charlson comorbidity index, SOFA = sepsis-related organ failure.

**Table 2**

*Results of the contingency table for the percentage response frequencies (answered “yes”) and the results of the chi square test detecting differences in response behavior concerning the future divided in spinal cord injury (SCI) and non-spinal cord (non-SCI)*

Items	SCI (%)	Non-SCI (%)	$\chi^2$	$p$
Are you afraid of losing your job	37.0	20.7	2.21	.137
Are you afraid of being unable to pursue hobbies?	54.3	41.4	1.20	.274
Are you afraid of needing constant help?	67.4	65.5	.028	.867
Are you afraid of being alone due to your disease?	56.5	51.7	.165	.684
Are you afraid that your partner could leave you?	47.8	27.6	3.03	.081
Are you thinking a lot about the future?	67.4	48.3	2.71	.100
Do you think your health will improve?	76.3	80.8	.179	.672

Items	SCI (%)	Non-SCI (%)	$\chi^2$	$p$
Do you think you get used to the current state of health?	31.6	11.5	3.45	.063
Do you think you will need permanent mechanical ventilation?	36.8	38.5	.017	.895
Do you think this device will improve your quality of life?	78.9	50.0	5.87	.015*

*Note.* \*  $p < .05$ .

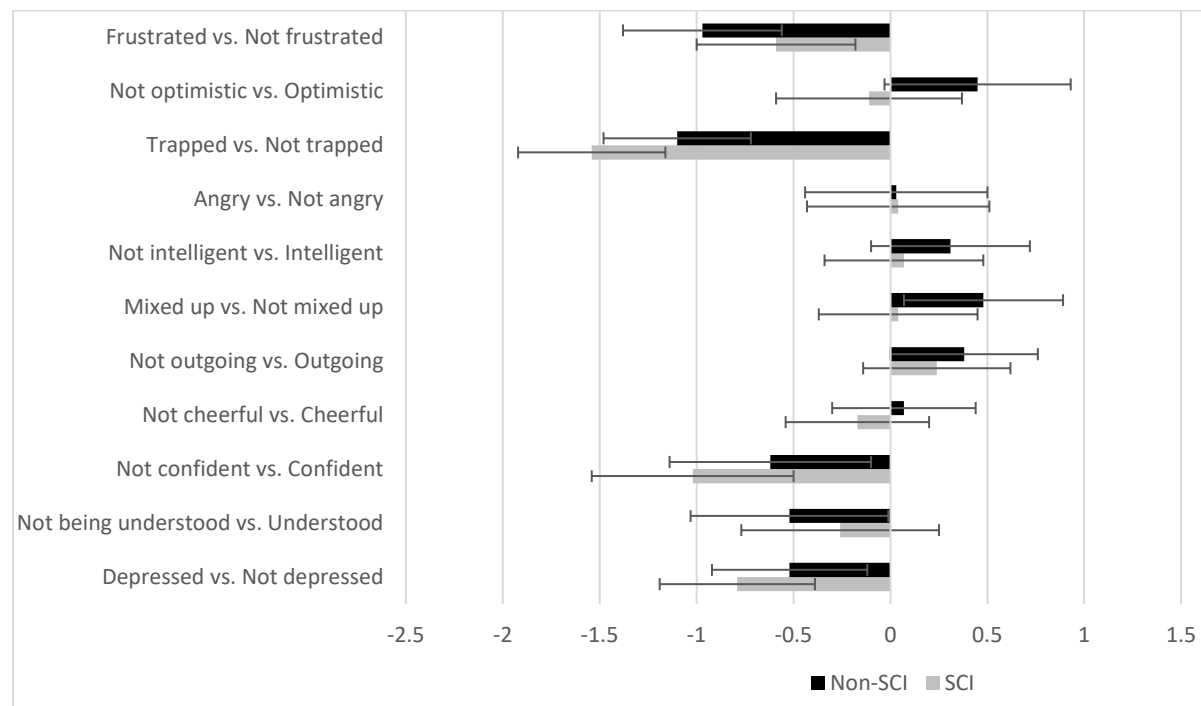
**Table 3***Results of the intergroup comparison of VASES items*

Item	<u>Spinal Cord Injury</u>		<u>Non-Spinal Cord Injury</u>		<i>t</i> (73)	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Depressed_Not depressed	-.72	.88	-.62	.815	-.545	.587
Not being understood_ Understood	-.31	1.12	-.41	1.04	.420	.676
Not confident_ Confident	-.83	1.18	-.90	1.07	.246	.806
Not cheerful_ Cheerful	-.03	.810	-.10	.718	.424	.673
Not outgoing_ Outgoing	.31	.822	.28	.793	.126	.900
Mixed up_ Not Mixed up	.19	.856	.23	.931	.431	.861
Not intelligent_ Intelligent	.19	1.01	.13	.731	.327	.744
Angry_ Not angry	-.14	.931	.21	1.01	-1.535	.129
Frustrated_ Not frustrated	-.64	.899	-.77	.810	.660	.511

*Note.*  $p < .05$ .

**Figure 1**

*Mean values for the VASES items throughout all patients*



*Note.* Definition of the response options: -2/2 = ++ (strong negative/strong positive), 0 = neutral; -1/1 = negative/positive. Error bars = 95% confidence interval of the SCI vs. non-SCI comparison for the respective item.

**Manuscript #2**

**Perceptions of critically ill individuals with acute and chronic spinal cord injury wearing a tracheostomy tube**

Christina Weckwerth<sup>1</sup> (MSc), Christian Waydhas<sup>2,3</sup> (MD, PhD), Uwe Hamsen<sup>2</sup> (MD), Oliver Cruciger<sup>2</sup> (MD), Aileen Spieckermann<sup>2</sup> (MD), Thomas Armin Schildhauer<sup>2</sup> (MD, PhD), Mirko Aach<sup>4</sup> (MD, PhD), Robert Gaschler<sup>1</sup> (PhD), Christopher Ull<sup>2</sup> (MD)

<sup>1</sup>Faculty of Psychology, FernUniversität of Hagen, Universitätsstraße 47, 58097 Hagen, Germany.

<sup>2</sup>Department of General and Trauma Surgery, BG University Hospital Bergmannsheil, Bürkle-de-la-Camp-Platz 1, 44789 Bochum, Germany.

<sup>3</sup>Department of Trauma Surgery, University Hospital Essen, Hufelandstr. 55, 45147 Essen, Germany

<sup>4</sup> Department of Spinal Cord Injuries, BG University Hospital Bergmannsheil, Bürkle-de-la-Camp-Platz 1, 44789 Bochum, Germany

**Corresponding author**

Christopher Ull (CU) (ORCID: 0000-0001-5633-3179), Department of General and Trauma Surgery, BG University Hospital Bergmannsheil, Bürkle-de-la-Camp-Platz 1, 44789 Bochum (North Rhine-Westphalia), Germany, e-Mail: christopher.ull@rub.de, phone: +(49)234 302-3576, fax: +(49)234 302-6425.

**Author information**

Christina Weckwerth (CWe)	christina.weckwerth@fernuni-hagen.de
Christian Waydhas (CWa)	christian.waydhas@uni-due.de
Uwe Hamsen (UH)	uwe.hamsen@bergmannsheil.de
Oliver Cruciger (OC)	oliver.cruciger@bergmannsheil.de
Aileen Spieckermann (AS)	aileen.spieckermann@bergmannsheil.de
Thomas Armin Schildhauer (TAS)	thomas.a.schildhauer@rub.de
Mirko Aach (MA)	mirko.aach@bergmannsheil.de
Robert Gaschler (RG)	robert.gaschler@fernuni-hagen.de

## **Abstract**

**STUDY DESIGN:** Observational study.

**OBJECTIVES:** To evaluate the perceptions of wearing a tracheostomy tube and to identify possible different perceptions in critically ill tracheotomized individuals with acute spinal cord injury (ASCI) and chronic spinal cord injury (CSCI).

