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# **ORIGINAL ARTICLE**

# The importance of 'global meaning' for people rehabilitating from spinal cord injury

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Study design: Qualitative study.

**Objectives:** To explore whether aspects of global meaning (that is, fundamental beliefs and life goals concerning core values, relationships, worldview, identity and inner posture) are associated with processes and outcomes in rehabilitation, as experienced by people with spinal cord injury (SCI).

Setting: People living in the community receiving outpatient rehabilitation in a Dutch rehabilitation center.

**Methods:** In-depth semi-structured interviews were conducted with 16 people with SCI. Interviews were analyzed using qualitative research methods: structural and provisional coding.

**Results:** Core values, relationships, worldview, identity and inner posture (that is, the way in which people relate to the facts of life) 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. 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.

**Conclusion:** All aspects of global meaning were positively associated with various processes and outcomes of rehabilitation. 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.

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# INTRODUCTION

Global meaning has been hypothesized to guide the process of adaptation to a traumatic event such as spinal cord injury (SCI), 1-3 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. In a previous study, we explored the content of global meaning in people with SCI. We found that global meaning in people with SCI comprises five interlinked, yet distinguishable aspects, that is, core values, relationships, worldview, identity and inner posture.4 Core values are fundamental beliefs about what is right and worthwhile. They give direction to thoughts and behavior. Relationships refers to a connection between a person and others, for example, children, a spouse, a therapist or even a pet. Meaningful relationships and the experience of being connected are important goals in life. Worldview is a more or less coherent set of 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. Expressing one's identity provides people with a sense of belonging, at the same time underlining their uniqueness and self-worth. Inner posture helps people bear what cannot be changed, which is an important goal in life. Inner

posture includes an element of acknowledgment and an element of action. It involves acknowledging the facts of life and relating to them. 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').<sup>2,3</sup>

In SCI research, psychological factors have been shown to be associated with indicators of adjustment to SCI, such as well-being, mental health and quality of life.<sup>5–9</sup> Psychological studies mostly focus on psychological processes, that is, situational meaning. Few studies have examined the role of global meaning in the process of adaptation to SCI. Supportive relationships have been identified as resources in adapting to SCI.<sup>10–14</sup> Spirituality, which is a part of *worldview*, has been found to influence adaptation to SCI.<sup>10,15</sup> These findings provide some support for the hypothesis that global meaning guides the process of adaptation to SCI. A comprehensive exploration of the role of fundamental beliefs and life goals in the adaptation to SCI (or other groups of people with disabilities) does not seem to be available.

On the basis of the general hypothesis that global meaning guides the process of adaptation to a traumatic event, <sup>1-4</sup> we explored whether

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people with SCI associated their global meaning with their rehabilitation, and if so with what elements of the various processes and outcomes of rehabilitation. Hence, the purpose of this study was to explore whether global meaning is associated with processes and outcomes of rehabilitation, as experienced by people with SCI.

## MATERIALS AND METHODS

### Design

Interviews were conducted with people with SCI by the first author 6–24 months after the participant was admitted to the rehabilitation center. The study was approved by the accredited Medical Research Ethics Committee Slotervaart Hospital and Reade (METC-study number P1153).

#### **Participants**

Participants were recruited from clients who had been discharged from Reade (center for rehabilitation) and were in outpatient rehabilitation. Clients with severe communication problems and psychiatric problems were excluded. 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). A letter was sent to potential participants, to which they could respond by returning a consent form.

#### Data collection

Between August 2012 and July 2013 the first author conducted semi-structured interviews with 16 participants, which resulted in 16 audio-recordings, with permission of the participants. The majority of interviews took place at the participants' homes. On average interviews lasted 1 h, the longest lasting 1 h and 38 min and the shortest lasting 24 min. The interviewer wrote down in field notes the observations she made before, during and after the interview, giving details of the broader interview situation, such as the occasional presence of a partner or friend, a radio playing religious songs and non-verbal aspects of the communication.

