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Published in:
Disability and Rehabilitation

DOI:
[10.1080/09638280701265687](https://doi.org/10.1080/09638280701265687)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2008

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Van De Ven, L., Post, M., De Witte, L., & Van Den Heuvel, W. (2008). Strategies for autonomy used by people with cervical spinal cord injury: A qualitative study. *Disability and Rehabilitation*, 30(4), 249-260.
DOI: 10.1080/09638280701265687

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Publisher Informa Healthcare

Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK



Disability & Rehabilitation

Publication details, including instructions for authors and subscription information:

<http://www.informaworld.com/smpp/title-content=t113723807>

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First Published on: 09 June 2007

To cite this Article van de Ven, Leontine, Post, Marcel, de Witte, Luc and Heuvel, Wim van den(2007)'Strategies for autonomy used by people with cervical spinal cord injury: A qualitative study',*Disability & Rehabilitation*,30:4,249 — 260

To link to this Article: DOI: 10.1080/09638280701265687

URL: <http://dx.doi.org/10.1080/09638280701265687>

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RESEARCH PAPER

Strategies for autonomy used by people with cervical spinal cord injury: A qualitative study

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Accepted February 2007

Abstract

Purpose. To identify strategies used by people with high cervical spinal cord injury (SCI) to function autonomously. A multidimensional concept of autonomy was used, with four dimensions: independence, self-determination, participation and identification.

Methods. Qualitative methods were used, involving literature study and semi-structured interviews with eight individuals with high SCI who had been discharged from the rehabilitation centre for several years and were members of a sports club.

Results. Strategies for independence included making independent functioning a personal challenge and learning from others with SCI. Strategies for self-determination included keeping oneself informed, setting personal goals and being assertive. Strategies for participation were making challenges out of barriers, planning and organizing, asking and accepting help, and dealing with reactions from others. Strategies for identification involved taking life as it comes and focussing on positive aspects of life.

Conclusions. Different strategies are necessary for different dimensions of autonomy. Some strategies seem contradictory in terms of their effects on different dimensions of autonomy. Patients can be made aware of strategies for autonomy during the rehabilitation phase.

Keywords: *Cervical spinal cord injury, strategies for autonomy, rehabilitation*

Introduction

The ultimate aim of rehabilitation is to help patients with disabilities regain and retain the highest possible levels of autonomy and functioning in social roles [1]. Traditionally, autonomy has been characterized as independence from others and from the influence of institutions as the church or the state; rational consideration of available alternatives; and authenticity [2]. Defining autonomy in this way has limitations, because it seems to be associated with physical independence (and in contrast with dependence) and seems to deny that individuals are social beings. This view is especially problematic for people with permanent disabilities [1]. The traditional concept of autonomy has been modified and elaborated on by many authors. Nowadays autonomy is regarded as a broad concept involving a wide variety of aspects depending on the interests and focus of the author who defines it. There is no standard definition of

autonomy. In fact various polarities can be distinguished within the concept of autonomy: decisional versus executional, direct versus delegated, competent versus incapacitated, authentic versus inauthentic, immediate versus long term and negative versus positive [3].

The concept of autonomy as used in this paper is derived from definitions by Proot et al. [4,5], Cardol et al. [1] and Agich [6], and consists of four dimensions:

- (1) Independence in daily life (executional autonomy): possessing skills and being able to perform activities necessary for functioning in daily life (self-care, mobility, communication, housekeeping) without the help of others.
- (2) Self-determination (decisional autonomy): making one's own choices and decisions about one's life and health.

- (3) Participation: taking responsibility for one's own life through planning and organizing one's own affairs, including social roles and social relationships.
- (4) Identification: the degree to which individuals feel comfortable with their way of living and feel that their way of living befits the person they are.

Individuals can perceive different levels of autonomy depending on their roles and activities [1,7,8].

Although much has been published about the concept of autonomy and ways of measuring autonomy, little is known about the strategies individuals employ in this respect. Strategies are ways of obtaining and maintaining high levels of autonomy [7]. Although it may seem difficult for people with severe disabilities to function autonomously, there are people with serious disabilities who manage to live the life they choose and which they feel comfortable with. They may use certain strategies for functioning autonomously, and such strategies could be copied by other people having trouble living the life they want to because of their disabilities.

The aim of this qualitative study was therefore to examine the strategies that people with serious disabilities use to function autonomously. Our respondents in this study were people with cervical spinal cord injury (SCI). Having a complete cervical SCI means having serious disabilities in terms of activities of daily living, such as dressing, bathing and outdoor mobility [9]. In addition, the SCI may force a person to change his social roles, which means a reorientation on his life and his self. These are all aspects of autonomy. As such, people with complete cervical SCI who function autonomously can be regarded as good informants in studies of strategies for autonomy.

This leads to the following research question: 'What strategies for autonomy do people with complete cervical SCI and successful in terms of autonomous living use?'