**SETTING:** Medical and surgical intensive care units and intermediate care unit of the BG University Hospital Bergmannsheil Bochum, Germany.

**METHODS:** All persons who met the inclusion criteria were asked to complete a 25-item questionnaire on two consecutive days regarding their experiences and perceptions in breathing, coughing, pain, speaking, swallowing, and comfort of fit.

**RESULTS:** A total of 51 persons with ASCI (n = 31) and CSCI (n = 20) were included with a mean age of 53 years. Individuals with ASCI reported significantly more frequent pain and swallowing problems as compared to individuals with CSCI ( $p \leq 0.014$ ) at initial assessment. No difference between ASCI and CSCI was reported with respect to speaking and overall comfort.

**CONCLUSIONS:** It is necessary to regularly assess the perceptions of critically ill tracheotomized individuals with ACSI or CSCI in the daily ICU care routine. With the used questionnaire, we were able to assess these perceptions in different categories. For the future, recording the perception of tracheotomized individuals with spinal cord injury in the ICU should be implemented to their daily routine care.

**TRIAL REGISTRATION:** DRKS00022073.



**Introduction**

The most important determinants during weaning in persons with acute spinal cord injury (ASCI) in the intensive care unit (ICU) are the patterns and levels of motor, sensory, and autonomic neurological impairment [1, 2]. The need for mechanical ventilation (MV) in persons with ASCI has a variable incidence. Still, up to 77 % of cervical spinal cord injury (SCI) have been shown to require at least temporary MV, and in 5 – 8 % of all individuals with chronic spinal cord injury (CSCI), long-term MV is necessary [3, 4]. SCI-related complications in individuals with CSCI are common and a frequent cause of morbidity and mortality with increased rehospitalization rates and the need for MV [5, 6].

Tracheostomy is a common procedure in prolonged mechanically ventilated spinal cord-injured individuals with a reported incidence of tetraplegia between 10 % and 60 % [7-9]. This procedure offers several benefits over prolonged endotracheal intubation in critically ill persons during weaning or for long-term MV, including reduction of dead space, airway resistance and labored breathing, improved personal comfort, decreased need for sedation, effective communication, airway clearance with reduced risk of aspiration, and improved oral care [10]. Despite these medical advantages during weaning, negative impacts on persons with a tracheostomy often occur and may include anxiety, inability to talk, swallowing dysfunction, pain due to the tube, and increased effort to sustain breathing [11]. Furthermore, guidelines of tracheostomy management in spinal cord injured individuals mainly focus on prognostic factors for respiratory dysfunction, prolonged ventilator support, the timing of tracheostomy, dysphagia, or decannulation and do not capture the experiences and perceptions of wearing a tracheostomy tube [12-16].

To overcome this, we prospectively tested critically ill tracheotomized individuals with ASCI and CSCI and aimed (1) to evaluate their perception of wearing a tracheostomy tube and (2) to find possible differences in perception between individuals with acute and chronic spinal cord injuries.

## **Methods**

### Study design and selection criteria

This prospective, monocentric, observational study was performed at three medical and surgical ICUs and one intermediate care unit (IMC) of a university hospital. One focus of the authors' university hospital is the treatment of SCI with a capacity of 78 patient beds (peripheral) and 10 ICU or IMC patient beds. Per year a total of 400 to 500 persons are treated due to acute spinal cord injuries or its complications. This includes about 80 acutely injured tetraplegic persons per year.

The study was approved by the author's institutional review board (No. of approval 20-6887) and registered at the German Clinical Trials Register (DRKS00022073). It adheres to the "Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement" (Supplementary Information) [17].

All eligible individuals were prospectively tested from June 8, 2020, to March 8, 2021.

All included individuals met the following criteria: (1) ASCI or CSCI; (2) inserted tracheostomy tube for more than 48 hours and expected to remain cannulated at least for the next 7 days; (3) adequate cognitive and motoric skills to answer the survey manually, verbally, or with support of eye-tracking (ET) devices; (4) over 18 years of age; (5) a score of -1, 0 or 1 points on the Richmond agitation-sedation scale (RASS) [18] or a score of < 3 points on the nursing delirium screening scale (Nu-DESC) [19] in individuals without sedation; and (6) successful completion of the questionnaire on

two consecutive days. The procedure was verbally explained to the persons and informed consent was obtained in written form, or if not possible, verbally, via head nodding, or by blinking. This was confirmed by persons who were unrelated to the investigation.

Out of 57 eligible tracheotomized participants, 6 participants were excluded because of the following conditions: language barrier ( $n = 3$ ), incomplete data ( $n = 2$ ), and refusal to participate ( $n = 1$ ). The remaining 51 people were enrolled in the study (Figure 1).

### Demographic data

Standard parameters, such as sex, age, reason for hospital admission, length of stay in hospital, etc., were applied to describe the demographic data of the included persons. The Charlson comorbidity index (CCI) as a measure of comorbidity burden was also calculated for each participant [20]. ASCI and CSCI were classified according to the recommendations as described by Fawcett et al. [21] and Burns et al. [22]. Both groups were divided into complete or incomplete tetraplegia or paraplegia of the cervical and thoracic spinal cord and classified according to the American Spinal Injury Association (ASIA) impairment scale (AIS) A to D [23]. The reasons for ICU or IMC admission were grouped into major trauma, non-abdominal sepsis, acute abdomen, exacerbation of chronic obstructive pulmonary disease, modification of long-term mechanical ventilation, and cancer.

### Questionnaire

Recently, we used a 25-item questionnaire (see Table 1) allowing the differentiation of six sub-categories (*respiration, coughing, pain, speaking, swallowing, comfort*) [24].

Participants report frequency of problems in the sub-categories by responding to items on a 4-point Likert scale (0 = never, 1 = sometimes, 2 = often, 3 = always).

The questionnaire was developed by the interdisciplinary ICU team consisting of critical care nurses, intensivists, psychologists, speech and occupational therapists, and physiotherapists. The list of items was also based on comments and suggestions of tracheotomized ICU persons who were in the weaning process, were on long-term ventilation, or had already been successfully weaned.

#### Standardized assessment

Individuals potentially fulfilling our inclusion criteria were identified during the daily ward round of the interdisciplinary ICU and IMC teams. Prior to inclusion and to each session, the person's level of consciousness was assessed using the RASS and the Nu-DESC. Depending on the current fine motor capabilities of their arms and communication skills, the participants were either able to answer the survey manually with paper and pen or were able to answer verbally after the questions were read aloud by the experimental supervisor, alternatively the persons were able to answer the questionnaire via ET devices. The Tobii Dynavox I-15+ ET device (Tobii Dynavox, Danderyd, Sweden) was used for this in nonverbally restricted persons with limited fine motor capabilities [25]. On the next day, the survey was repeated with each participant.