Interviews were loosely structured using a topic list, based on literature concerning global meaning.<sup>4</sup> (see Appendix 1) Part of the questions evolved around the rehabilitation process and whether the respondents thought that their global meaning affected the process and outcome of their rehabilitation. The interviewer did not use these exact words, but she would summarize the conversation so far and then ask for the influence on process and outcome of rehabilitation.

### Data analysis

Verbatim transcriptions were made of the recorded interviews, which were then analyzed by two researchers (EL and SD), using structural and provisional coding.<sup>16</sup> In the structural coding phase, the researchers structured the interviews in line with the research question about the relationship between global meaning and rehabilitation and identified quotes about processes and outcomes of rehabilitation. These quotes were then analyzed provisionally, using aspects of global meaning and determinants of process and outcome of rehabilitation as codes, to determine in what way global meaning affects the process and outcome of rehabilitation. During the interviews and at the beginning of the analysis, we did not have specific variables of process and outcome in mind. This is in line with the exploratory nature of qualitative research. We did not ask our respondents for specific components of the International Classification of Functioning, Disability and Health (ICF) or specific dimensions of quality of life; we used the generic term rehabilitation and analyzed afterward which domains of rehabilitation were mentioned by the respondents. During the analysis, we structured the quotes regarding rehabilitation using the ICF17 and rehabilitation literature. In that process, we found that the ICF provided descriptions for the quotes regarding processes and that the quotes regarding outcomes were best described using quality of life terminology. 18,19 The processes and outcomes we found are presented in the results section in Box 1: rehabilitation processes and Box 2: outcomes of rehabilitation.

Data were entered into a software program for qualitative data analysis and research, Atlas.ti (version 7.1.8). The analysis was based on the transcribed interview recordings, using interviewer's impressions, reported in field notes, as background material. The actual recording was readily available through Atlas.ti and used to listen to the tone of statements and remarks. The analysis reached a saturation point at 13 interviews, after which 3 more interviews were conducted that added no new information.

## **RESULTS**

Out of 29 invitations, 17 participants sent back the consent form, leading to 16 interviews; 1 interview was canceled because of medical reasons. Nine participants were male and seven were female; the age ranged from 26 to 79 years (Table 1). Two respondents were living in a nursing home, the other fourteen were living in the community.

All five aspects of global meaning (that is, core values, relationships, worldview, identity and inner posture) were found to affect various processes and outcomes of rehabilitation in people with SCI. Elements of the rehabilitation process that were affected by global meaning were motivation, regulation of emotion, making decisions and handling

Motivation	Regulation of emotion	Making decisions	Handling stress
Mental functions that produce the incentive to act; the conscious or unconscious driving force for action.	Mental functions that control the experience and display of affect.	Making a choice among options, implementing the choice and evaluating the effects of the choice.	Carrying out simple or complex and coordinated actions to cope with pressure, emergencies or stress.

Physical functioning	Emotional functioning	Social functioning	Subjective sense of meaning	
The ability to perform self-care activities (for example, eating, bathing, dressing), mobility and more strenuous physical activities.	Experiencing and acting on feelings of well-being or distress.	Maintaining social contacts and other activities (for example, visits with friends and relatives), and social ties or resources (for example, close friends and relatives who can be relied upon for tangible and intangible support).	The experience that life is meaningful or has a purpose and is worth living.	

Table 1 Respondent characteristics

Characteristics	Mean (range)
Age (years)	57.25 (26-79)
Time post-injury (months)	16.19 (9-24)
	No.
Sex	
Male	9
Female	7
Country of birth	
Netherlands	13
Morocco	1
Curacao	1
Egypt	1
Social status	
Single	5
Single with children	1
Married/living together with children	2
Married/living together without	7
children	
Living apart together <sup>a</sup>	1
Education	
Vocational training	2
High school	6
Community college	2
Undergraduate school	4
Graduate school	2
Religious background	
Christian	4
Muslim	3
Atheist	1
None	6
Other	2
Type of lesion	
Paraplegia	11
Tetraplegia	5
Completeness of lesion	
Complete	3
Incomplete	13

<sup>&</sup>lt;sup>a</sup>Married but living in a nursing home apart from spouse.

stress (see Box 1 for details). Rehabilitation outcomes affected by global meaning were physical functioning, emotional functioning, social functioning and subjective sense of meaning.

