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### How do men with paraplegia choose activities in the light of striving for optimal participation? A qualitative study, based on a phenomenological-hermeneutical method

Dominique Van de Velde <sup>a</sup>, Piet Bracke <sup>b</sup>, Geert Van Hove <sup>c</sup>, Staffan Josephsson <sup>d</sup> & Guy Vanderstraeten <sup>a e</sup>

<sup>a</sup> Department of Rehabilitation Sciences and Physiotherapy, Ghent University, Ghent, Belgium

<sup>b</sup> Faculty of Political and Social Sciences, Ghent University, Ghent, Belgium

<sup>c</sup> Department of Special Education, Ghent University, Ghent, Belgium

<sup>d</sup> Division of Occupational Therapy, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden

<sup>e</sup> Department of Physical and Rehabilitation Medicine, University Hospital Ghent, Ghent, Belgium

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## How do men with paraplegia choose activities in the light of striving for optimal participation? A qualitative study, based on a phenomenological–hermeneutical method

Dominique Van de Velde<sup>a\*</sup>, Piet Bracke<sup>b</sup>, Geert Van Hove<sup>c</sup>, Staffan Josephsson<sup>d</sup> and Guy Vanderstraeten<sup>a,c</sup>

<sup>a</sup>Department of Rehabilitation Sciences and Physiotherapy, Ghent University, Ghent, Belgium; <sup>b</sup>Faculty of Political and Social Sciences, Ghent University, Ghent, Belgium; <sup>c</sup>Department of Special Education, Ghent University, Ghent, Belgium; <sup>d</sup>Division of Occupational Therapy, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden; <sup>e</sup>Department of Physical and Rehabilitation Medicine, University Hospital Ghent, Ghent, Belgium

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The objective of this study was to explore the experiences of men with paraplegia with regard to how they choose activities. The study involved a qualitative research design, based on a phenomenological–hermeneutical method. The findings revealed that the activities participants were choosing could be on a continuum between the individual's self and the influence from their environment. On this continuum, the choice to perform activities was influenced by two mediating factors: the individual's activities performed during their life-history, and their activity challenges for the future. We conclude that choosing activities is an individually constructed internal process of negotiation. Feelings of resignation and revolt appear in combination with feelings of justice and injustice when balance is not found. This knowledge provides a better understanding of the impact of spinal cord injury, sheds light on the development of distress after spinal cord injury and sheds new light on individuals' feelings of participation.

**Keywords:** participation; activity; spinal cord injury; self-concept; justice

### Points of interest

- To prevent emotional distress, it is recommended to enable individuals to choose activities in line with their 'self', the environment, the performed activities during their life-history and their future activity challenges.
- Taking these four aspects into consideration leads to a balanced choice of activities.
- Unbalanced choices can lead to emotional distress, and four different types of stress emerged from the data: revolt and justice, revolt and injustice, resignation and justice, and resignation and injustice.
- When striving for optimal participation; it is recommended to help clients to become aware of their own (highly individual) choice-making process with regard to activities.

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\*Corresponding author. Email: dominique.vandavelde@ugent.be

## Introduction

### *Participation as the ultimate goal of rehabilitation in spinal cord injury*

Over the years, different perspectives on disability have been developed. During the past decades, the health and social policy in western countries was based on a biomedical model that viewed disability as a purely personal problem (Wade and Halligan 2004). This biomedical conception of disability has been the subject of critique (Imrie 2004) because it has been argued that these models can no longer explain all the different forms of illness (Wade and Halligan 2004). Despite the importance of the biomedical models and the relevance for many disease-based illnesses and the supporting biological findings, it is argued that there is an increasing acceptance that health is determined not merely by behavioural, biological and genetic factors, but also by a range of economic, environmental and social determinants. These other factors affect the perception of the individual on what it feels like to be ill, and what it means to be healthy (Timmermans and Haas 2008). It has been identified that this growing emphasis on social determinants created a paradigm shift towards a social model of illness and focuses on the causation of disability by society rather than the whole spectrum of illness (Timmermans and Haas 2008). Also this purely social thinking has been the subject of critique, and different authors responded and criticized this excessively narrow focus of illness (both social or biomedical) and offered a holistic alternative to the prevailing biomedical model and social model (Engel 1980). Engel was the first to emphasize the various dimensions of illness (biological, psychological, and social dimensions) and created a new model that came to be known as the bio-psycho-social model (Borrell-Carrio, Suchman, and Epstein 2004). The paradigm shifts to this bio-psycho-social model had implications in the rehabilitation approach. Concepts such as community integration, inclusion, customer orientation, autonomy, and also the concept of participation became more important in rehabilitation (Van den Heuvel 2000). Nowadays, it is argued that rehabilitation medicine strives to enable people to perform daily activities and resume participation in life-roles after being affected by injury. There has been a tendency to regard participation, defined as 'involvement in life situation' (World Health Organisation 2001) as the ultimate goal of a rehabilitation programme (Stucki, Ewert, and Cieza 2003).