#### Statistical analysis

Statistical analysis was performed using Microsoft® Office Excel® for Mac 2019 (Microsoft Corporation, Redmond, WA, USA) and IBM® SPSS® Statistics Version 28

2021 (IBM Corporation, Armonk, NY, USA). Evaluation of categorical variables was carried out using the Pearson's Chi square test or Fisher's exact test. The Student's t-test was applied to analyze continuous variables. For an initial overview of the participants' perceptions on both days of the survey, mean values for each category were mapped in a profile plot. Profile plots for each category were also generated by participant group (ASCI and CSCI) for both survey days. Mean values for the profile plots were calculated from the responses of the corresponding categories on a 4-point Likert-Scale (0 = never, 1 = sometimes, 2 = often, 3 = always). For differences in perceptions per category between survey days without differentiating patient groups, a t-test for paired values was applied. For differences in perceptions of individuals with ASCI or CSCI, a t-test for independent samples was performed. Significance for both methods was set at  $p \leq 0.05$ .

## Results

### Demographic and clinical Data

The demographic and clinical data of the 51 enrolled participants are listed in detail in Table 2 and in Table 3. In all participants, a flexible tracheostomy tube was used for MV. No person of both groups had a spinal cord injury of the lumbar spine. In 12 of the 20 participants with CSCI (60%), long-term ventilation via tracheostomy was required before admission to the ICU with a mean time of  $11.1 \pm 7.9$  years.

The distribution of tetraplegia and paraplegia, as well as the loss of neural function according to the AIS are described in Table 4. The majority of participants in both groups (ASCI 83.8 % vs. CSCI 70 %) suffered a lesion of the cervical spine with subsequent tetraplegia. The rate of complete tetraplegia was 38.7 % in participants with ASCI and 40 % in participants with CSCI.

### Results on perceptions and appraisals

Analysing the data of the first day of the evaluation we obtained a different profile for ASCI and CSCI persons across the six categories (Figure 2). ASCI persons on average reported significantly more frequent pain ( $p \leq 0.014$ ) and problems in swallowing ( $p \leq 0.002$ ) as compared to CSCI persons. The ASCI persons also reported more problems with breathing and coughing, but this difference didn't reach significance.

Interestingly, no difference between ASCI and CSCI was reported with respect to speaking and overall comfort.

On day two the ASCI group still reported more problems with swallowing than the CSCI group ( $p \leq 0.002$ ). With respect to perceived pain symptoms, there was a

marginally non-significant difference pointing towards a higher report in the ASCI group as compared to the CSCI group on day two as well ( $p \leq 0.065$ ) (Figure 3).

## Discussion

Assessing the critically ill individuals' perspective is highly relevant for securing and improving the quality of tracheostomy usage in the ICU. In the current study we explored whether the six sub-categories (*respiration, coughing, pain, speaking, swallowing, comfort*) of the tracheostomy well-being score allow to differentiate the perceptions and appraisals of ASCI and CSCI persons self-report [24]. Our results suggest that differentiating among the sub-categories can indeed help to obtain a differentiated profile: At first assessment ASCI persons reported more frequent pain and problems in swallowing than CSCI persons. This confirms the relevance of well-being as previously described in the aforementioned review and assessed with a short self-report instrument [26].

Receiving a tracheostomy tube can enormously impact critically ill individuals. Anxiety and fear are very often attendant emotions [27]. For individuals with ASCI, these feelings are compounded, first due to the severity of the injury and second due to the severity of the altered body image [28]. It is widely accepted in the literature that quality care for tracheotomized persons must include a patient-centred approach, but for this to happen, the experiences and perceptions of those persons should be understood [10, 11, 29]. However, current guidelines on tracheostomy management in persons with SCI focus on timing, used technique, or attendant complications.

Additionally, previous work has not focused on persons in the ICU [26]. Further understanding of the experiences and priorities of tracheotomized individuals in the ICU could help improve clinical care and patient-centred outcomes [11]. This was also emphasized by Whitmore et al. who concluded that more research was needed into participants' experiences [30].



In the context of this study, we were able to highlight the experiences and perceptions more clearly. We used a questionnaire, developed by an interdisciplinary team, to assess the perceptions and experiences of critically ill tracheotomized individuals in terms of breathing, coughing, pain, speaking, swallowing, and comfort. A first review has shown that, apart from swallowing and comfort difficulties in ASCI persons, both groups report no or rarely perceived problems in the remaining categories. Consistent with the results of Newman et al. [11], we found no respiratory problems.

On day one of the survey, individuals with an ASCI reported more frequent pain symptoms and swallowing problems than individuals with CSCI. Potentially, acute individuals may not have a suitable cannula yet or they might still need to get used to their condition with a tracheal cannula. The ASCI group continued to report increased perceived pain symptoms and problems with swallowing. However, some attention must be drawn to the aspect that persons with an ASCI report increased problems in only two of the six categories. Pointing out breathing as one category, ASCI persons seem to adjust to the new form of breathing within a relatively short timeframe.

These results emphasize that it is enormously important to capture individuals' perceptions by default. For example, individuals with ASCI in particular may need better coverage with analgesics, more frequent suction, or a better fitting canula to increase their comfort. Complementing the recommendations from previous research, it can be stated that it is necessary to record the individuals' perceptions regarding the categories of breathing, coughing, pain, speaking, swallowing, and comfort of fit. In addition, the ASCI population reported increased pain symptoms and problems with swallowing.

**Limitation**

This study is the first to report the perceptions of critically ill tracheotomized spinal cord injured individuals with special emphasis on differences between persons with ASCI and CSCI in a tertiary healthcare center. Future studies should extend our knowledge about the frequency of tracheostomy problems in ASCI and CSCI persons with larger cohorts. To obtain a more elaborate picture of the changes in problems with respiration, coughing, pain, speaking, swallowing, and comfort, more than two assessments per patient are needed. This would allow relating changes in treatment to changes in perception and appraisal of tracheostomy problems.

**Conclusion**

It is necessary to regularly assess the perceptions of critically ill tracheotomized individuals in the daily ICU care routine. With the used questionnaire, we were able to assess subjective perceptions in critically ill individuals with ACSI or CSCI in different categories. For the future, recording the perception of tracheotomized individuals with SCI in the ICU should be implemented to their daily routine care.

**Data Availability Statement**

Data that was generated and analyzed during this study can be found within the published article. Additional data are available from the corresponding author on reasonable request.

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### **Author Contribution Statement**

Concept/design: CWe, CWa, RG, CU; Data analysis/interpretation: CWe, CWa, RG, CU; Writing of article: CWe, AS, CU; Critical revision of the article: CWe, CWa, UH, OC, AS, TAS, RG, MA, CU; Approval of article: CWe, CWa, UH, OC, AS, TAS, RG, MA, CU; Funding secured by: CU; Data collection: CU.

