

«It takes two to tango» revisited –

participation and integration of people with spinal cord injury in Europe from an insider perspective

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Besides the cooperation with ESCIF, the collaboration with the national SCI organisations of the ESCIF member countries is indispensable for the projected study presented below. In the spirit of community-based participatory research we are interested in your input, critique and comments at every stage of the research process. Please do not hesitate to tell us your opinions and ideas about the current summary of the research protocol (if you are interested we will send you the actual draft of the full research protocol of the Swiss pilot study).

In particular, we would like to hear your comments about the suggested sampling procedure and how this could be achieved in your home country. Remember that the biggest challenge is to recruit people who perceive problems with their integration or participation.

It is also very important for us to know what you think about the questions designed to differentiate between people who feel well integrated and those who do not.

Moreover, please comment on the actual interview guideline: Is it understandable? Have we forgotten any important aspects? Do the questions match the study objectives? Remember that we tried to avoid leading questions and leave it to the interviewees to name the concepts (e.g. work) that they associate with the terms 'integration' and 'participation'. We are aware that it is possible that in one country integration is associated with work and in another it is not.

In addition, we would appreciate ideas with respect to the data analysis and possible implications of the study results for people living with SCI and the policy of your association, e.g. the determination of major obstacles and facilitators to integration or participation may be a first step to overcome barriers and provide facilitators.

Of course, it may be interesting to add questions concerning the policy of your organisation and ESCIF respectively to our interview guide. We would very much welcome your suggestions on that.

The identification of factors that facilitate or hamper successful integration and participation will, undoubtedly, have implications for rehabilitation, social and health policies, and even for legislation in some countries. We hope that our common European effort to study integration and participation in the ESCIF member countries will be a first important step towards improved integration and participation, and, thus, an improved quality of life of people living with SCI throughout the world.

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1 Protocol abstract

«It takes two to tango» revisited – participation and integration of people with spinal cord injury in Europe from an insider perspective

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1.1 Background

Various studies show restrictions of or problems with social participation and integration among people with spinal cord injury (SCI). So far, however, only a limited amount of variance can be explained. Furthermore, factors that have a positive or negative impact on participation are still far from being clearly understood. By the same token, people living with SCI are seldom asked what they themselves understand by participation or (social) integration and what their goals are in this regard. People living with SCI, however, are the primary and most important experts on this question.

Based on the idea of the qualitative study «It takes two to tango: The integration of people with disabilities into society» by van de Ven et al.¹ the intended project **«It takes two to tango» revisited** focuses on the insider perspective in order to explore the understanding of integration and participation as well as their consequences and determinants based on the experiences and life worlds of people with SCI.

1.2 Objectives

Therefore, the main objective is to expand the scope of the original study by van de Ven et al. in particular by comparing a) the perception of integration and participation in different European countries and b) within those countries, two groups of people with SCI, those who feel well integrated into society and those who have problems. The specific aims are to assess **1)** the understanding and meaning of integration and participation in the different European countries, **2)** differences between the concepts of participation and integration,

¹ van de Ven L, Post M, de Witte L, van de Heuvel W. It takes two to tango: the integration of people with disabilities into society. *Disability & Society* 2005; 20 (3): 311-329.

3) the identification of personal and environmental factors that are perceived as facilitating or hampering integration and participation, **4)** the strategies applied to achieve participation and integration, **5)** how and where such strategies were developed, and **6)** if people think that strategies can be made accessible to others.

1.3 Methods

1.3.1 Study Design

The study will be conducted as a qualitative survey using guided narrative interviews.

1.3.2 Sampling

Sampling is extremely challenging. Many countries do not have a central register making it impossible to draw random samples that truly represent all groups of the SCI population in the country. Since people who perceive problems with their social integration or participation may be less likely to be members of the national SCI associations, a recruitment strategy that is based solely on the associations' contacts is not sufficient either.

In order to enable the most comprehensive sample that is possible under the specific circumstances of the particular country, a pool of potential participants is created in a first step. The major goal of this is to inform as many people as possible about the project and ask them to take part in the study. There will be several independent procedures used to build such a pool: (amongst others) information by letter, information-forms posted on the websites of the European Spinal Cord Injury Federation (ESCIF) and possibly on the websites of the national SCI associations, flyers with information at the outpatient departments of the rehabilitation centres performing yearly check-ups for people with SCI, snow-ball procedure (participants are asked to inform potential participants about the project) etc. With the info material people will receive a prepaid envelope, a form in which they can give their permission to be contacted by the research team and a short questionnaire (two questions, see appendix) intended to distinguish people who perceive problems with integration and participation from those who do not.

The final sampling procedure applied will then be a stratified random sample. People with SCI who feel well integrated and those who perceive problems will be treated as two different sub populations. Random samples are drawn from both groups. The sample size, in both cases, will be determined by the saturation method (or theoretical sampling): after ten initial interviews in each group, new subjects from the pool will be interviewed as long as additional information emerges. If no additional information emerges in two following interviews, recruitment is finalized.

1.3.3 Measurement

Guided narrative interviews will be conducted. Questions have been designed in partial accordance with van de Ven et al.'s study, but also on our own further considerations. The preliminary interview guide in English and its link to the specific goals of the study can be found in the appendix.