Methods

Our aim was to explore the experiences of people with cervical SCI as regards autonomy, in order to identify successful strategies. The most appropriate methods for exploring experiences are qualitative methods. Qualitative methods allow for studying the understanding and meaning of experiences through the perspective of the participants and within a particular context. New phenomena can be studied best making use of qualitative research to generate theories [10]. Besides this, qualitative research aims at exploring processes rather than outcomes of a

phenomenon [10,11]. The strategies of autonomy are a relatively newly studied phenomenon and relate to the process of functioning autonomously. Our data were based on literature study and semi-structured interviews. The literature study focussed at theories of autonomy and the characteristics and aspects influencing autonomy in individuals with SCI. The literature study formed the basis for the theoretical framework of the research.

Respondents

Because we wanted to identify strategies of successful autonomous functioning we needed to interview individuals who were functioning autonomously. The strategies they use may be relevant for other people with SCI who are not (yet) successful with respect to autonomous functioning. Earlier research had shown that people with disabilities who were members of sports clubs were well integrated in society [12]. We expected them to be good informants because being well-integrated implies that a person leads an active life and is able to direct his life in such a way that he or she can function within society despite of barriers. Therefore we choose respondents who were members of quad rugby clubs. Within qualitative research methods this is called purposive sampling. It involves a strategy in which particular persons are deliberately selected to provide information that would not be obtained with another selection of persons [10,13]. Specific inclusion criteria were: having tetraplegia due to a spinal cord injury at the C6–C7 level or higher, being 18 years of age or older, and being a member of a quad rugby club.

Procedure

We sent out an announcement via the website of the Dutch quad rugby association. People were invited to contact the research team by email if they were interested in taking part in the study. Those who expressed an interest were sent a letter with further details of the study, together with a response form. We contacted people who completed this form to make an appointment for the interview. Six interviews were held at the respondents' homes and two at our institute each lasting about two hours. The study was approved by the SRL/iRv Medical Ethics Committee. The respondents received the research report after the study had been completed.

Content of the interview

We used a semi-structured interview guide, developed from our literature study, to gather our data. Questions involved general questions about personal

and injury characteristics. After that, the four dimensions of autonomy were discussed. Each dimension of autonomy began with a 'grand tour question'. This type of question aims at introducing the topic of conversation while allowing respondents to talk about the topic in their own words and involving those issues most important to them with respect to the topic. The grand tour question asks for descriptions about how respondents experience their situation [14]. In example, our grand tour question with respect to participation involved: 'How would you describe your life in society?' The remaining questions in our interview guide involved questions expanding on the based question. For instance, questions about differences before and after the injury, about the manner respondents managed to function autonomously and about impediments they had experienced in achieving autonomy.

Analyses

All interviews were tape-recorded and typed out verbatim. We started the analyses with the first four transcripts. The transcripts were read one by one. The primary researcher marked the relevant passages in each interview. Relevant passages were those passages relating to: (i) the description of dimensions of autonomy, (ii) constraining and facilitating factors of autonomy, and (iii) strategies used to function autonomously. The selected passages from each interview were coded, using words to describe the content of the passage. The passages and the codes were discussed within the research group until consensus was reached about the passages that were relevant and the codes that were appropriate given the research questions. Following this step, the primary researcher made a description of the content of the different codes, resulting in themes. The themes were discussed within the research group until consensus was reached about the descriptions of the themes. After that, the primary researcher categorized the passages according to the four different dimensions of autonomy, i.e., independence, self-determination, participation and identification. If themes could not be fit in with the four dimensions this information would be remained and could form a category of its own. The categorizations were discussed within the research group until consensus was reached about the categorizations. Each category included a description of themes related to the dimension of autonomy according to the respondents; constraining and facilitating factors; and strategies belonging to this particular dimension of autonomy. After this, the following four interviews were read and analysed. They were treated as a check to find out whether the themes from the first four interviews were complete. The primary researcher

marked relevant passages and checked whether emerging themes from the second set of interviews could be fitted into the categories and themes of the first four interviews. If not, a new category could be constructed. (However, the primary researcher was able to fit in all themes into the existing categories.) The categories were extended or refined based on the information from the remaining four interviews. The primary researcher described the results from the check-up and these were discussed within the research group until consensus was reached about the description. The primary researcher made necessary adaptations. In the last step of the analyses, descriptions of different dimensions of autonomy and of strategies used were confronted with existing literature on autonomy.

Results

Respondents were five men and three women (Table I). One respondent was no longer a member of a quad rugby club, but he had been a member for several years in the past. The age of the respondents varied between 27 and 55 years. The mean time that had elapsed since the injury was 14 years, and most had been injured as a teenager. The type of SCI ranged from C4 to C7 complete lesions. Four respondents had a partner and one or more children. Five respondents were living in an adapted ordinary house and three were living in a FOKUS project. FOKUS is a project of independent living with on-demand support in activities of daily living (ADL) [15].

Strategies for independence

All respondents were wheelchair-users and able to move around in a hand-rim wheelchair. However, their abilities ranged from being independent except for housekeeping activities to needing help with all tasks of daily living (Table I). These differences were only partly related to the seriousness of the SCI. Some respondents deliberately chose not to function independently for some activities of daily living because this saved them energy to participate in society, for instance to have a job. The respondents in our study mentioned several strategies that helped them to become as independent as possible.