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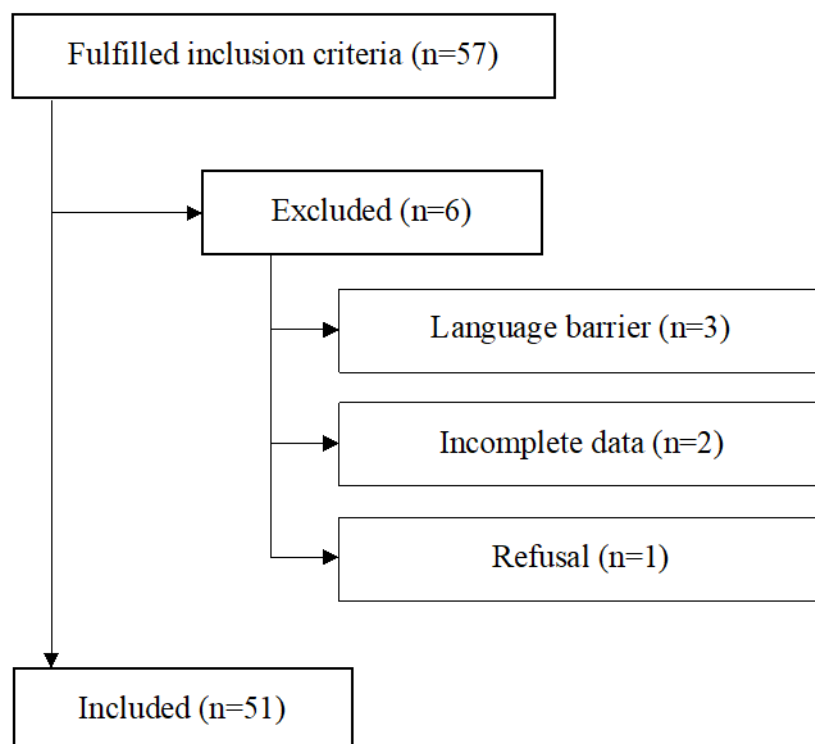
**Ethical Approval**

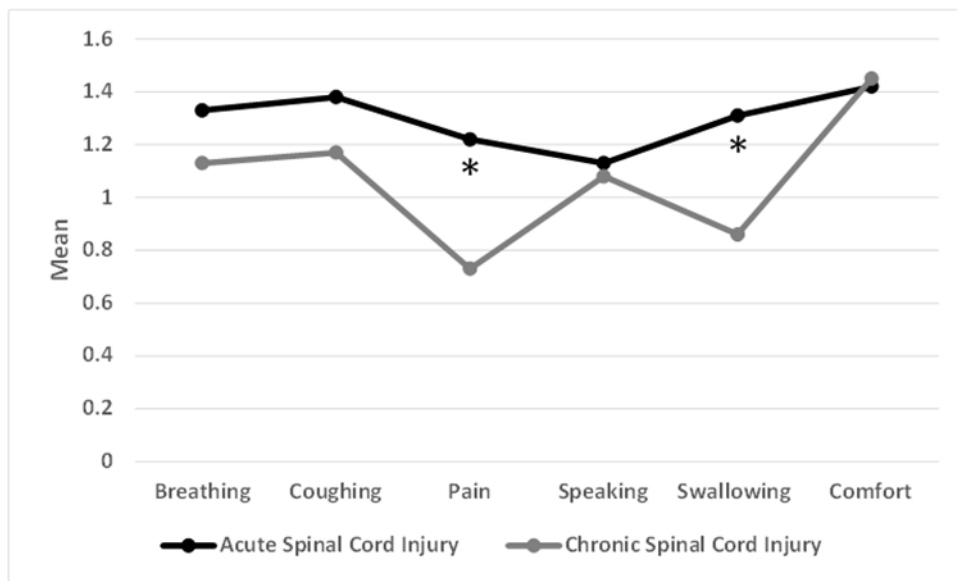
This study was performed in line with the principles of the Declaration of Helsinki. It was approved by the local ethics committee (Ruhr-University Bochum, Germany, grant number of approval 18-6620-BR). Informed consent was obtained from each person. We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during this research.

**Competing Interests**

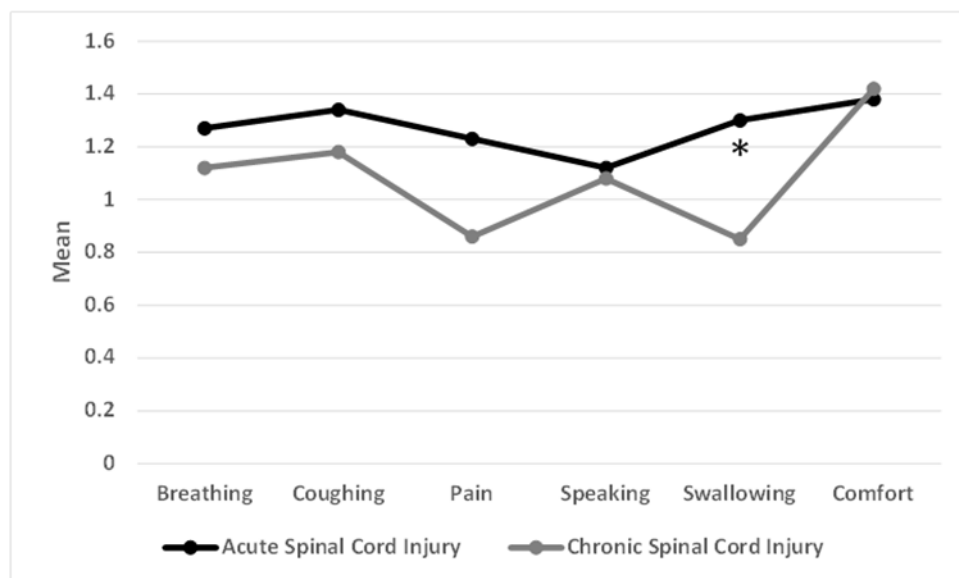
The authors declare no competing interests.



**Figure Legends****Fig. 1** Flow diagram showing results of participant search (n=51).



**Fig. 2** Mean values of the given responses for the respective categories for the first day of survey differentiated by diagnosis. Mean values calculated from the responses of the corresponding categories on a 4-point Likert-Scale (0 = never, 1 = sometimes, 2 = often, 3 = always). The asterisk indicates significant differences in perception of pain and swallowing for individuals with ASCI ( $p \leq 0.05$ ).



**Fig. 3** Mean values of the given responses for the respective categories for the second day of survey differentiated by diagnosis patient group. Mean values calculated from the responses of the corresponding categories on a 4-point Likert-Scale (0 = never, 1 = sometimes, 2 = often, 3 = always). The asterisk indicates significant differences in perception of swallowing for individuals with ASCI ( $p \leq 0.05$ ).

**Manuscript #3****Pain can be reliably reported by intubated spinal cord injured patients via eyetracking and does not dominate appraisals of self-esteem and anxiety**

Christina Weckwerth<sup>1</sup>, Robert Gaschler<sup>1</sup>, Uwe Hamsen<sup>2</sup>, Aileen Spieckermann<sup>2</sup>,  
Thomas Armin Schildhauer<sup>2</sup>, Oliver Cruciger<sup>2</sup>, Christian Waydhas<sup>2,3</sup>, Christopher Ull<sup>2</sup>

<sup>1</sup>Faculty of Psychology, FernUniversität of Hagen, Universitätsstraße 47, 58097 Hagen,  
Germany

<sup>2</sup>Department of General and Trauma Surgery, BG University Hospital Bergmannsheil,  
Bürkle-de-la-Camp-Platz 1, 44789 Bochum, Germany

<sup>3</sup>Department of Trauma Surgery, University Hospital Essen, University Duisburg-Essen,  
Hufelandstraße 55, 45147 Essen, Germany

**Author Note**

Christina Weckwerth, Faculty of Psychology, FernUniversität of Hagen,  
Universitätsstraße 33, 58097 Hagen, Germany, email: christina.weckwerth@fernuni-  
hagen.de, phone: +49 (2331) 987 41 03.