The relationship between aspects of global meaning and elements of process and outcome varied between respondents. However, over all respondents, all five aspects of global meaning were found to affect the various elements of process and outcome.

# Influence of global meaning on rehabilitation processes

Motivation. All aspects of global meaning were perceived to affect motivation in people with SCI. According to one respondent, relationships affected his motivation to rehabilitate:

"Life has a meaning, yes. In relation to other people, my wife for example. (...) I believe I still have value for other people. If you don't, you can just as well end it right away. (...) That has given me motivation during my rehabilitation. I want to be able to really contribute something again." (man, 59).

One respondent explicitly stated that his core values and his worldview gave him focus to rehabilitate. According to his worldview,

positivism and kindness are part of life, and this motivated him to stay focused in the process of rehabilitation:

"Positivism, kindness, (...) that fortunately still exists in the world. (...) I strongly believe that when you do good, you will be treated well. When you do bad things, you get bad things back. (...) I just say, like..., come on, bring it on. I'll just see what comes my way. And er..., that provides focus to rehabilitate." (man, 42).

For another respondent, global meaning was counterproductive to the rehabilitation process. His identity as a laid-back person, together with his worldview that everything just happens and you cannot influence it, and his inner posture of letting things come as they come affected his motivation to rehabilitate in a negative way:

"I always was a down-to-earth person, easy-going. I was contented. I still am. (...) What shall I say, it is fate. Everybody gets his fate. You cannot get around that. (...) I can't practice. I just can't." (man, 67).

Regulation of emotion. Identity, worldview, inner posture, relationships and core values were perceived to affect the regulation of emotion. One respondent's identity as a strong, religious woman helped her direct her energy to the rehabilitation process and not to waste it on crying. She thought it was all right to cry sometimes, but she did not want it to consume all her energy:

"Respondent: And then I told myself: 'you are not going to cry today'. (...).

Interviewer: Why not cry?

Respondent: Because it is a sign of weakness. And I am strong, am I not? I was the one capable of anything. I always said... I am religious too, you know. And I thought: what God has meant for me, bring it on, I can handle it. You know, like that. (...) I did not want to cry all the time." (woman, 59).

Another respondent's worldview helped him regulate his emotions when things got difficult. His worldview was that life is circular: everything goes on, back to the source, and then it starts again. This, combined with his inner posture of 'wanting to go on', got him back on track when he got overwhelmed:

"When we are sad, when things are heavy, my wife and I cry together, but then I say: 'stop, I have to go on'. And then I go on again. You just have to go on. (...) Everything goes on. Back to the source. And then it starts again. (...) One would be stupid to not go on, wouldn't one? Of course you go on, you just do." (man, 74).

Making decisions. Global meaning was found to affect the way in which people make decisions, as well as the content of the decisions. In the above-mentioned respondent, his worldview and inner posture of 'going on' helped him make the decision to do all he could, to be transferred out of a nursing home where, in his view, people were waiting for death to come. He could not live among people who did not want to keep going. He was transferred to another nursing home, where he was stimulated every day to exercise and to try and make progress. He chose to live in an environment that was in line with his worldview and his inner posture:

"Go on. That's the only thing, that's what I want, yes. (...) Well, it was a problem, for those people, every day, they were just waiting to go to sleep, and eventually die. They just wanted to die. They

didn't want to go on, but they had to. I thought that was terrible. (...) Here it is different. I like it here; this is much better. I had to do it, to move here." (man, 74).

For another respondent, her core values, identity, inner posture and worldview influenced the decisions she made concerning her rehabilitation. Her core value of being useful, her identity as a pastor and her inner posture of carefully prioritizing and choosing how to spend her energy increased the pace of her rehabilitation. Part of her worldview was that Jesus suffered for mankind; hence, suffering should not be necessary. She avoided what she saw as unnecessary suffering by not doing heavy physical exercises. This brought her in conflict with some of the therapists, but it also helped her to hold on and to accomplish her goals in her own way:

"I have become very dependent and now I try to be more independent, and not let myself be restricted too much by the physical aspects. But take up the other parts first: being useful in society, in church. By picking up those things and giving them priority, actually, the whole process of rehabilitation has gained momentum. But in (the rehabilitation center) they regularly told me that I could accomplish more. (...) Some therapists got the wrong impression that physical rehabilitation wasn't important to me. (...) On the one hand I like to bend things to my own will, and on the other hand I just go with the flow. (...) That is how I explore the boundaries and I recognize, that it is important to start close at hand." (woman, 57).