Making independent functioning a personal challenge

By trying to do just a little more than they expected to be able to, respondents discovered new activities they were capable of. The respondents did not give in easily and tried out alternative ways to perform activities before labelling them as impossible. Some had explicitly made independent functioning their

Table I. General characteristics of respondents and autonomy in activities of daily living and participation.

Respondent	A	B	C	D	E	F	G	H
General Characteristics:								
Gender	F	F	M	M	F	M	M	M
Age	36	33	45	29	33	35	27	55
Type of injury:								
Age at onset of the injury	17	30	13	15	10	16	19	48
Level of injury	C5-C6	C6/C7	C4-C7	C6-C7	?	C5-C6	C6-C7	C6-C7
Cause of injury	Diving accident	Car accident	Diving accident	Fall from height	Progressive muscle disease	Diving accident	Diving accident	Motor cycle accident
Getting help from others:								
Personal care	Yes	Yes	No	No	No	No	No	Yes
Dressing	Yes	Yes	No	No	No	No	No	Yes
Hygienic care	Yes	Yes	No	No	No	Yes	No	Yes
Bathing/showering	Yes	Yes	No	No	Yes	Yes	No	Yes
Eating	No	No	No	No	No	No	No	Yes
Housekeeping	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Indoor mobility	No	No	No	No	No	No	No	No
Outdoor mobility	Yes	Yes	No	No	Yes	Yes	No	Yes
Transfers	No	Yes	No	No	No	No	No	Yes
Participation:								
Living arrangements	FOKUS ¹⁵	Independent	Independent	Independent	Independent	FOKUS ¹⁵	Independent	Independent
Partner	No	Yes	Yes	No	Yes	No	No	Yes
Children	No	Yes	Yes	No	Yes	No	No	Yes
Work	Yes	No	Yes	Yes	No	Yes	Reintegration	Yes
Volunteer work	Yes	Yes	Yes	Yes	Yes	Yes	No	No
Hobbies (other than quad rugby)	Singing in a choir, travelling	-	-	Hand archery, handbiking	Clay modelling	Handbiking	Travelling	Handbiking, travelling

personal challenge. In order to achieve this goal they had to be perseverant and discover alternative ways of functioning with their disabilities without help from others. They had developed a set of tricks and aids for this over the years.

My motive is independence. And not just in taking care of myself, the daily activities. But also with respect to income. With everything. Total independence. (Respondent G)

We never say 'We'd better not do that'. No, we just go to the beach and we'll just see how we'll get there. But we go anyway. (Respondent B)

You try things, taking a trip by a pedal boat, also canoeing. At the rehabilitation centre I said I wanted to try canoeing. Of course, I don't have enough hand functions to grasp the paddles. So you have to improvise a bit. Eventually it went well and we canoed a fine 15 kilometres. Well, that was just great. (Respondent D)

Learning from other people with SCI

Respondents mentioned that other people with SCI whom they had met at training sessions at their quad rugby club were an important source of information on ways of independent functioning. In addition, they had received support and stimulation from others in the same situation. Seeing other team members functioning independently stimulated the respondents to learn how to do things themselves.

At the end of the quad rugby session we always hang around for a while at the bar. And that is the time for me to ask questions and get answers from the others. 'How do you do it with passing water, how do you manage with sex, how do you use the wheelchair?' And those guys together know more than any rehabilitation doctor will ever know. (Respondent H)

When I started to play rugby there was a boy with a higher spinal cord injury than I have. He had less physical functions left. But he had a hand rim wheelchair. And then I thought: 'If he can function in that kind of wheelchair, what am I doing in an electric wheelchair?' (Respondent E)

Strategies for self-determination

The respondents stated that their SCI had a strong influence on their choices and the goals they set for themselves. They felt limited in the number of alternatives from which they could choose because of the SCI. However, the respondents indicated that the injury did not influence their capacity to make choices or set goals. Having difficulty in making choices was seen as a personality trait. Not all

respondents were aware of their choices or felt they had to make choices. Some respondents mentioned that the process of making choices had become more explicit since the SCI because choices had more implications. The respondents mentioned several strategies that were related to self-determination.

Keeping oneself informed

Respondents mentioned they collected informed about rights, regulations and assistive devices for people with disabilities by visiting fairs, exchanging information with fellow patients, consulting professionals, reading relevant literature and scanning the internet. Keeping themselves informed in this way was important for their self-determination for two reasons. In the first place it made them see what options they had and secondly it made their position stronger when negotiating with service providers or other professionals.

You have to go there [fairs for people with disabilities and service providers] every year. I think everyone with disabilities should do that. Because you have to know what's available. (Respondent A)

It's a matter of phoning a lot, asking for information a lot. I also attended workshops about regulations for people with disabilities. And the patient organization also has a lot of information. And friends or acquaintances in the same situation. I was also active in a platform for disabled people in my city. So, you get information from different angles. And maybe one day it's applicable to you. (Respondent D)

Setting personal goals

Some of the respondents were focussed on achieving personal goals. They set their goals through conscious consideration of their options and the consequences. They first tried to find out whether what they wanted to do was possible, by thinking through the steps of the activity. They weighed up the pros and cons of their goals and plans and talked about their plans with others. Some respondents mentioned that since they had sustained the SCI they were more focussed at achieving goals and were more tenacious in doing so. To achieve their goals, they had to set priorities and make choices, which fitted in with the goals set. This could mean accepting to be dependent on help from others in order to be able to function in certain social roles, like having a job.