### *The development of distress through activity limitations in spinal cord injury*

The progress achieved in medical treatment has a major impact on the survival rate of individuals with spinal cord injury (SCI), and life expectancy continues to increase substantially (Strauss et al. 2006). That means that the focus has shifted to the importance of the long-term consequences of SCI (Spreyerman et al. 2011). One of the aspects in considering the long-term consequences is the ability to perform preferred activities after the rehabilitation period (in the domains of self-care, productivity and leisure). Furthermore, it is widely accepted that not taking part in activities is a major contributor to the burden of disease in people with SCI. Research has shown that it prevents people from leading a satisfying life and from participating in society (Hammell 2010). There is evidence that physical environmental factors influence the level of involvement in activities (Fekete and Rauch 2012). For example, lack of financial resources (Scelza et al. 2005), lack of equipment (Kerstin, Gabriele, and Richard 2006) and low accessibility (Kehn and

Kroll 2009) are described as barriers and exclude individuals from taking part in activities. In turn, positive and negative attitudes from others are also reported as possible barriers or facilitators (Levins, Redenbach, and Dyck 2004). Additionally, the existing knowledge shows that a low level of autonomy in choosing and performing activities is a major indicator for developing psychological distress (Scivoletto et al. 1997) and that the loss of control in choosing and performing activities negatively influences self-concept and may lower self-esteem (Blanes, Carmagnani, and Ferreira 2009). Experiences of chaos, inner tension, uncertainty, lack of knowledge, vulnerability, defencelessness, fear, instability, emotional loss of control, sorrow, guilt, shame, aggression and depression are described as the outcomes of this psychological distress (Lohne 2009). Although these experiences have been extensively described, the nature and the development of this psychological distress after SCI still has not been completely investigated and needs further exploration (Österaker and Levi 2005). Furthermore it is described that interrelations between psychological resources and participation (as a key outcome of rehabilitation) are rarely studied in SCI (Peter et al. 2012).

Taking into consideration the above-described barriers and the development of psychological distress, it is not surprising that people with SCI have a different activity pattern in comparison with the able-bodied population. People with SCI spent on average 7.2 h in leisure activities during one day (able-bodied men = 6.0 h), 4.7 h in productivity (able-bodied men = 7.7 h), and 3.7 h in self-care (able-bodied men = 2.3 h). The authors of this study concluded that individuals with SCI are somewhat socially isolated and lead a life dominated by inactive leisure pursuits and limited productive activities in comparison with the able-bodied population (Pentland et al. 1999). This changed activity pattern together with the described barriers and the accompanying development of distress provides a valuable insight into the importance of being able to perform meaningful activities. It is a known principle that activity choices are influenced by three variables: organic variables (i.e. the medical condition), person variables (i.e. personality), and environmental variables (i.e. family support) (Scivoletto et al. 1997), but it remains unclear how individuals with SCI choose their activities and what happens during this process. It was the goal of this study to focus on this choice-making process as it is experienced because this aspect remains under-investigated.

## **Materials and methods**

### ***Study design and theoretical basis***

The present study used a qualitative research design with a phenomenological–hermeneutical method (Lindseth and Norberg 2004). This method is interpretative and consists of three phases. The first phase is the naïve interpretation. This is followed by a structural analysis. In the final phase, a comprehensive understanding is formulated.