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Correspondence concerning this article should be addressed to Christina  
Weckwerth, Faculty of Psychology, FernUniversität of Hagen, Universitätsstraße 33,  
58097 Hagen, Germany, email: christina.weckwerth@fernuni-hagen.de

### **Abstract**

Acute pain is a crucial survival response of the body to threats, which triggers flight and avoidance behavior. Early studies on pain describe its purpose as something constructive. Chronic pain, however, may permanently hamper Quality of Life (QOL). Pain perception and transmission are of special significance in individuals with (high) spinal cord injury (SCI). The mechanism of pain transmission, particularly neuropathic pain, is still unclear in SCI patients. Approximately 70% of SCI patients suffer from chronic pain. In people with chronic pain, attention is disrupted by pain. This study aimed to investigate (1) whether pain can be assessed via eyetracking-based self-report instruments from patients who are unable to speak or use gestures, (2) whether there is a difference in the subjective pain of SCI and non-SCI patients, and (3) whether self-reported pain is correlated with self-esteem and anxiety. Pain was expected to dominate reports on self-esteem, depression, and anxiety. This was not the case. The study showed that intubated patients who are unable to speak and use gestures can reliably report perceived pain and that pain is mainly independent of appraisals concerning self-esteem, depression, and anxiety.

*Keywords:* Pain, Spinal Cord Injury, Subjective Perception

## Introduction

The International Association for the Study of Pain (IASP) defines pain as “an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage” (2020). Three significant features of the experience of pain are acknowledged in this definition: (1) pain possesses distinctive sensory and perceptual qualities; (2) there is no definite association between pain and damage to bodily tissues; and (3) pain is an unpleasant emotional encounter (Eccleston & Crombez, 1999). Pain elicits avoidance and withdrawal behaviors, as we make every effort to evade this distressing and exceedingly unpleasant sensation. Our brain even has a mechanism for pain reduction through the release of the body's own opioids (Navratilova et al., 2015). Early works describe the pain and stress as constructive (c.f. Sternbach, 1968). Different variants of perception have been tied to different mechanisms in the brain (Price, 2000). On the one hand, the purely sensory components of pain are conveyed via the spino-thalamic tract (ascending fiber pathway in the lateral spinal cord) to the thalamus (ventral postero-lateral part) and from there on to the primary and secondary somatosensory cortex of the cerebellum. The emotional staining of pain is accomplished via pathways targeting the cingulate gyrus and the cortex of the insula. In contrast, the long-term emotional consequences are mediated via fiber pathways to the prefrontal cortex.

The majority of SCI patients report persistent pain (van Gorp et al., 2014). The perception and transmission of pain in patients with (high) spinal cord injury deserves special consideration. Collecting self-reports on pain is essential in an ICU. The Numeric Rating Scale (NRS; Thong et al., 2018) and other verbal rating scales are recommended for this task (Ull et al., 2021). However, patients with high SCI are unable to respond verbally or using gestures to these scales due to the severity of the

injury. In addition, verbal communication is made impossible by artificial ventilation. Given that it has been difficult to assess pain in these patients, adequate treatment is threatened. This is troubling since chronic pain is known as a common co-morbidity in people with SCI. For instance, Finnerup (2013) report that about 70% of SCI patients suffer from pain, 1/3 of them even suffer from very severe pain with a corresponding influence on mood and perceived QOL. Pain in SCI patients is divided into three classifications defined by the International Spinal Cord Injury Pain Group: (1) nociceptive – subcategorized into musculoskeletal, visceral and other types of pain, (2) neuropathic – pain above/below the injury level and other types of pain as well as (3) pain caused by, for example, osteoarthritis in the shoulder or a bladder spasm.

There is a lack of understanding regarding the mechanisms that cause pain in patients with SCI (Siddall & Loeser, 2001). It is known that nociceptive pain transmission/perception occurs in SCI patients in the same way as in patients with an intact spinal cord (Hadjipavlou et al., 2016). This is not the case for transmission of neuropathic pain. At the injury level, neuropathic pain is thought to be caused by hyper-excited neurons. This hyperexcitability results from an altered expression of N-methyl-D-aspartate and glutamate receptors as well as sodium and calcium channels, increased activity of glial cells, and/or an underfunction of endogenous inhibitory neurons (Hadjipavlou et al., 2016). Various mechanisms of the brain are involved in the development of neuropathic pain. These include changes in the activity and perfusion of the thalamus, the expression of sodium channels in the thalamus, and the occurrence of thalamocortical dysrhythmia. The latter is believed to involve a slowing of cortical EEG activity (Wydenkeller et al., 2009). A significant slowing of EEG activity has been observed in patients with SCI and neuropathic pain (Llinás et al., 1999).

Below the injury level, pain perception is less clearly explained. If the spinal cord is completely severed, the origin of the pain should be in the intact part of the central nervous system (CNS) above the injury. The cause of the pain could be a spontaneous activity of the disinhibiting pathway, sensitization of the spino-thalamic tract, or located at the level of the brain in the thalamus or cortex (Hadjipavlou et al., 2016). As an alternative explanation, the authors state that the origin of the pain below the injury level is a dysfunctional relationship between the fast lateral spino-thalamic tract and the medial slower polysynaptic pathway. The latter may dominate the spino-thalamic tract after an injury and cause late-onset pain as well as a diffuse coloration of the pain.

Pain is known to interfere with and influence the control of attention, especially in people with chronic pain (Eccleston & Crombez, 1999; Moore et al., 2012). It remains unclear which aspects of attention are involved (Moore et al., 2012). Various models on attention-grabbing have provided approaches as to why one piece of information is considered relevant while other information is ignored (e.g. Broadbent, 1958; Kahneman, 1973). There are also theories as to why attention may be interrupted (e.g. Graham & Hackley, 1991), which have been adapted for pain research (Eccleston, 1994; Lorenz & Bromm, 1991). Eccleston and Crombez (1999) linked these two lines of research and developed the model of the interruptive function of pain, which aims to explain how and why pain in a complex environment affects the control of attention (Eccleston & Crombez, 1999). Several influencing factors were identified, which moderate the interrupting function of pain. These include novelty, predictability, and threat (relating primarily to pain) as well as task difficulty and emotional arousal (relating to demands in the environment; Eccleston & Crombez, 1999).



When pain directs attention away from other aspects of daily life, this negatively affects QOL. The extent to which people provide a positive and optimistic evaluation of their situation and see basic needs as satisfied is strongly dependent on whether they can direct attention to positive aspects of the current situation (Schwarz & Clore, 1983; Wilson & Gilbert, 2005). Processes of sense-making can help to alleviate the burden of aversive situations (Wilson & Gilbert, 2005). Yet, such reasoning processes might be hampered if pain prevents a person from directing their attention towards other aspects (Eccleston & Crombez, 1999). This reasoning suggests that in patients with high pain appraisals of self-esteem, depression, and anxiety might be more negative as they are dominated by pain.

The current study aimed to investigate 1) whether pain can be assessed via eye-tracking-based self-report instruments in patients who are unable to speak or use gestures, 2) whether subjective pain perception differs between SCI and non-SCI patients, and 3) whether pain dominates appraisals of self-esteem and anxiety. Stronger correlations between pain and appraisals might be found in SCI patients as the mechanisms underlying pain are different (generated centrally) from those of non-SCI patients. For patients who are intubated and cannot speak or use gestures, special processes in pain generation and reduced behavioral expression make obtaining data on subjectively perceived pain even more important.

## **Method and Material**

### **Demographic data**

This prospective, monocentric, and observational study was conducted from February 1<sup>st</sup>. 2020 to November 30<sup>th</sup>, 2020 in three intensive and intermediate care wards (ICU/IMC) of the Department of General and Trauma Surgery of the University Hospital Bergmannsheil in Bochum and its department for spinal cord injured patients.