I always wanted to go to college and then find a job. Self care does not fit in with this. I receive professional care and within half an hour I am ready for work. If I had to do this myself it would take much more time and I

wouldn't be able to work the 32 hours a week I work now. (Respondent A)

I always strove to be what you call a 'Renaissance man', a widely developed human being. I think people should not focus on one's ability, but that you should be able to do a lot of different things. And I wanted to continue this after my accident. (Respondent H)

Being assertive towards others

In their efforts to live a life of their own choice, the respondents sometimes faced a lot of opposition from other people and organizations. Hence, they had to react in an assertive way. This started by developing a new sense of self-esteem and realising that they had the right to express their own opinions and personal goals. Further, respondents had to know what they wanted and be able to express this to others, which meant having good verbal skills. They had to come up with good arguments to convince others, like health professionals and service providers, to take account of their wishes. When claiming their rights it was important to be tenacious. If the service providers were not convinced by the respondents' argumentation, some of them even started lawsuits to exercise their rights. If necessary, the respondents were not afraid to antagonize other persons, including not only professionals but sometimes also parents or partners.

You have to know what you want and then you must tell them what rights you have. If you explain it well and you come up with arguments, you can get things done. (Respondent D)

I don't listen to the doctors anymore. I just do what feels good for me. They told me I couldn't use the handbike or play quad rugby because it would be too much of a burden on my shoulders, arms and hands. But, what would I have got left if followed their advice? Should I just stay in bed all day? Well, not for me. For me the quality of my life is more important than the quantity. (Respondent E)

My mother is someone who can't let go of experiences. So, if something happens, everything that has happened to her in her youth comes back to her. I can put a stop to these kind of thoughts and just continue with my life. But she can't. So, me getting the SCI totally brought her down. And then she began dragging me and my brother into her negative cycle and that is when we decided to end our contacts with her. (Respondent G)

Strategies for participation

The respondents led active lives, taking part in society in various ways and maintaining social relationships with friends, colleagues, relatives, spouses and children. The respondents mentioned

several social roles, like being employed, being a housewife taking care of young children, functioning in volunteer work and hobbies. They mentioned that some of their relationships with others had changed because of the SCI. This was due to the help they needed from others and the lower expectations that some others had about them. As regards spousal relationships the sex life changed drastically because of the impairments. Some of the respondents had lost their partners because of the SCI. All respondents perceived serious impediments in terms of participation, due to the barriers they had to face within society, caused by inaccessibility aspects, negative attitudes towards people with disabilities and bureaucracy. Participation was also impeded by, secondary conditions like incontinence, pain and fatigue. The respondents mentioned several strategies relating to participation.

Making challenges out of barriers

Taking up challenges broadened respondents' opportunities to engage in certain activities in society. They perceived barriers as challenges and tried to find ways to overcome them. For some respondents, their experiences with quad rugby helped to overcome fears about the barriers when participating in society. Some of them actually mentioned a difference between people with SCI who were members of a sports club and those who were not, members being more active and outgoing than non-members.

A lot of people are afraid of certain activities. Hesitation. They ask themselves: What if I go outside and fall? If I did this, what would happen? There are always things to worry about. But, when you're playing rugby you're working with the wheelchair so intensively, it feels like the wheels become your legs, and you overcome your fears. (Respondent G)

Planning and organizing

Functioning within their social roles requires good planning and organizing. The respondents would think in advance about their activities and the precautions they would have to take, for instance, by trying to find out whether the buildings they wanted to enter were accessible to them, and by arranging professional care at the places they wanted to go to.

Having SCI means organising. That is the most important skill you must have. And of course, a lot of people don't have it. Not everyone was born to be a manager. Some people are just untidy. You can't have that if you have SCI. Because you have to plan your whole day. I always know in advance exactly what I will do that day and what I have to arrange for that. (Respondent A)

I have noticed that I am thinking and arranging a lot in advance. I don't see other people doing that, people who do not have SCI. They just go somewhere and see what happens, while I have to think in advance: Will it be possible for me to go to the toilet? Will my dog, who is trained to help me, be allowed inside? That kind of stuff. (Respondent E)

Asking and accepting help from others

Asking for help when necessary was an important strategy for the respondents because it increased their opportunities to do what they wanted to do. The most commonly needed types of help were help with transfers, lifting and reaching for objects, and help with hygienic care. Most of the respondents were not reluctant to ask for help if necessary, even if their first goal was to strive for as much independence as possible. Not asking for help seemed to reduce the options for activities, as was mentioned by one of the respondents.