### ***Participants, sampling method***

The cases were selected purposively using a homogeneous sampling strategy (Patton 2002). Male participants were recruited from a SCI rehabilitation unit based on the following criteria: sudden onset of thoracic SCI; medically stable, with no other diseases possibly influencing the level of participation; age between 20 and

65 years; cognitive ability to understand both verbal and written information; the capacity to respond to questions during the interview; a minimum of one week and a maximum of two months post discharge from the rehabilitation centre (defined as the transition period); and before their injury, having been involved in the regular economic circuit (meaning being an employee or employer, earning money and being able to make a living).

The choice to include only male participants with a thoracic SCI was based on a methodological feature of qualitative research to gain a clear insight into the experiences of a purposively selected group of participants. Because there is an evident relationship between the physical dimensions of health-related functional status and the lesion level (Dallmeijer and van der Woude 2001) and there are important differences in how certain symptoms may be experienced by men and women (Kalpakjian et al. 2009) with SCI, we chose to focus on this homogeneous group. The transition period from the rehabilitation centre to home was chosen for two reasons: at this stage, individuals gain independence and begin to make decisions that will affect the rest of their lives (Kendall, Ungerer, and Dorsett 2003); and individuals engage in self-reflection or dialogue with themselves, especially when they are in a transitional phase in life (Stanley and Cheek 2003). It was assumed that rich information about their experiences could be gathered during this transition period. Moreover, this period was also chosen because it is argued that engagement in meaningful activities is relevant for a successful transition period (Gage, Cook, and Fryday-Field 1996). The study sample initially included nine individuals who met the inclusion criteria. As the interpretive process emerged, the nine initial participants were interviewed a second time and a third time between one and two months after discharge, and three new participants who met the same criteria were recruited until saturation of the data within this specific sample was achieved. The 12 participants ranged in age from 25 to 56 years.

### ***Data collection***

The participants were asked to narrate their experiences through an open-ended initial question: 'Can you please tell me something about the activities that you like to do?' Then they were encouraged to go deeper into their narratives through follow-up probes, such as: 'What exactly do you mean by?', 'What did you feel when you were performing this activity?', 'Why do you like this activity so much?', 'What exactly did you do when you felt like this', and so forth. The probes were altered based on the participants' responses. All interviews took place at the home of the participants. The interviews were conducted and analysed in an iterative process, whereby information obtained in previous interviews was used to amend the later interviews. The interviews were disc-recorded and transcribed verbatim. Twenty-eight interviews were performed and resulted in 1455 minutes of recorded data. The study was approved by the local Ethics Committee. Interviewees gave written informed consent.

### ***Data analysis***

To achieve a naïve understanding, the data material was first read through. The naïve understanding of the data is a very preliminary interpretation of the meaning of the whole and it is a circular rather than a static process. The analytical process

started with the first interview and ended when all interviews of all the participants had been conducted. Each interview was read thoroughly several times to capture the first understanding of this specific interview of one participant. After the follow-up interviews of this participant, all of the interviews were clustered and read as a whole. This clustered set of interviews of one participant was called 'a narrative'. Eventually, all of the narratives from the 12 participants were read in relation to each other. This was a process of going back and forth until a first naïve understanding was conceived. In a second phase, a structural analysis was performed to validate or invalidate the understanding gained from the naïve understanding. The connections and the patterns of the text were uncovered by dividing the text into 'meaning units', condensed meanings, subthemes and themes (Table 1), and resulted in a description of different themes. In the third phase (interpretive phase), relations between the different themes were searched for and different typologies were discovered. Finally, the findings were recontextualized in a comprehensive understanding. In this phase; the text was read again as a whole and the research question, the pre-understanding of the influences on activity choices and the generation of distress related to the inability to perform, the naïve understanding, and the results of the structural analysis were taken into consideration. Techniques to ensure trustworthiness of the analytical procedures included: a prolonged engagement of the interviewer in the field to obtain trust and an adequate representation of the participants' 'voice' by understanding the culture the participants live in; and member checks (Lincoln and Guba 1985) to check the authenticity of the ongoing analysis

Table 1. Example of a structural analysis of a meaning unit.

