

## Summary

After a major physical injury, people are confronted with loss of health and physical abilities. Most people need rehabilitation in order to learn to live with the consequences of their injury. Multidisciplinary teams of professionals help people to find new ways to live with their limitations and to develop new skills in order to adjust to the changes. Besides, or as a result of, the physical challenges, questions of meaning tend to arise when people encounter stressful life events like that. To address these questions, healthcare institutions in the Netherlands are obliged by law to provide or give access to chaplaincy or spiritual counseling. In most cases, however, rehabilitation focuses on physical factors, along with psychological and social adaptation, and considerably less on questions of meaning. This is understandable, since rehabilitation care is based on the biopsychosocial approach of the ICF. Even though this approach is more comprehensive than a strictly medical model, it does not automatically include a dimension of meaning and spirituality. The importance of meaning in rehabilitation is more and more recognized, although research on meaning in rehabilitation is scarce. A better understanding of what meaning can comprise and its role in rehabilitation may be important in supporting people in the process of adaptation to a major physical injury. In our research project, we focused on this somewhat neglected, but important area of rehabilitation.

**Chapter 1** introduces the diagnosis groups we focused on, and the concept of global meaning. We focused on two diagnosis groups: spinal cord injury (SCI) and stroke. The consequences of SCI and stroke affect all areas of life and often result in permanent changes that make daily life challenging. People with SCI face mostly physical consequences, whereas people with stroke may be confronted with consequences in the areas of cognition and personality as well. Each person with SCI or stroke reacts to this challenge in their own way. Some adapt seemingly easily, others experience more difficulty adapting, or distract from society. However different, people need to find a way to live a meaningful life again.

The goal of our project was to study global meaning in people rehabilitating from SCI or stroke. The term 'global meaning' refers to fundamental beliefs and life goals that guide people in living their lives, help them interpret their experiences and motivate them in their actions. Global meaning can be considered as the more fundamental level and needs to be differentiated from situational meaning. Situational meaning refers to specific beliefs about the traumatic event (appraisals), psychological processes aiming at reduction of distress ('meaning making'), and the outcome of these processes ('meanings made').

This study addresses two related research questions: (i) the content, as well as perceived continuity or change of global meaning in people with SCI or stroke and (ii) the perceived



influence of global meaning on processes and outcomes of rehabilitation according to people with SCI or stroke.

**Chapter 2** presents the results of the first part of our project: global meaning in people with spinal cord injury, content and changes. Since little is known about global meaning relating to SCI and whether global meaning changes after SCI, in this chapter we aimed to explore the content of global meaning of people with SCI, and to explore whether or not global meaning changes after SCI.

We conducted in-depth semi structured interviews with 16 people with SCI, who were living in the community, and were receiving outpatient rehabilitation in a Dutch rehabilitation center. Participants were purposively selected to include both men and women, younger and older clients, clients with or without a religious background, and clients with a more optimistic or a more pessimistic attitude (according to the physician in attendance). The interviews were audiotaped and analyzed according to the method of grounded theory.

The analysis resulted in five aspects of global meaning: core values, relationships, worldview, identity and inner posture. Core values are global beliefs about what is right and worthwhile. They give direction to thoughts and behavior. Relationships refer to a connection between a person and others, e.g. children, a spouse, a therapist or even a pet. Meaningful relationships and the experience of being connected are life goals. Worldview refers to fundamental beliefs about life, death, and suffering, that structure people's ideas on how life events are related. Identity refers to fundamental beliefs about one's deepest self, about who, rather than what a person is. Expressing one's identity provides people with a sense of belonging, at the same time underlining their uniqueness and self-worth. The fifth aspect, inner posture, refers to the way in which people relate to the facts of life.

Overall, we found little change in the content of global meaning after SCI. However, specific aspects of global meaning were foregrounded after SCI.

**Chapter 3** aimed to explore whether aspects of global meaning (i. e. fundamental beliefs and life goals concerning core values, relationships, worldview, identity and inner posture) were associated with processes and outcomes of rehabilitation, as experienced by people with SCI.

In the second part of the interviews with the 16 people with SCI, the questions evolved around the rehabilitation process and whether the respondents thought that their global meaning affected the process and outcome of their rehabilitation.

We found that core values, relationships, worldview, identity and inner posture were associated with various processes and outcomes of rehabilitation. Elements of the rehabilitation process included motivation, regulation of emotion, making decisions, and handling stress. Elements of the outcome of rehabilitation included physical functioning, emotional functioning, social functioning, and subjective sense of meaning. We found that the influence was positive, with the exception of one case in

which worldview and inner posture were negatively associated with motivation. Besides that, respondents emphasized the importance of rehabilitation professionals attuning to their global meaning.

In the conclusion of this chapter, it is recommended that rehabilitation professionals are aware of the importance of global meaning to people with SCI and that they take people's fundamental beliefs and life goals into account.

**Chapter 4** reports about the second part of our study: the content of and changes in global meaning in people with stroke. This chapter aims to explore global meaning in people with stroke and to explore whether global meaning changes after stroke.