The more you ask others for help, the more you are able to do. (Respondent B)

I do not feel any shame about asking others to help me. That is why I can go my own way. For instance, two weeks ago I went to a congress in Amsterdam. After I while I had to go to the bathroom, which I can't do on my own. So, I just asked the host of the day to call and see if someone could help me go to the toilet. Well, not everyone will have the courage to ask that. But, it always works. (Respondent H)

I don't want to be dependent on other people. I don't ask for help easily. It's not in my personality. But if you have such a personality like mine and you need help, it's annoying. I think that if I asked for help more often, I'd make more out of my life. (Respondent F)

Some respondents strove for reciprocity in their relationships with those who helped them, for instance by listening to their life stories, doing paper work or taking them on holidays. Reciprocity was important to them because it made it easier to accept help from others and made them feel less dependent.

I have a friend who's gone with me on holiday several times now. I pay for her flight and accommodation and she helps me during the holiday. If you take someone with you to help it's important it's someone you like. And for this friend it gives her the opportunity to go somewhere. Without me she would never be able to do this. And for me it is the ideal situation. So, now we do fun things together. (Respondent A)

So much has been done for you by many different people. So, if you see you can do something in return for them it gives you confidence. Just little things like paying for a drink in a bar, or taking someone to dinner, or

picking someone up to go somewhere. Things like that. It gives you confidence. Because then it's not just one-way, but you can do something in return. It feels good. (Respondent G)

Dealing with negative reactions from others

Most respondents were frequently faced with negative responses by others because of their SCI. For example, others assumed that they were homebound, treated them like fools or as if they were incapable of accomplishing anything at all, praised them for everything because of their disability, or criticized them for having a child while being seriously disabled. Being stared at by others was also a common experience to them. Most respondents said they did not feel bothered by such responses. When other people reacted negatively to them because of the SCI the respondents chose not to respond to this and just ignored the comments. Some did not notice the reactions from others, because they paid no attention to such reactions.

It says more about the people who say those things than about me. So, I just ignore it. (Respondent E)

I think it's funny and also normal. If I see a wheelchair out on the streets I also look to see what kind of wheelchair it is. And if I see someone with another kind of abnormality, who looks slightly different from other people, I also look. For instance, if someone has purple hair. So, I think it's just a normal phenomenon. (Respondent C)

I remember when I was still under treatment at the rehabilitation centre, sometimes you could go home for the weekend. One time my sister asked me: 'Do you see that? Everyone is staring at you'. Well, I didn't see a thing. So, I have shut it out, or it doesn't interest me. (Respondent F)

The respondents had developed their own ways of dealing with reactions from others. They realized that when introducing oneself, it is the first impression that counts. Therefore they carefully presented themselves, using humour, patience and educational skills, to make others feel at ease with the situation and to get control over the situation. For instance, a respondent who was a teacher always explained about his SCI when meeting a new class. He also let the students sit in the wheelchair to experience what it is like. Respondents said that people in a wheelchair should be extra careful about their appearance in clothes, hairdo etc. in order to distract the attention from the wheelchair.

If I get a chance, I immediately make it very clear who I am. For instance, I say: "I am John. I am handicapped

but I don't smoke", or something like that. Mostly I make a joke. And if people see that they immediately think: "Oh, it's okay". I make that very clear to others. (Respondent G)

If you're in a wheelchair you have to look good. I think that's important. Maybe even more important than for others. You have to be extra careful about the way you dress and your make-up. I think it's important because if you take the effort, people will pay attention to you first and only after that they see the wheelchair. (Respondent B)

The respondents mentioned that they tried to maintain a positive attitude towards their friends and others about their lives and the way they felt. Only close friends and relatives were informed about their real experiences. To convince others of their abilities, they made extra efforts to show what they were capable of. This involved not accepting help from others if it was not really necessary. In addition, they mentioned that starting a conversation was an important strategy to show others that they were just a person like anyone else. Respondents mentioned they often had to take the initiative because others do not feel comfortable making contact with people in a wheelchair.

When my daughter was 3 years old, other mothers often first wanted to come in and see how I was caring for my daughter before their child was allowed to play at our house. They found it a bit scary. But when they saw that everything went well, it was okay for them. (Respondent E)

In some situations, the respondents would mention they were in a wheelchair and that this had certain consequences before meeting someone new, for instance, when applying for a job, or in the case of a child adoption procedure. In other cases, however, respondents surprised the other party by not telling them beforehand that they were in a wheelchair, to prevent the other person from forming an opinion about them based on the SCI before meeting them. And some respondents mentioned they just found it interesting to see the other person's reaction.

If I have a meeting with people from another company, I am not going to tell the other person: "Prepare yourself, I'm in a wheelchair". Because, it's not relevant. Sometimes I deliberately don't tell them. Like when I get called by organizations who're involved in reintegrating disabled people. Of course they call me as the head of the personnel department. They will say things like: 'Disabled people are very motivated people and I have a very competent applicant'. I just let them tell their story and when they ask me if we can meet, of course I won't tell them about my disability. I just make an appointment. I find it so funny. They enter the room and they

won't say a word but I can see their embarrassment in their whole appearance. (Respondent A)

Strategies for identification

For most respondents, the SCI meant a great change in their lives and they experienced the SCI as an important part of their lives. Some respondents perceived the SCI to be part of their selves and found it difficult to imagine a life without the SCI. Whether a person had incorporated the SCI into their sense of self or not did not appear to be an indicator of the level of identification with the life they were living. Some respondents had incorporated their impairments into their sense of self, but did not identify with their lives because they could not accept the fact that they were unable to do certain things they used to do. On the other hand, there were respondents who did not perceive the SCI as part of their selves, but did identify with their lives. Respondents described several strategies which showed how they managed to identify with their lives.