Meaning unit	Condensation	Subtheme	Theme
To me it has always been important to have a job and ...	Important to have a job	Having a job as a personal ideal or goal	Being connected to the self
Euh something I used to talk about and I now might have the time to do, is politics	Talking about activities	Past interest in activity	Mediating through life history and future challenges
And then, I will continue to be involved in sports as I have always been, I'm a sportsman you know	Politics as possible future activity Continuing to be involved in sports, being a sportsman	Future interest in politics as an activity Present interest in sports as an activity	Being connected to the self
And now I have started again, playing basketball ...	Starting sports again	Connecting past to future	Mediating through future challenges
It is hard, you know, starting from zero, but I'm a go-getter and ...	Tough to start again	Positive experiences through involvement in activities	Being connected to the self
Euh ... furthermore, I'm involved in a project from the local municipality, ....	Involvement in a local activity	Involvement in activities through environmental pressure	Being connected to the environment

Source: From Participant 7, In-depth Interview 15.

process. After these first member checks, the new acquired information was used to amend the follow-up interviews. A second member check was used to validate the phase of the theme development (Lincoln and Guba 1985). Debriefing of the analysis and the preliminary results and discussing this within the research team were performed to triangulate the findings.

## Results

### *Phase 1: naïve understanding*

The narratives showed that they directed their focus at three points in time: before the injury, the injury itself, and the future. The experience of choosing activities appeared to be an ongoing process dominated by their earlier interest in specific activities within different domains (self-care, productivity and leisure). After the injury, their choices appeared to be related to the traumatic moment and the participants were preoccupied with thoughts of what their activities might have been like. Their future ability to choose preferred activities was described as being uncertain, but hopeful.

### *Phase 2: structural analysis*

The structural analysis resulted in three themes, which are presented in Table 2. These themes are described separately in the following section and are illustrated with quotations from the interviews. Abbreviations (P, participant; IDI, in-depth interview) following each quote indicate from which interview the quote has been derived.

#### *Choosing activities by being connected to the self; being faithful to your ‘self’*

The central tenet that emerged from the analysis was the participants’ urge to describe who they were by doing activities in which they showed interest or fascination. Choice of activity before and after SCI was triggered by and closely linked to the view individuals had of their self in relation to the environment. One participant who had been interested in car tuning before the SCI and still was after the injury (with help from his 14-year-old son) expressed this as follows: ‘You show them who you are, I tune my car to show people what I can do, some do it in a marginal way, I do it well and people respect me for what I’m doing’ (P-3, IDI-16). In the process of choosing activities after the SCI, the participants’ experiences of not being able to perform desired activities resulted in feelings of ‘frustration’. These feelings motivated them to adopt a new way of reasoning and decision-making. Some participants continued with the same activity, expressing that the

Table 2. Themes related to how persons with SCI choose activities.

Theme
Choosing activities by being connected to the self; being faithful to your ‘self’
Choosing activities by being connected to the environment; experiencing environmental pressure, facilitators or barriers
Activities during life-history and activity challenges as mediating factors in the process of choice



only way to show who they were was the activity itself. Thus, the activity itself was a primary goal. If the participant was no longer able to perform the activity, he searched for social support by appealing to family and friends or by taking advantage of specialized organizations (such as specific SCI associations, voluntary groups, professional organizations and governmental support). Other participants described that it was not necessary to hold on to the exact same activity as before the SCI. Being able to show who they were by performing activities (regardless of the type of activity) was far more important. One of the participants, a former soccer player, expressed this as follows: 'I will continue to be involved in sports, I have always been, I'm a sportsman you know, ... and now I have started again, playing [wheelchair] basketball ...' (P-7, IDI-7). In this particular situation, the activity itself was not the primary goal, but alternative activities were performed in line with the activities that the participants engaged in prior to the SCI. The analysis identified yet another common experience in the participants' narratives: besides the urge to tell who they were by doing activities, the participants momentarily found themselves in a precarious situation because of the uncertainty of being able to perform activities. The fear of losing one's identity because of the loss of valued activities was frequently stressed by the participants:

I'm afraid I won't be able to do these things anymore [small jobs around the house] ... it was my life if I could fix the roof-gutter or clean the driveway, this is how I'm conceived ... what if I cannot longer, ... who the hell will I be? (P-11, IDI-26)

In conclusion, the analysis of the whole set of interviews suggests that choosing activities was fundamental and related to the individual's self; who was he, and who did he want to be by performing activities?