Data were collected from patients who met the following inclusion criteria: (1) age 18 years or above (2) a score of -1, 0, or +1 on the Richmond Agitation Sedation Scale (RASS; Ely et al., 2003), (3) or a score of less than 3 on the Nursing Delirium Screening Scale (NU-DESC) for patients without sedation (Gaudreau et al., 2005), (4) an inserted endotracheal cannula or tracheostomy and mechanical ventilation, (5) current mechanical ventilation for more than 48 hours and the expectation that ventilation will continue for at least 24 more hours; and 6) inadequate non-verbal skills. Consent was obtained from all patients (if possible) or their legal representatives. Of the 95 eligible patients, 20 were excluded for not fulfilling all inclusion criteria. Eight patients were awake but cognitively impaired, six patients were prematurely extubated, three patients had language barriers, two patients withdrew their consent to participate in the study and one patient died before the study was conducted. Seventy-five patients remained, of which 46 patients had a diagnosis of spinal cord injury and 29 were ventilated in the intensive care unit as well, but due to other diagnoses. An overview of relevant demographic data is provided in Table 1.

**Table 1***Demographic data from all enrolled patients (N = 75)*

	Total
Gender m:f	59 (78.7%) : 16 (21.3%)
Age (years)	58.3 ± 17.8
LOS hospital (days)	88.7 ± 81.9
CCI (points)	2 ± 2
SOFA score (points)	8.8 ± 1.9
Intubation (thereof tracheostomized)	75 (64)
NRS	3.95 ± 2.29
EQ-Pain	2.65 ± 0.97
<i>Reasons for ICU Admission</i>	
Acute Spinal Cord Injury	31 (41.3%)
Chronic Spinal Cord Injury	15 (20.0%)
Other Diagnoses	29 (38.7%)

*Note.* Data presented as absolute numbers (percentage) or mean ± standard deviation.

Abbreviations: m = male, f = female, LOS = length of stay, ICU = intensive care unit,

CCI = charlson comorbidity index, SOFA = sepsis-related organ failure, NRS =

Numeric Rating Scale, EQ-Pain = Dimension Pain on the EQ-5D-5L

## **Eyetracking and Scales**

Since all of the patients were unable to communicate orally and none were able to reliably communicate their pain by using non-tech augmentative and alternative communication (e.g. lip reading, nodding, paper-pencil), the study was conducted using an eyetracking system (ET) from Tobii (Tobii Dynavox I-15+; Tobii Dynavox, Danderyd, Sweden). This ET is a commercially available device. The basic operating system is a Microsoft Windows 10 software. The ET was mounted on a holder with wheels and could therefore be used flexibly within the ICU/IMC. The ET has integrated infrared sensors, which generate a light pattern on the eyes of the user. The also integrated camera creates a picture of the user's eyes. Special processing units, detect specific details in the eye of the user. The obtained gaze data is calculated with the help of algorithms to calculate the gaze point, which is then displayed on the monitor and used like a mouse pointer, allowing the patient to answer a question by means of their gaze.

### *Scales and Scores*

Subjectively perceived pain was measured via one of the dimensions of the *EQ-5D-5L* (Herdman et al., 2011): (1) no problems, (2) slight problems, (3) moderate problems; (4) severe problems, and (5) extreme problems. Additionally, the patient's subjective pain perception was measured on the NRS. This is an 11-point scale, where 0 is no pain, while a score of 10 represents the worst pain imaginable.

The Visual Analogue Self-esteem Scale (VASES; Brumfitt, 1999) was developed to measure self-esteem, depression, and anxiety in patients with aphasic stroke. The 10 items depicted in pairs of pictures include the subjective perception of: (1) frustrated – not frustrated, (2) not optimistic – optimistic, (3) trapped – not trapped, (4) angry – not angry, (5) not intelligent – intelligent, (6) mixed up – not mixed up, (7)

not outgoing – outgoing, (8) not cheerful – cheerful, (9) not confident – confident, and (10) not understood – understood. In our study, the image pairs were displayed on the ET monitor. Among the image pairs there was a rating/response scale, where “++” was in strong agreement and “+” was in agreement, while “0” was indifferent. An example item is shown in the Appendix. Furthermore, a questionnaire on the basic needs of the patient was used (Ull et al., 2020, 2022). Here we focus on those items that reflect anxiety.

A standardized study protocol was used for the study. The RASS or NU-DESC score was determined for each individual patient and a calibration of the ET was performed. For calibration, the patient followed a view point on the monitor (9-point calibration). The patients familiarize themselves with the use of the device by means of so-called look-to-learn games pre-installed on the ET device.

The local ethics committee (Ruhr-University Bochum, Germany, grant number of approval 18-6620-BR) has approved this study. We confirm that all relevant institutional and governmental guidelines for ethical use of human volunteers were followed during this research.

Statistical analysis was performed using Microsoft Excel (2019) and IBM SPSS Statistics Version 29 (2022).

## **Results**

For a better visual comparability of the distribution of the 11-point scale NRS and the 5-point EQ-Pain scale, a linear scale transformation of the NRS was performed (see figure 1). Thereby, the value 1 of the transformed scale contains the values 0 and 1 of the original scale, the value 2 contains the values 2 and 3 of the original scale, the value 3 contains the values 4, 5 and 6, the value 4 contains the values 7 and 8 of the

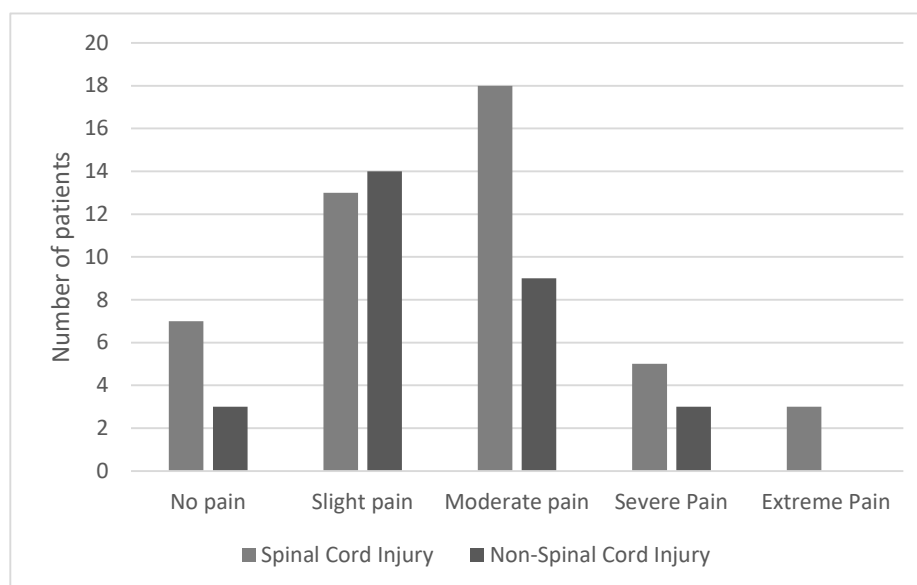
original scale, respectively the value 5 of the transformed scale contains the values 9 & 10 of the original scale. The frequency distributions for the NRS and the EQ-Pain for the respective groups are shown in Figures 1A and 1B. For all further calculations concerning the NRS, the original scaling was used.