Taking life as it comes

To appreciate their new lives, respondents had to accept that their lives as they were before their injury, were over. They chose not to loose themselves in thoughts like 'what if...' and started to shape a new life accepting their disabilities. Some drew strength from their faith in God and/or from the idea that misfortune and suffering are a normal part of life. Some of them saw what had happened to them as a learning experience. To a certain extent, the respondents accepted that their choices and goals had changed because of the SCI and did not cling to activities they were no longer capable of. The respondents started to set goals within the range of their abilities and looked for alternatives to activities that had become impossible.

Of course you can complain about what you can't do anymore, that you want to take up your usual life in the wheelchair, that kind of stuff. I tried to live with the SCI as a starting point. I wanted to make something positive out of it. That's how I approached it. Call it a survival strategy, but for me it was the right way of dealing with it. (Respondent F)

I couldn't imagine a meaningful life without Christ, without Him as a focus, without a connection to God. And I think because of that, other and higher values are more dominant than the values in the commercial world for example. Physical health or disabilities dwindle next to these values. Within the Christian religion, especially the Catholic religion, disease and suffering have their own meaning. Not negative, but a meaningful

significance for life as a whole. And I think that's very important for happiness and a sense of living a meaningful life. (Respondent C)

What I notice is a shift in the hobbies I do. I was a fanatic flute player. I can't do that anymore because of my poor hand function. And there are more hobbies that I just can't do anymore. But, I always find a new hobby to replace the other. (Respondent E)

Focussing on the positive sides of life

The respondents managed to focus on the positive aspects of their lives, thereby putting the difficulties they experienced into perspective. The changes in their lives they were forced to make because of the SCI appeared to have favourable aspects as well. The respondents gained satisfaction from small achievements and valued the things they were still able to do despite their injuries. Small successes boosted their self-esteem and stimulated them to try more. For some of them, humour was an important help in putting things into perspective. Some respondents compared their own situation to those of other people with SCI who experienced more severe disabilities. Some compared their own life with those of others without disabilities, to see that no life is perfect. They counted their blessings and saw that everyone has their own troubles.

I just think more people should realise this. Not sticking to what you can't do anymore, but looking at what you *can* do. You'll see that's a lot. Anything is possible in principle. Just, not in the way you see everybody else doing it. (Respondent G)

I see so many people around me who are healthy and who are so unhappy. That is when I feel very rich. I feel very happy then. And those people don't have disabilities. (Respondent E)

Discussion

The aim of this study was to identify the strategies used by people with SCI who are successful in terms of autonomous functioning. Each of the four dimensions of autonomy strategies could be identified based on the respondents' stories. No strategies were found that could not be categorized in one of the four dimensions of autonomy. The different dimensions of autonomy ask for different types of strategies. Strategies for independence are aimed at an individuals' physical functioning and involve goal setting and interaction with others in the same situation, in order to learn new ways of independent functioning. Strategies for self-determination are aimed at the decision-making process and at convincing others that the decisions or choices made are the right ones. Participation strategies are aimed

at influencing or dealing with others and with barriers in one's societal environment, in order to allow people to function in their preferred social roles and relationships. Identification strategies aim at giving positive significance to a life with SCI.

Different dimensions of autonomy become relevant at different stages during the rehabilitation process [4,5,8,16]. This has consequences for the approach to be used by rehabilitation professionals. At the beginning of the rehabilitation process, patients and professionals focus on regaining independence. Near the end of the clinical phase, participation aspects become relevant. During rehabilitation, professionals should change their approach from paternalistic to a more coaching role, in which they provide room for planning and decision-making by the patient [16]. Although the process of identification with the SCI starts soon after the injury, it continues after discharge as patients reshape their lives in order to adapt to their new situation. Most patients with SCI experience a break in their identity. Repairing this takes time, varying between individuals from several months to several years [17–21].

Contradictory strategies

Some strategies seem contradictory in terms of their effects on different dimensions of autonomy. For instance, whereas asking and accepting help from others appears to be an effective strategy for participation, this strategy would seem less suitable in terms of independent functioning. For most individuals with SCI, however, there are limits to the levels of independence they can achieve and they will always need some degree of help from others [9]. In addition, many patients with SCI have low energy levels and self care is time- and energy-consuming. As a consequence, individuals with SCI must set priorities with respect to the activities they find most important, i.e., activities of independence or activities of participation.

The participation strategy of making challenges out of barriers seems to contrast with the identification strategy of taking life as it comes. However, our respondents reported that they made use of both strategies. They found it important to persevere in learning to perform activities which others, and sometimes even they themselves, thought were impossible for them to achieve. In this way they managed to develop their skills and opportunities. However, this approach has its limits when the desired skills remain out of reach. This is when it becomes important to accept the situation as it is, and not to desire what really is impossible, because this only leads to frustration, disappointment or anger. Of course, there may be to a certain tension

between these two strategies within individuals. Our respondents, however, did not consider this tension to be problematic. The respondents in our study all had several years of experience living with the SCI. It may be that individuals who have recently sustained an SCI have more trouble striking a balance between these different strategies. As regards the concept of changing autonomy it could be expected that individuals who have recently sustained an SCI focus more on challenging barriers than on taking life as it comes.