***Choosing activities by being connected to the environment; experiencing environmental pressure, facilitators or barriers***

While performing activities to achieve something supporting their identity (in line with their self as described above) was highly valued by the participants, it was frequently stressed that choices to engage in activities were often triggered by the environment. The participants expressed that they were insecure about their own physical capacities. Through the analysis and data comparison, it became clear that the central tenet from the first interviews was slightly different compared with the follow-up interviews. In the beginning of their transition from the rehabilitation centre to home, the participants actively searched for social support and a connectedness with the social environment, and they were only passively involved in the choice of their activities. This connectedness with the environment was two-fold: experiencing expectations from the environment, and experiencing opportunities created by the environment. Two excerpts illustrate this primary analysis. With regard to expectations, one participant said: '... my friends expect me to be there and help them to prepare the fish bait. It is hard [because he can't join them for fishing], but I'll try to meet their wishes' (P-4, IDI-3). With regard to opportunities, another participant said:

Piekernie [an organization that organizes special events for people with SCI] made it possible for me to go to the movies because I had been wanting to do this for a long time already ... I hadn't gone to the movies since last summer ... I just couldn't do it without help. (P-12, IDI-21)

However, it should be stressed that the participants considered this environmental steering to perform activities as positive (facilitating the choice of activities) in some occasions and as negative (inhibiting the choice of activities) in others. When comparing the analyses from the first interviews with the follow-up interviews, it became clear that, over time, the participants were no longer satisfied with a passive role, while this had not been so much of an issue at first. The participants' choice-making process changed from being passive and relying on the environment to being active. Unexpected negative feelings towards environmental influence and dissatisfied desires influenced this shift. They started to react against these feelings, and this triggered them to start acting accordingly. An example of how choice-making changed over time is described in the following excerpt when a participant was confronted with the story from his first interview during his second interview (five weeks later):

Remember when I talked about my friends going fishing ... you know I don't help them out any longer [to prepare the fish bait]. I struggled a lot about what to do, and I was friendly when they came to me asking to help them out. I think it was because they wanted to help me, and give me a reason to exist. It was so important for me to say 'please leave me alone', I don't need this stuff any more. Somehow, it strengthened me, I have to do things I want to do, not because they feel they have to ask me. (P-4, IDI-11)

These feelings about and confrontations with environmental steering depend on the impact from the environment on their own activity preferences and is a complex inner process, which will be further described in the next theme.

### *Activities performed in life-history and activity challenges as mediating factors in the process of choice*

As described above, the participants expressed their concern about the impact of the environment on their choices. Participants experienced feelings of not being genuine in the way they made choices. Different participants told stories about this experience:

... I peeled the potatoes, because D. [his wife] told me to do so, it was supposed to be good for me ... In the beginning it felt good ... They know better and I just try to act the way they want me to act ... After a while, I started to peel the potatoes without being asked, and then my wife has the feeling that it was my choice ... let me tell you something, it isn't, it's her choice. But I saw that she felt good, ... I realised that I just did it for her ... (P-10, IDI-25)

Excess environmental steering can lead to 'non-genuine' choices. The participants felt that choices could only be genuine when they were exclusively triggered by who they were. However, they stressed that this was not achievable and the goal should rather be to find balance between environmental steering and who they were. In this balancing process, two aspects were considered: the individual's activities performed in life-history, and the individual's activity challenges. Participants stressed that in their process of choice of which activities to perform, they reflected on how they did it in the past and took into consideration which activities they wanted to perform currently and in the near future. One participant explained this in one sentence:

... it felt good when I prepared the plaice, ... see ... I was always around in the kitchen and my mother forced me a little bit to cook when I was younger. It became a part of me and now I want to improve my skills ... in cooking, she [his wife] loves it when I make a special dish. (P-4, IDI-3)

The findings revealed that activities were chosen on a continuum between the individual's self (Figure 1) and the influence from his environment (Figure 1). In the early stages of the analysis process it seemed that the self and the environment were two arbitrary different concepts. However, through further and deeper analysis by constantly comparing the data to find similarities and differences, it became clear that for the participant himself the two concepts were more adjacent than initially thought. Within the process of choosing activities, the participant himself is not aware of this detachment between the self and the environment, but considers this as a continuous series of a whole; it is a continuum of experiences in which choices are made. On this continuum, the choice to perform activities is influenced by two mediating factors; the individual's activities performed during life-history (Figure 1) and his activity challenges for the future (Figure 1). The lines between the different topics of this representation show the dynamics of the process and the possibility of getting out of balance.