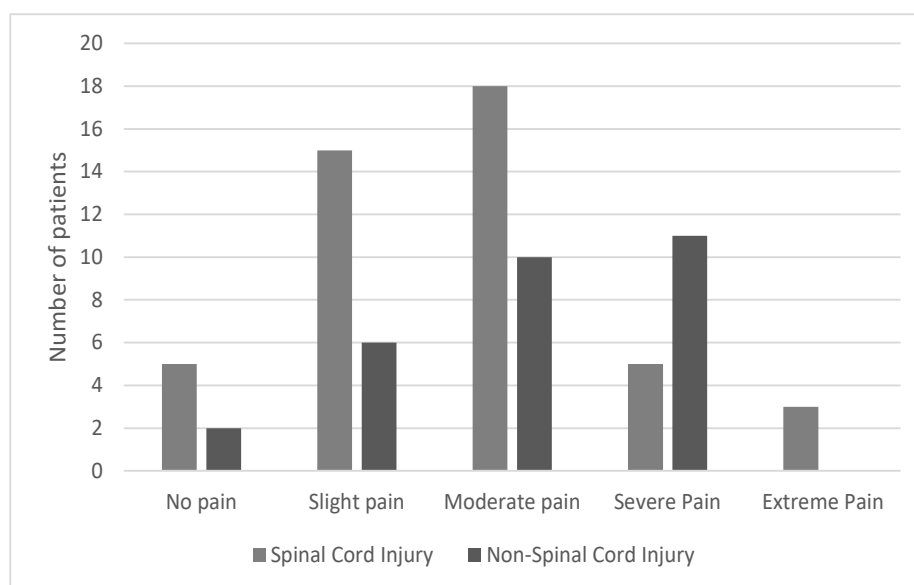
The Pearson correlation between the NRS and EQ-Pain scale was high ( $r = .78$ ,  $p < .001$ ) for the whole sample as well as in the sub-samples of SCI patients ( $r = .75$ ,  $p < .001$ ) and non-SCI patients ( $r = .82$ ,  $p < .001$ ). As this high correlation was found despite differences in answering format we can confirm that patients were indeed able to respond to the pain questions using the ET.

### Figure 1

*Frequency Distributions for the NRS (1A) and the EQ-Pain (1B)*

#### 1A



**1B**

The average NRS in patients with spinal cord injury ( $M = 4.20$ ,  $SD = 2.56$ ) was not different from the non-SCI group ( $M = 3.55$ ,  $SD = 1.74$ ;  $t(73) = -1.190$ ,  $p = .238$ ). Similarly, there was no difference for the dimension pain on the EQ-5D-5L between the spinal cord injury group ( $M = 2.70$ ,  $SD = 1.03$ ) and the patients without spinal cord injury ( $M = 3.03$ ,  $SD = .94$ ;  $t(73) = 1.432$ ,  $p = .64$ ). Overall, the values indicate mild to moderate subjective pain in the patients.

As pain demands attention (Eccleston & Crombez, 1999; Moore et al., 2012) it is conceivable that pain dominates reports concerning appraisals of health and well-being and fear. We therefore checked correlations between the pain measures and VASES as well as basic needs with a special focus on anxiety. Testing for correlations of the VASES score with the NRS ( $r = -.037$ ,  $p = .752$ ; SCI group:  $r = -.025$ ,  $p = .871$ ; non-SCI group:  $r = -.051$ ,  $p = .794$ ) and with the EQ-Pain ( $r = .094$ ,  $p = .424$ ; SCI group:  $r = .038$ ,  $p = .802$ ; non-SCI group:  $r = .176$ ,  $p = .361$ ) suggested that reports on self-esteem, depression and anxiety in the VASES are not dominated by perceived pain.

Table 2 and 3 in the Appendix show the correlations between the single items of the VASES with the NRS and the EQ-Pain. There were no significant differences in correlation among the two sub-samples. The upper and lower limits of the equivalence interval were set at  $-.2/.2$  (small effect) according to Cohen (1988).

To provide yet another test for whether pain rating might dominate appraisals, we determined with how many of the five basic needs patients dealing with anxiety agreed with (Ull et al., 2022). Again, there was no significant correlation for the NRS ( $r = -.02, p = .857$ ). For the correlation of the anxiety items with the EQ-Pain scale, a significant correlation could be shown ( $r = -.24, p = .041$ ). When considering the group level, a significant correlation was found for the non-SCI patient group ( $r = -.42, p = .023$ ), but not for the SCI patient group ( $r = -.15, p = .390$ ). When comparing the values between acute and chronic SCI (aSCI and cSCI), so likewise no significant differences in responses on the VASES or the anxiety items were observed.

## Discussion

In this study we investigated whether pain can be assessed via ET-based self-reports from patients who were unable to speak or use gestures. Additionally, we compared pain self-reports in SCI and non-SCI patients and assessed whether pain ratings might dominate self-esteem and anxiety. The main results of the study were as follows: (1) We were able to demonstrate that (despite different response format) the two self-report measures showed a high correlation. This means that the patients were able to report on pain via ET. (2) Comparing the two groups, the means and distributions were very similar. (3) Self-reported pain does not correlate with self-esteem and fear, so it can be assumed, that pain does not dominate appraisals.

Previous research of pain suggests that pain can significantly negatively affect an individual's behavior and cognitive processes, such as attention (Eccleston &



Crombez, 1999). Pain holds a special position among patients with spinal cord injuries due to altered transmission and perception of pain, and a secondary pain syndrome, which frequently accompanies SCI (Demirel et al., 1998). Additionally, Mueller et al. (2017) pointed out, that patients with SCI affected by at least moderately perceived pain showed higher scores on the depression scale and reported lower QOL. We found no difference among SCI and non-SCI patients in self-reported pain and its correlation with fear and self-esteem. This is in line with Khandelwal et al. (2022) who reported that the level of injury does not have a significant effect on the depression scale or anxiety.

Pain is a very common comorbidity in patients with SCI. One third of patients report pain (Brinkhof et al., 2016), with neuropathic pain being the most prevalent (Burke et al., 2016). Despite therapeutic approaches, the pain remains persistent (e.g. Finnerup et al., 2016). According to a statement by Siddall et al. (2003), individuals with neuropathic pain perceive it as severe to unbearable. This perspective suggests that we frequently find dominating self-reports of very strong and moderate pain in SCI- as well as non-SCI patients. This result is consistent with previous studies on pain perception in SCI patients (cf. Ullrich et al., 2008). The moderate pain intensities in patients with acute SCI may also be due to the fact that it may take up to a year for neuropathic pain to occur below the level of the lesion (Siddall et al., 2003). Furthermore, it can be argued that due to the severity of the injury and the resulting physical and psychological consequences for the patient, pain has not yet come into focus of consciousness, so neuropathic pain may not yet have played a significant role in these patients. Still it is relevant to note that SCI-patients perceive moderate pain, despite a good coverage with analgesia and pain management being standard in the ICU.

Based on the biopsychosocial model of illness (Engel, 1977), person- and context-related factors can also have influence on pain processing and perception in patients. Negative emotions, such as anxiety or low self-esteem, do not necessarily have to be caused by pain, as previous research has reported (Carver & Harmon-Jones, 2009). An environment perceived as stable, for example, can lead to pain being perceived as less dominant, and therefore attitudes and appraisals remaining unaffected by pain. A previous study by Weckwerth et al. (2022; in prep.), it was also shown that patients with SCI are less pessimistic than originally assumed despite the immense impact of the injury on their life.