Limitations of the study

The type of respondents we included, namely members of a sports club, may have influenced the conclusions of this study. Since, this was a selective group, which may have other experiences than non-members. We might have identified other strategies if we had included non-members. However, this does not mean that the strategies identified among the sports club members are not relevant to non-members. Our reason for selecting sports club members was the link between being active in sport and societal integration which was pointed out by Pluijm et al. [12]. We thought that sports club members would be good informants with respect to autonomous functioning. Our respondents did appear to be active within a variety of social roles and were therefore indeed suitable informants.

Most of our respondents had sustained their SCI more than five years prior to the interview. This means that our respondents were experienced in living with the SCI, which makes them different from patients at a rehabilitation centre. It is possible that other dimensions of autonomy are more prominent in the lives of individuals who have recently sustained an SCI. During the rehabilitation process, patients begin to develop strategies for autonomy. Proot et al. [8] found that stroke patients used various strategies to function autonomously during the rehabilitation process, including self-care skills, taking initiative and responsibility, instructing their families, and shared decision-making [8]. At the start of the rehabilitation process, patients were more passive and had fewer strategies than before they had sustained their stroke [5].

Practical implications

What can other individuals with SCI in rehabilitation centres learn from our results and how can rehabilitation professionals help them with this learning process? First, it is important to realise that different dimensions of autonomy require different strategies. During the rehabilitation process, the focus is on independence, and goals are aimed at reaching this

step by step. In this way, professionals help patients with SCI to make independence their personal goal. Professionals can make their patients aware of the fact that this kind of personal goal setting remains important after discharge from the rehabilitation centre. Learning from experienced patients with SCI is a strategy for independence, which can be facilitated at the rehabilitation centre. The rehabilitation setting is the most obvious where people with similar disabilities are present. In some centres, former patients are present at the centre as peer educators or coaches.

Rehabilitation centres could help train patients strategies for self-determination. In this respect, the attitude of rehabilitation professionals towards their patients is an important factor [22]. Proot [16] found that the preferred attitude towards patients with stroke was paternalistic in the first stages of the rehabilitation process, and then developing towards shared decision-making near discharge. In other words, during rehabilitation, patients must be allowed to gradually grow towards self-determination. Professionals can stimulate patients to identify personal goals, as setting personal goals is one strategy used by our respondents to achieve self-determination. Rehabilitation professionals can tailor the rehabilitation process to their patients' personal goals or life goals, the latter including aspects like education, career, parenthood and religion or life philosophy. Life goals can be identified using qualitative methods like interviews and written narratives, or using various questionnaires [23]. Tailoring treatment goals to patients' life goals can be motivating patients to commit themselves to the rehabilitation process [23]. With respect to the strategy of keeping oneself informed, professionals should not only provide information, but also teach patients how to obtain information about services, assistive devices and regulations by themselves. The third strategy of self-determination involves assertiveness. Programmes teaching assertiveness could be introduced in the rehabilitation programme.

The strategies for participation identified in this study ask for empowerment of the individual with disabilities. Empowerment training programmes that focus on aspects of asking for help and dealing with reactions from others could be offered to patients with SCI near the time of discharge from the rehabilitation centre. Some studies have shown the effectiveness of programmes designed to teach people with disabilities the skills to ask for help [24,25].

According to the stories told by our respondents, identification strategies involve taking life as it comes and focussing on the positive sides of life as it is. Carpenter [18] and Yoshida [21] mention the importance of taking a positive view of life. One way our respondents managed to keep up positive

attitudes was to compare their own situation with that of others, a strategy known as social comparison [26]. Comparing oneself with others can result in positive or negative feelings depending on whether the other is better or worse off (upward vs. downward comparison), the degree of identification with the other and whether one focuses on oneself or the other [26]. Using social comparison as a strategy is therefore a complicated matter and its effects depend on the situation and the orientation of the individual who makes the comparison. Our respondents used both upward and downward comparisons [26,27].

Future research

Although it would be important to know whether the strategies identified within this study can be trained within or after the rehabilitation phase, this was beyond the scope of the present study. Our respondents had all been living in society with their SCI for several or many years. Future research could be done to identify strategies used by people who have recently sustained their injury. Research into the training of strategies to cope with chronic diseases has shown that such training can be effective. For instance, Savelkoul [28] developed an effective training programme on coping strategies for social support for patients with rheumatic disease. Balcazar et al. [24] developed a training programme on asking help to attain personal goals. A future research project could try to develop and evaluate a training course aimed at teaching strategies for autonomy to persons with SCI.

Successful autonomous functioning is not only influenced by the strategies individuals employ, but also by an individual's situation before and after onset of the injury, including character and life history [4,5,8,16]. In addition, autonomous functioning may be influenced by educational level and socio-economic status. Future research could address the question how these factors influence autonomy and how they interact with strategies for autonomy.