### *Phase 3: comprehensive understanding of choosing activities*

When an individual has made a balanced choice, he experiences a feeling of justice. In particular, justice was experienced when in the process of choice-making there was no significant difference with the choice-making process in the past. It can be defined as the experience when the chosen activities (guided by who they were or the environment) satisfy the person's inner needs or promote him to being part of the community. Although it is the goal to make balanced choices in activities, in normal day-to-day situations, optimal balance as shown in Figure 1 is not always achievable. A conflict between what the person wants and what the environment expects from him could result in a feeling of injustice. Injustice was experienced when the participants had a feeling of missed opportunities in the past and/or had

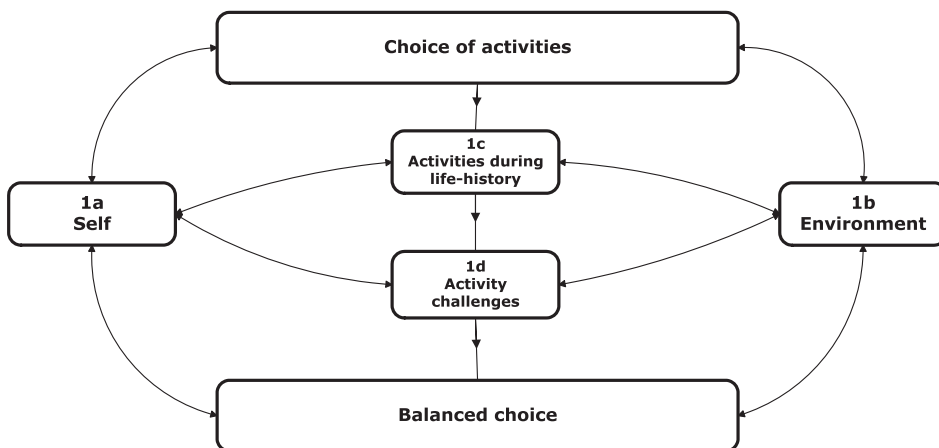


Figure 1. Diagrammatical representation of a balanced choice.