In order to answer the research questions, we conducted in-depth semi structured interviews with 16 people who sustained a stroke for the first time. They had been discharged from the rehabilitation center, and were in outpatient rehabilitation. Participants were purposively selected to include both men and women, younger and older clients and clients with or without a religious background. Clients with severe communication problems were excluded. The interviews were analyzed using the method of grounded theory, using the interviewer's impressions, recorded in field notes as background material. Although previous research on people with SCI had already shaped ideas about global meaning, the researchers who analyzed the interviews were especially focused on the possibility that the interviews with people with stroke might provide different outcomes. Therefore, as customary in grounded theory, the initial interviews were open coded, close to the text, in order to find aspects of global meaning and change in global meaning.

Nevertheless, the same five aspects of global meaning were found: core values, relationships, worldview, identity and inner posture. Both continuity and change were found in global meaning, according to people with stroke. Continuity in all aspects was reported, but worldview, identity and inner posture were also subject to change. Continuity and change were found not to be mutually exclusive, but appeared to co-exist. The change in global meaning found in people with stroke contrasts with the results of our study on global meaning in people with SCI, in which no prominent changes were found. This may be a result of the fact that after stroke it takes a longer time to reach an end-state, compared to SCI. Or it may be related to the fact that the consequences of SCI are mostly physical, whereas stroke can have consequences in the areas of cognition and personality as well.

**Chapter 5** describes the perceived influence of global meaning on processes and outcomes of rehabilitation, according to people with stroke. The aim of this chapter was to explore whether global meaning is associated with processes and outcomes of rehabilitation, as experienced by people with stroke.

All aspects of global meaning were associated with the following elements of process and outcome of rehabilitation: motivation, handling stress and emotions, interaction with rehabilitation professionals, physical functioning and acceptance. The influence



was mostly positive. If rehabilitation professionals took global meaning into account, respondents tended to associate this with quicker or better recovery. This suggests that it is important for rehabilitation professionals to address their patients' global meaning. Addressing global meaning may lead to greater patient satisfaction and better rehabilitation care.

**Chapter 6** focuses on one of the aspects of global meaning: inner posture. Based on our empirical research on global meaning in people with SCI and people with stroke, we formulated 'inner posture' as a concept in rehabilitation. Inner posture, as we concluded from our empirical data, refers to the way in which people bear what cannot be changed. It helps them to live with their injury. Considering that much has already been written about meaning from a variety of disciplines, the question arises whether the concept of inner posture adds something new to the existing healthcare literature, or is just another name for a phenomenon that has already been described before in different terms. In this chapter, we aimed to investigate this and to clarify our conceptualization, by comparing the concept of inner posture with four influential concepts in healthcare literature which seem to be more or less related to our concept of inner posture. For each concept, we focused on one author. The four concepts (and authors) are spirituality (Puchalski), religion (Pargament), hope (Elliott) and attitude (Frankl). Because these concepts have various theoretical backgrounds, the comparison can help to better understand our concept of inner posture, through a process of dialogue between traditions, following Gadamer's notion of dialogue as fusion of horizons of understanding. We described each concept in its own context and related it to our concept, to explore how each concept can shed light on the phenomenon addressed in our concept of inner posture. We concluded that inner posture differs from the other concepts in several ways. Some of these differences are more fundamental, other are partial. This suggests that we identified a new perspective on a phenomenon partially described earlier. The comparison also inspired us to slightly adjust our definition and to formulate new research questions.

**Chapter 7** discusses the findings of the study and elaborates on them. We describe the differences between the two research groups, and discuss that these may be related to the way in which people talk about their lives with their injury. We relate this to Arthur W. Frank's theory on illness narratives.

After that, we discuss inner posture in relation to the other aspects of global meaning. Inner posture seems to be always interwoven with the other aspects, whereas the other aspects can also be found standing alone. Besides that, it seems to be neither a fundamental belief, nor a life goal, although it is based on beliefs and bearing the facts of life can be considered a life goal. This suggests that the definition of global meaning could be broadened to include fundamental attitudes, in addition to fundamental beliefs and life goals.

Next, we describe global meaning in rehabilitation care. The impact of global meaning on motivation is an important observation in our study. In rehabilitation, motivation is

considered a key element. Motivation is seen as an important predictor of rehabilitation outcomes. This suggests that future research may focus on the impact of global meaning on motivation in people in rehabilitation.

After that, we focus on global meaning in relation to psychological concepts, such as coping, and personality. We describe how modern personality theory is showing an increasing interest in aspects of global meaning.

This chapter concludes with methodological considerations and implications for future research and practice. We recommend developing a tool to incorporate global meaning in the process of goal setting, in order to improve motivation for and outcome of rehabilitation. Besides that, we recommend that rehabilitation professionals receive training in order to enhance awareness of the importance of global meaning, of their own global meaning, and how this may correspond or interfere with their patient's global meaning.

Finally, we discuss the relation of the healthcare chaplain and the multidisciplinary team: integrated or separated from the team in a free-space/sacred-space model.

In this study, we opened up a new field of rehabilitation and chaplaincy research. With global meaning, we addressed an important aspect of rehabilitation care. Addressing global meaning may improve rehabilitation care, including outcomes of rehabilitation.