Handling stress. All aspects of global meaning were found to be helpful in handling stress and other psychological demands. A 42-year-old man with SCI chose to pay more attention to the good things than to the bad things in life. This inner posture, along with his core values of commitment and being the best person you can be, and his identity of a positive, active person helped him when he was tired or frustrated or when he felt sad. This provided him with a source of energy to handle the stress of living with SCI:

"[In two years, after rehabilitation,] which boss is waiting for me, 44 years old and having SCI? No, I can forget that. (...) [People ask:] does it not gnaw at you? I say: no. No. I won't allow it to gnaw at me. (...) I know that I am a strong person. I know that I am sporty. I have perseverance." (man, 42).

## Influence of global meaning on outcomes of rehabilitation

Physical functioning. Several respondents reported an influence of global meaning on their physical functioning. One respondent's worldview that God gives her strength affected her ability to walk again, hence she reported the following:

"Interviewer: has your life stance affected your rehabilitation process and your current functioning? Respondent: yes, of course, that is logical. (...) it has to do with my faith. I have a strong faith. That definitely helps. (...) People say: 'six months ago you could do nothing, and now you are walking again'. (...) That is strength. And my strength comes from my faith." (woman, 68).

Another woman's worldview that all people can grow and her identity of a strong woman, along with her positive inner posture of keeping on trying and fighting, affected her ability to shower and brush her teeth while standing:

"People can grow; I think everybody can. (...) You can feel how you grow inside. It is difficult to explain, but, you know, in the beginning I had to sit while showering, sit while brushing my teeth, that did cost a lot of strength. For you need strength you know, when you brush your teeth at the sink. Now I shower standing up, I brush my teeth standing up. (...) I always keep fighting, I keep my strength." (woman, 61).

Emotional functioning. All aspects of global meaning were found to affect emotional functioning. In one respondent, her inner posture of 'letting things come as they come and working hard', along with her core values of harmony and reliability, and the global goal of the relationships with her sons affected her emotional functioning:

"Angry, no. I don't get angry. That is energy for nothing. (...) It wouldn't help, because the boys also need to go on and pick up their lives again. And then there should not be some angry mother behind them." (woman, 65).

A 78-year-old man, with core values of humor and being interested in others, regarded the relationships in the rehabilitation center as an important factor in his emotional rehabilitation. Hereby he implied that relationships were important for his emotional functioning:

"My life has a meaning, even now. For my children, my friends, my girlfriend. They are happy with me, and I am happy with them. (...) When you are emotionally struggling and they can help you with that, that is important in rehabilitation too [besides the physical aspects]. For example, they forced me to eat in the common dining room. Then you are in a community, you start to talk with people. That is important. To live together, with other people. Not keeping yourself apart. Showing an interest in others." (man, 78).

Social functioning. Inner posture, identity, core values, relationships and worldview were found to affect social functioning. One of the above-mentioned respondents, the woman with the identity of being a pastor, the core value of being useful in society and her worldview of the kingdom of God breaking through, took up her responsibilities in society as soon as she could. During her in-patient rehabilitation, she tentatively took up her profession again by taking care of the sermon in a Christmas service in the rehabilitation center. In a memorial service for the shooting incident, as a result of which she got her SCI, she had an essential contribution, which meant a lot to many people and to herself:

"Well, I believe. In God. And also that the shooting accident does not have the last word, but that the kingdom of God breaks through. (...) Easter Monday was the memorial service and I was able to say something there too. (...) And that afternoon I could attend the prayer-service. (...) I am taking up my preaching again. That is one of the first things that has been taken up, actually." (woman, 57).