Additionally, there may be a discrepancy between reported subjective pain and actual pain experienced. Maroney et al. (2004) report in their study that 31% of surveyed patients experience severe pain, but patients still report that this perceived severe pain is acceptable to them. The authors attribute this effect to the acceptance of intense pain by patients, due to the belief that the perceived pain is untreatable and must therefore be tolerated. This effect could also be transferred to the completion of pain scales and self-report instruments, raising the suspicion that the responses are influenced by a form of optimistic bias. As already mentioned, a possible less profound explanation for the moderate pain intensity, may simply be the good coverage with analgesia, good pain management, and good pain control in the intensive care unit. Perhaps the moderately perceived pain intensity has not yet affected subjective attitudes and appraisals, and the patient's responses to the self-report instruments were given while almost pain free patients'.

### **Conclusion and Future Perspective**

Using ET, we were able to assess self-reported pain in ICU patients who cannot use oral communication or gestures. Pain level was predominantly moderate, although

sufficient analgesia and pain management should have been provided. Mean levels and correlations with anxiety and self-esteem suggested that SCI and non-SCI intubated ICU patients are similarly affected by pain. Future research should make a stronger distinction between chronic and acute pain, and differentiate between chronic and acute SCI.

**Limitations**

Given the characteristics of the sample we were able to support our conclusions with a decent sample size. Yet, future studies and meta-analyses should strive for an even broader basis for conclusions. Furthermore, measuring neuropathic pain and recording the exact localization of the perceived pain might be possible in future studies.

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## Appendix

**Table 2**

*Correlation values for the respective VASES Items with the NRS*

VASES-Item	SCI		Non-SCI	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Not understood – understood	.095	.529	.092	.637
Not confident – Confident	.102	.501	-.041	.831
Not cheerful – Cheerful	-.087	.564	.351	.062
Not outgoing – Outgoing	.077	.609	.426	.021*
Mixed up – Not mixed up	-.098	.517	-.202	.294
Not intelligent – Intelligent	-.016	.917	.167	.385
Angry – Not angry	.181	.228	-.373	.046*
Trapped – Not trapped	.068	.655	.101	.601
Not optimistic – Optimistic	-.059	.699	.287	.131
Frustrated – Not frustrated	.014	.925	.268	.160

*Note.* \* $p < .05$ .

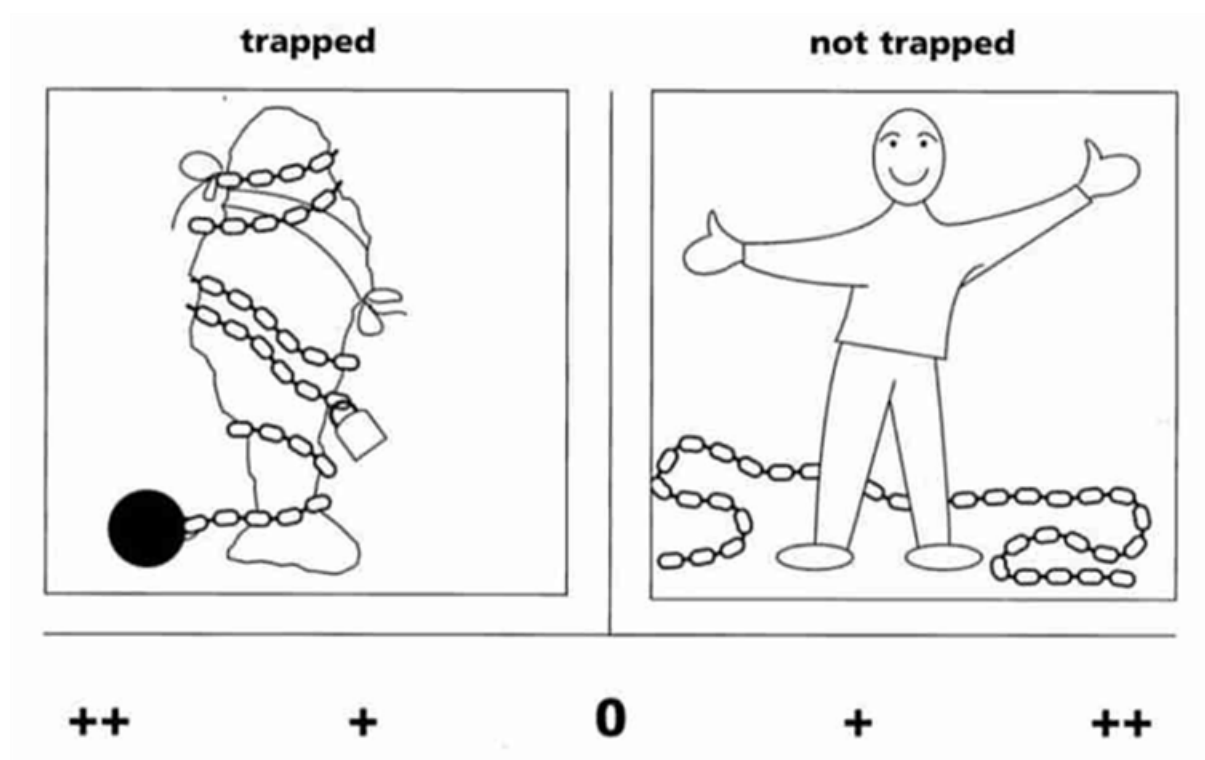
**Table 3***Correlation values for the respective VASES Items with the EQ-Pain*

VASES-Item	SCI		Non-SCI	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Not understood – understood	-.023	.882	-.174	.366
Not confident – Confident	.153	.311	-.104	.592
Not cheerful – Cheerful	-.032	.832	-.047	.810
Not outgoing – Outgoing	.033	.825	.082	.673
Mixed up – Not mixed up	.032	.831	-.220	.251
Not intelligent – Intelligent	.142	.346	-.045	.816
Angry – Not angry	.000	1.000	-.005	.981
Trapped – Not trapped	-.080	.596	-.133	.490
Not optimistic – Optimistic	.189	.209	-.007	.969
Frustrated – Not frustrated	.011	.944	-.023	.905

*Note.* \*  $p < .05$ .

**Figure 1**

*Bipolar scale of the VASES item feeling “trapped – not trapped”*



### **Erklärung der Autorin**

Hiermit versichere ich an Eides statt, dass ich die vorliegende Dissertation selbstständig und ohne unzulässige Inanspruchnahme Dritter verfasst habe. Ich habe dabei nur die angegebenen Quellen und Hilfsmittel verwendet und die aus diesen wörtlich, inhaltlich oder sinngemäß entnommenen Stellen als solche den wissenschaftlichen Anforderungen entsprechend kenntlich gemacht. Die Versicherung selbstständiger Arbeit gilt auch für Zeichnungen, Skizzen oder graphische Darstellungen. Die Arbeit wurde in gleicher oder ähnlicher Form weder derselben noch einer anderen Prüfungsbehörde vorgelegt und auch noch nicht veröffentlicht. Mit der Abgabe der elektronischen Fassung der endgültigen Version der Arbeit nehme ich zur Kenntnis, dass diese mit Hilfe eines Plagiatserkennungsdienstes auf enthaltene Plagiate überprüft und ausschließlich für Prüfungszwecke gespeichert wird. Es ist mir bekannt, dass wegen einer falschen Versicherung bereits erfolgte Promotionsleistungen für ungültig erklärt werden und eine bereits verliehene Doktorwürde entzogen wird.

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Ort, Datum

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Christina Weckwerth