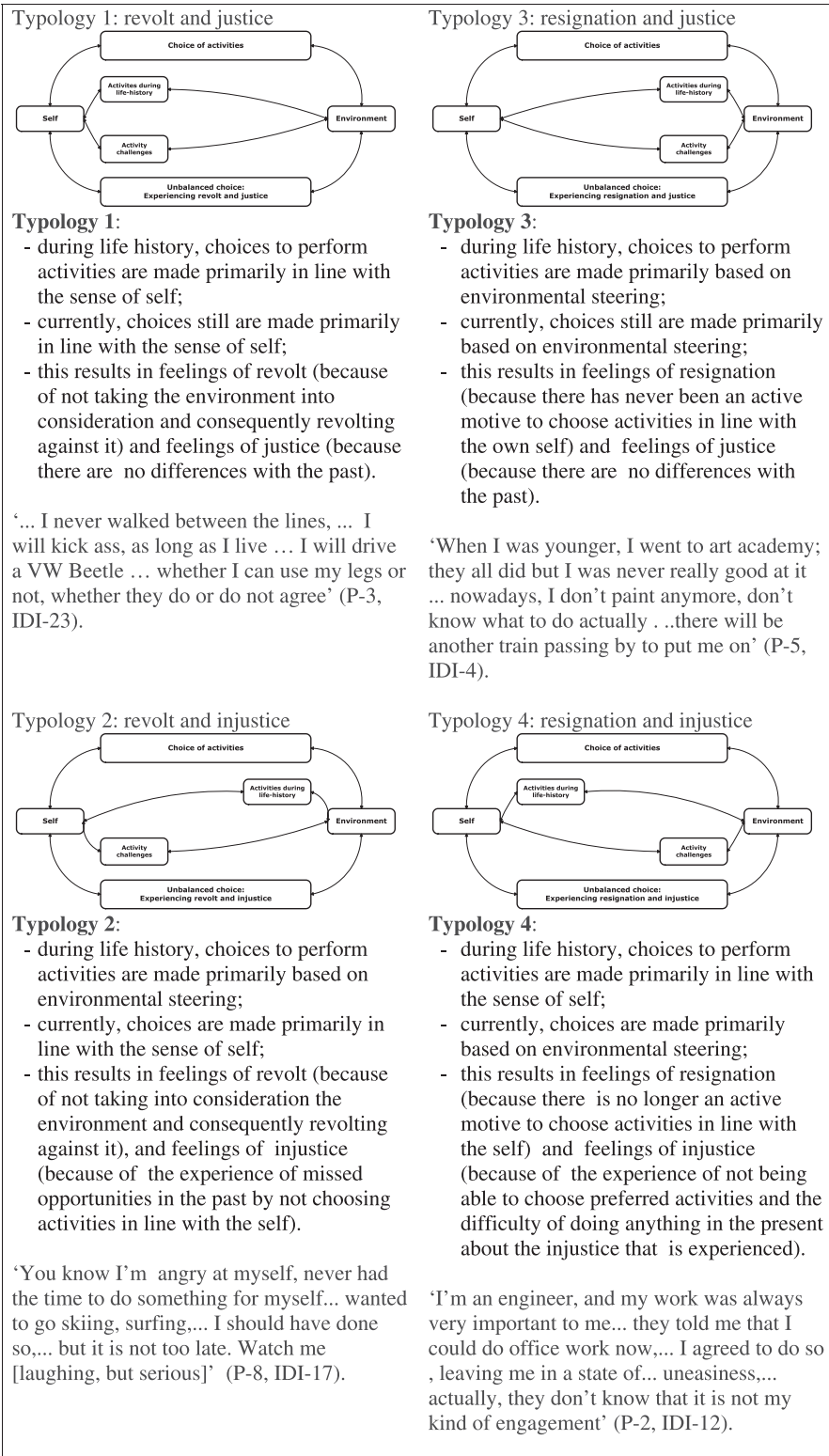


Figure 2. Unbalanced choices: typologies of choice-making.

the feeling of not being able to choose preferred activities. While justice and injustice were only one aspect of this analysis, two more feelings emerged from the data. First, the feeling of revolt was experienced when participants did not take the environment into consideration when choosing activities. Analysis identified revolt as the experience when the chosen activities satisfy the person's inner needs in spite of the environment's wishes and demands. Second, feelings of resignation occurred when there was no longer an incentive to choose activities in line with the person's sense of self. Resignation is defined as the experience when there is no active choice-making process and the person's inner feelings are not satisfied. The analysis suggests four typologies of unbalanced choices: experiencing feelings of justice and revolt, feelings of justice and resignation, feelings of injustice and revolt, and feelings of injustice and resignation. A description of the four typologies is presented in Figure 2.

### ***Conclusion: comprehensive understanding***

In their transition period, the men with paraplegia were constantly considering which activities to choose. Their sense-making was an internal process of negotiation and appeared to be based on finding a balance on a continuum between their self and the environment's expectations. Individuals experienced a sense of justice or injustice by having the opportunity to choose activities on this continuum, taking their activities during their life-history and their future activity challenges into consideration in the decision-making process. Feelings of revolt and resignation appeared when an unbalanced choice about activities was made.

### **Discussion**

The unique experiences of 12 men with paraplegia contributed to the development of a framework that explains how these individuals chose activities during the transition period from the rehabilitation centre to home. It explains what the possible perils are when unbalance in choosing activities occurs. Contrary to the idea of personal and environmental variables as being two separate concepts as described by Scivoletto et al. (1997), these two concepts are on a continuum rather than as variables contributing to activity choices. Moreover, the individual's activities performed during their life-history and his activity challenges for the future were the variables contributing to activity choices. Within this continuum and the two contributing variables, the participants were dealing with their diminished physical capacities with regard to their ability to perform activities.