Acknowledgements

We would like to thank our respondents for telling us their life stories. We are grateful to Roelof Wessels and Guy Widdershoven for their contributions to this project.

References

1. Cardol M, Jong BAd, Ward CD. On autonomy and participation in rehabilitation. *Disabil Rehabil* 2002;24:970–974.
2. Have HAMJt, Meulen RHJt, Leeuwen Ev. *Medische ethiek*. Houten: Bohn Stafleu van Loghum; 1998.

3. Saadah MA. On autonomy and participation in rehabilitation. *Disabil Rehabil* 2002;24:977–982.
4. Proot IM, Abu-Saad HH, Oorsouw GGv, Stevens JJ. Autonomy in stroke rehabilitation: The perceptions of care providers in nursing homes. *Nurs Ethics* 2002;9:36–50.
5. Proot IM, Crebolder HF, Abu-Saad HH, Macor TH, Meulen RHt. Facilitating and constraining factors on autonomy: The views of stroke patients on admission into nursing homes. *Clin Nurs Res* 2000;9:460–478.
6. Agich G. *Autonomy and long-term care*. New York: Oxford University Press; 1993.
7. Proot IM. *Changing autonomy*. New perspectives on the care for stroke patients in nursing homes. Maastricht: Datawyse: University Press Maastricht; 2000.
8. Proot IM, Abu-Saad HH, Esch-Janssen WPd, Crebolder HF, Meulen RHt. Patient autonomy during rehabilitation: the experiences of stroke patients in nursing homes. *Int J Nurs Stud* 2000;37:267–276.
9. Davis EL. What a psychiatrist needs to know about spinal cord injury. *Psychiat Ann* 1995;25:329–337.
10. Maxwell JA. *Qualitative research design. An interactive approach*. Thousand Oaks, CA: Sage Publications; 1996.
11. Creswell JW. *Qualitative & quantitative approaches*. Thousand Oaks, CA: Sage Publications; 1994.
12. Pluijm SMF, Keur TJA, Gerritsen J, Post WMW. Community integration of wheelchair-bound athletes: A comparison before and after onset of the disability. *Clin Rehabil* 1997;11:227–235.
13. Creswell JW. *Research design: qualitative, quantitative, and mixed method approaches*. Thousand Oaks, CA: Sage Publications; 2003.
14. Stuifbergen AK, Rogers S. The experience of fatigue and strategies for self-care among persons with multiple sclerosis. *Appl Nurs Res* 1997;10:2–10.
15. Willems CG, Dijcks B, Ritzen W, Willen A. Evaluation of the FOKUSWONEN living and care arrangement in the Netherlands. In: Pruski A, editor. *Assistive technology: From virtuality to reality*. Amsterdam: IOS Press; 2005.
16. Proot IM, Crebolder HF, Abu-Saad HH, Macor TH, Meulen RHt. Stroke patients' needs and experiences regarding autonomy at discharge from nursing home. *Patient Educ Counsel* 2000;41:275–283.
17. Brillhart B, Johnson K. Motivation and the coping process of adults with disabilities: A qualitative study. *Rehabil Nurs* 1997;22:249–256.
18. Carpenter C. The experience of spinal cord injury: The individual perspective—Implications for rehabilitation practice. *Phys Ther* 1994;74:614–628.
19. Duggan CH, Dijkers M. Quality of life V Peaks and valleys: A qualitative analysis of the narratives of persons with spinal cord injuries. *Can J Rehabil* 1999;12:181–191.
20. Kleiber DA, Brock SC, Lee Y, Dattilo J, Caldwell L. The relevance of leisure in an illness experience: Realities of spinal cord injury. *J Leis Res* 1995;27:283–299.
21. Yoshida KK. Institutional impact on self concept among persons with spinal cord injury. *Int J Rehabil Res* 1994;17:94–107.
22. Cott CA. Client-centred rehabilitation: Client perspectives. *Disabil Rehabil* 2004;26:1411–1422.
23. Sivaraman-Nair KP. Life goals: the concept and its relevance to rehabilitation. *Clin Rehabil* 2003;17:192–202.
24. Balcazar FE, Fawcett SB, Seekins T. Teaching people with disabilities to recruit help to attain personal goals. *Rehabil Psychol* 1991;36:31–42.

25. Block P, Skeels SE, Keys CB, Rimmer JH. Shake-It-Up: Health promotion and capacity building for people with spinal cord injuries and related neurological disabilities. *Disabil Rehabil* 2005;27:185–190.
26. Buunk BP, Kuyper H, Zee YGvd. Affective response to social comparison in the classroom. *Basic Appl Psychol* 2005;27:229–237.
27. Ybema JF, Buunk BP. Affective responses to social comparison: A study among disabled individuals. *Br J Social Psychol* 1995;34:279–292.
28. Savelkoul M, Witte Ld, Candel M, Tempel Hvd, Borne Bvd. Effects of a coping intervention on patients with rheumatic diseases: Results of a randomized controlled trial. *Arthr Care Res* 2001;45:69–76.