A respondent who as a result of his SCI was not able to work at the time of the interview chose to regard his rehabilitation as if it were his work. This allowed him to participate in society in a meaningful way. His inner posture of paying more attention to the good things than to the bad things in life, and his identity of a positive, active person, helped him do so:

"I think of it [rehabilitation], as my work now. Now I work on my health, my senses, my emotions, my personal things. And then I go to (the rehabilitation center) three days, the whole year, to exercise. (...) You go out to go to work, I go out to go work on my health. I was working on my future before, and I still am. Only the goal is different." (man, 42).

Subjective sense of meaning. All aspects of global meaning provided participants with a subjective sense of meaning. They experienced their lives as meaningful, despite, or sometimes as a result of, the changes due to their SCI.

A 63-year-old woman, who previously suffered from depression and felt lonely, now enjoys contact with people around her, such as friends, or strangers in the street, or the people who help her with her daily care. Relationships, being part of her global meaning, had always been important to her, but previously it was a struggle to maintain meaningful relationships. After SCI, as she reported, her inhibitions decreased. Her SCI had been a catalyst in this process. The possibility to shape her relationships and her core values of being interested in people and being helpful to another person gave her life a new meaning:

"In general, my life hasn't gotten worse. Of course there are many disadvantages, and it isn't nice, not being able to go to bed by yourself, I mean... and being dragged along, but that is only now and then. And moreover, I have become closer to my friends. (...) Most people talk more about themselves to me now. About their worries, their problems. Even in a way that now and then I get the feeling: I resemble the local Wailing Wall." (woman, 63).

In one of the above-mentioned respondents, his global meaning affected his motivation to rehabilitate in a negative way; however, it also provided him with a subjective sense of meaning, which made it easier to live with his SCI:

"Respondent: It is fate. I don't blame anyone. Not anyone else, not myself. (...) When I die tomorrow, well, I think... it would be sad for my wife, but, yes, I have had a good life. I have done everything that I wanted to do and have got everything I want to have. (...) I am a contented person. Wife: He is rather cool about it. He may be a bit lazy, but perhaps that's a good thing. Makes it bearable." (man, 67).

# **DISCUSSION AND CONCLUSION**

### Discussion

In this study, we found that aspects of global meaning (that is, core values, relationships, worldview, identity and inner posture) were associated with various processes and outcomes of rehabilitation in people with SCI. Our respondents reported about the following elements of the rehabilitation process—motivation, regulation of emotion, making decisions and handling stress—and the rehabilitation outcomes—physical functioning, emotional functioning, social functioning and subjective sense of meaning.

## Global meaning and processes and outcomes of rehabilitation

Associations for global meaning with various processes and outcomes of rehabilitation augment the current literature, which mostly focuses on the impact of situational goals, beliefs and processes. For example, in literature, the importance of supportive relationships in the adaption to SCI is widely recognized. Social support from family

and friends, peer mentoring and support from professionals have been found to be resources for emotional adjustment and motivation. <sup>10,20,21</sup> However, these studies focus on the processes in relationships that affect adaptation to SCI. Our study addresses the impact of relationships as a life goal. Our respondents reported about relationships as an aspect of global meaning to influence elements of the rehabilitation process, such as motivation, regulation of emotion, making decisions and handling stress, and outcomes such as physical, emotional and social functioning, as well as a subjective sense of meaning. Global meaning has been hypothesized to guide the process of adaptation to SCI. <sup>1–4</sup> Therefore, relationships as an aspect of global meaning (*viz* a life goal) may guide the psychological processes through which social support affects adaptation to SCI. More research is needed to study the mechanisms behind this.

The same applies to coping. In current literature on adjustment to SCI, coping is an important factor.<sup>8,9,21,22</sup> Coping can be seen as related to the concept of inner posture. However, coping strategies are applied in a specific situation,<sup>23</sup> whereas inner posture refers to the way people deal with life events in general. Inner posture, being part of global meaning, may drive coping processes, which are part of situational meaning.