### ***The balancing process***

To determine what the men with paraplegia were doing while choosing activities to find balance, and how they responded when choices were not balanced, was the main goal of this study. For a successful rehabilitation and transition to home and a full participation, Österaker and Levi (2005) believe an important care component is performing a psychological assessment of individuals with SCI. We believe that the results of our study can help shed a new light on the development of psychological and emotional distress. In the study, the characteristics of distress were described as experiencing feelings of revolt and resignation in combination with

feelings of justice and injustice in the choice-making process. The main results suggest that revolt is defined as the experience when the chosen activities satisfy inner needs in spite of the environment's wishes and demands from the environment. Resignation is defined as the experience when there is no active choice-making process and inner feelings are not satisfied. Injustice can be defined as the experience when the chosen activities do not satisfy inner needs and do not promote being part of the community. The concept of experiencing justice or injustice is new and, to our knowledge, has not been described in earlier studies. By adding the feelings of justice and injustice to the characteristics of emotional distress, a new light is shed on the dynamic choice-making process. Four different typologies emerged from the data: revolt and justice, revolt and injustice, resignation and justice, and resignation and injustice. This knowledge highlights that choice-making is a dynamic, purely individual and highly subjective process based on former activity experiences and future activity challenges.

### ***Recommendations for the rehabilitation professional***

This knowledge about the choice-making process provides a better understanding of the impact of SCI and it creates opportunities for rehabilitation professionals to identify individuals at risk who experience inner conflicts through feelings of revolt and resignation in combination with feelings of justice or injustice. Secondly, it creates possibilities to use the different typologies as tools to guide the client in his choices and start the clinical reasoning process from a client-centred and societal perspective. It is recommended: to consider this knowledge and to focus on the individual's internal choice-making process by interacting with the client; and to try to discover the type, all the more so because it is argued (Macleod and Macleod 1998) that the rehabilitation success is determined by cognitive and emotional factors, and that nurturing of these factors should receive the same degree of attention as physical functions.

### ***Strength and limitations of the study***

The strength of this study lies in the interpretive approach to show how persons with SCI in their transition period from the rehabilitation centre to home choose activities. However, there are some limitations. Selecting participants based on a purposive sampling strategy also has its limitations. The initial themes were not investigated on a broader level to include people with more diverse demographic profiles, and persons with SCI living longer in the community were also not included in the sample. Consequently, future studies should focus on a larger spectrum of the SCI population, including patients with different injury levels, and even on the whole spectrum of people with and without disabilities. Expanding this methodology across different contexts – including length of period following SCI, gender, class, race, ethnicity, other pathology domains, geographic locations, and so forth – could reflect the diversity of experiences. Further research is mandatory about how feelings of revolt and resignation in combination with justice and injustice affect the way individuals cope with SCI over a longer period, how they affect their level of participation, and how, for example, the intensity of these feelings differ according to the lesion level. This sample only gives an answer to how men with paraplegia choose their activities in their transition period; it does not focus on

an extended time frame beyond rehabilitation discharge. Follow-up of these participants over a longer period is recommended. The individual interview data could also have been supplemented with: participant observations through applying a participatory research strategy; confronting the different ways of reasoning from the participants through a focus-group methodology; and interviews with the proxies of the persons with SCI to broaden the scope and the diversity of the findings. Further research, including the broader context by also interviewing, for example, the partner of the participant, might add to the understanding of this complex process of choice-making. Furthermore, the fact that all of the participants received psychological counselling during their rehabilitation period needs some attention. This could have biased the data because they were trained in coping with their diminished possibilities to choose activities.

### Conclusion

Participation has in the literature been described as the central goal of rehabilitation (Gandek et al. 2007). Not being able to choose preferred activities prevents individuals from experiencing feelings of participation (Milner and Berni 2009; Van de Velde et al. 2010). Therefore, to prevent emotional distress and to promote being included in society, it is recommended to enable individuals with SCI to choose 'balanced activities'. In a qualitative study, Cott (2010) found that participants want a better transition between the hospital and the community. He argued that from the participants' perspective, a proper preparation for the real world is an essential component of client-centred rehabilitation. The results of our study could be helpful in planning the treatment and the preparation for discharge when taking the different typologies into consideration. It is hoped that this knowledge can lead to a better discharge planning, to a more successful transition and to a higher level of participation.

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