Studies on spirituality of people with SCI focus mainly on spiritual or religious coping<sup>24</sup> or on the question whether spirituality grows or decreases after SCI.<sup>25</sup> In general, spirituality is found to influence general health and to provide motivation in life.<sup>3</sup> Some state that spirituality influences adaptation to living with SCI<sup>15</sup> or gives strength to continue with life.<sup>10</sup> The present study provides a broader perspective: not only spirituality but also other aspects of worldview, for example, the thought that life is circular or that everything just happens and one cannot do much about it influence the rehabilitation process.

Respondents reported about the influence of global meaning on the outcome of rehabilitation in terms of physical, emotional and social functioning. Besides that, they indicated that they experienced their lives as meaningful, despite, or sometimes as a result of, the changes due to their SCI. This subjective sense of meaning appeared to be an important outcome of rehabilitation to them.

For the most part, participants felt that their global meaning positively affected processes and outcomes of their rehabilitation. However, in one case, several aspects of global meaning were counterproductive to an element of the rehabilitation process. In this particular case, the respondent's laid-back identity, his worldview that things just happen and one cannot do much about it, and his inner posture of letting things come as they come had a negative influence on the motivation to practice.

Besides that, global meaning can sometimes cause conflict with rehabilitation professionals when they do not respond to it or do not recognize it as valuable and helpful. The response of professionals, or the lack of it, to the global meaning of people with SCI can affect, for example, a person's motivation. One respondent's core values affected her motivation to rehabilitate. Her core values of respect, valuing people and treating each other with warmth, were met in one rehabilitation center and not in another. She related this to her ability to open up and fully engage in the rehabilitation process. In the first rehabilitation center, the rehabilitation professionals addressed her core values. This motivated her to actively engage in the rehabilitation program. She felt that later on her rehabilitation was not showing any progress, which she regarded as a consequence of the fact that her core values were not met in the second rehabilitation center.

### Methodological considerations

In this qualitative study, we assessed how people experience the role of global meaning in rehabilitation. It clearly shows that, according to people with SCI, global meaning is important in several processes and outcomes of their rehabilitation. All respondents reported an influence of global meaning on processes and outcomes of rehabilitation. However, the sample size was small and selection bias cannot be excluded: the respondents may have had a prior interest in global meaning. We do not have information from the people who refused to take part in the study.

This qualitative study generated hypotheses on the role of global meaning in rehabilitation. Future research is needed to empirically test whether global meaning is associated with these and perhaps other processes and outcomes of rehabilitation.

In some interviews, a spouse or a friend was present. This can be seen as both a limitation and a strength. The respondent may not have told everything, because he wanted to protect his spouse from certain ideas. Yet, the interaction between the respondent and the spouse or friend provided the interviewer with information that would otherwise be unavailable (for example: the friend of one of the respondents reminded him of his belief in miracles, which led to the respondent telling about the importance of his faith in his rehabilitation).

## Conclusion

All aspects of global meaning, that is, core values, relationships, worldview, identity and inner posture, were positively associated with various processes and outcomes of rehabilitation; the elements of the rehabilitation process included motivation, regulation of emotion, making decisions and handling stress; the outcome elements included physical functioning, emotional functioning, social functioning and subjective sense of meaning. It is recommended that rehabilitation professionals are aware of the importance of global meaning to people with SCI and that they take people's global meaning into account.

## **DATA ARCHIEVING**

There were no data to deposit.

## CONFLICT OF INTEREST

The authors declare no conflict of interest.

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## APPENDIX 1

Topic list global meaning

- 1. Could you tell me what happened to you?
- 2. What has changed?
- 3. What has remained the same?
- 4. Do you think your SCI has a meaning or a purpose?
- 5. Do you think life in general has a meaning or a purpose?
- 6. What is really important to you in life?
- 7. When do you get annoyed?
- 8. What do you hope others will say or think about you?
- 9. If I ask you: 'Who are you?' what would be your answer? (Please finish the sentence: I am ... someone who ...)
- 10. Could you share some of your thoughts about death with me?
- 11. How do you manage to live with your SCI?
- 12. Has what we have discussed so far affected your rehabilitation? In what way?
- 13. Is there anything else you would like to say, in reaction to the interview so far?
- 14. How did you experience this interview?