In addition to the insider perspective that is the primary focus of the study, basic information on SCI prevalence and rehabilitation, health insurance, health policy, labour market conditions, anti-discrimination laws etc. will be collected for every European country participating in the study.

1.3.4 Data Collection Procedure

The research team is committed to community-based participatory research at every stage of the research process. Specific efforts will be made to recruit interviewers with SCI. Interviewer training will be provided at a 2-day course held by Jane Horsewell and Jan Reinhardt.

1.3.5 Data Analysis

Grounded theory will be used for an initial interpretation of the findings, i.e. the detection of salient categories (open coding) and uncovering of connections between categories (axial coding).

For comparison with the study of van de Ven and colleagues, meaningful constructs found in the material will be coded based on the components of integration and factors influencing integration mentioned there. In addition, meaningful concepts occurring in the answers will be linked to the International Classification of Functioning, Disability and Health (ICF). This will provide important information with respect to the ongoing development and validation of ICF Core Sets for SCI.

In each case, analysis is performed separately for the different European countries and for both groups of individuals with SCI, i.e. those who do not have problems with integration and participation and those who do, in order to reveal differences. Likewise, people are compared with respect to age, gender, education and injury related aspects such as time since injury.

Coding is done independently by two researchers. In the case of disagreement between the two, a third researcher will be involved.

2 Appendix

2.1 Short questionnaire to determine whether people feel well integrated or not



The short questionnaire intended to distinguish people with respect to their subjective perception of integration and participation comprises the following two questions:

1. How would you rate your social integration in general?

excellent good acceptable rather poor extremely poor

2. How satisfied are you with your participation in society?

very satisfied fairly satisfied acceptable rather dissatisfied highly dissatisfied

People who rate their integration as rather poor, or extremely poor or who are rather or highly dissatisfied with their participation will be considered as individuals who subjectively perceive problems with social integration or participation., Other respondents are assigned to the group of people who see no or minor problems with their integration and participation in society.

2.2 Covering letter and response form (Pretest; English)



YOUR PARTICIPATION IS IMPORTANT!

«IT TAKES TWO TO TANGO» REVISITED

PARTICIPATION AND INTEGRATION OF PEOPLE WITH SPINAL CORD INJURY FROM AN INSIDER PERSPECTIVE

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People with spinal cord injury (SCI) are important contributors to society. Their integration and participation in social life is important to their personal well-being as well as for the benefit of societal diversity. Therefore, our study tries to fundamentally examine the social integration and participation of people with SCI living in the community.

The study is conducted by **Swiss Paraplegic Research** in cooperation with the **European Spinal Cord Injury Federation**. It consists of personal interviews with open questions. One of the main study objectives is to **reconstruct the meaning of integration and participation from an insider perspective**. All interviewees will thus contribute to definitions of integration and participation which are factually rooted in the experiences of people living with SCI. Furthermore, the study aims to **identify factors which foster or hinder integration and participation** as well as to learn more about what people do to achieve satisfactory levels of integration and participation. The knowledge gained through the study serves the **ultimate goal to further the integration and participation of individuals with SCI. Your personal experience counts!**

At the moment the study is in the pre-testing phase. In order to collect initial data and to check the suitability of the questions, we are looking for persons living with SCI who would like to participate in the study (personal interview of ca. one hour). Certainly, we guarantee you **full anonymity with all the data**, which will solely be used for **scientific purposes!**

Protocol abstract and information material: «It takes two to tango» revisited

Please do not hesitate to contact the leaders of the study for additional information.

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«IT TAKES TWO TO TANGO» REVISITED

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PARTICIPATION AND INTEGRATION OF PEOPLE WITH SPINAL CORD INJURY FROM AN INSIDER PERSPECTIVE

I am very interested in participating in this study. Please contact me at the following address:

NAME	
ADDRESS	
PHONE	
MOBILE	
E-MAIL	

2.3 Interview guideline (Pretest; English)

«It takes two to tango» revisited - participation and integration of people with spinal cord injury from an insider perspective

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Semi-structured Interviews

My Name is «XY» [**► interviewers name**] from Swiss Paraplegic Research.

First of all, I would like to thank you very much for taking the time to participate in our study which is about the integration and participation of people living with spinal cord injury (SCI). The study is conducted by Swiss Paraplegic Research in cooperation with the European Spinal Cord Injury Federation. One of the main study objectives is to reconstruct the meaning of integration and participation from an insider perspective. All interviewees will thus contribute to definitions of integration and participation which are rooted in the experiences of people living with SCI. Furthermore, the study aims to identify factors which foster or hinder integration and participation as well as to learn more about what people do to achieve satisfactory levels of integration and participation. The knowledge gained through the study thus serves the ultimate goal to further the integration and participation of individuals with SCI. To hear about your own experiences will importantly contribute to that goal.

At this point, it is important to mention that this interview is a so-called pre-test. In the long run, we plan a large, representative sample of all people living with SCI in Switzerland. Before that we need to extensively test the questions developed so far. Therefore, beyond the initial collection of information concerning the participation of people with SCI, an additional aim of this inquiry is to optimize the questions for the upcoming survey. For this reason, it would be very helpful if you could tell me whenever you do not understand a question or when you feel there is a repetition in the questionnaire. Of course, you are welcomed to make any further notes regarding the questions asked. Please answer spontaneously. There are no right or wrong answers. Your personal experience counts. In order to be able to analyse all answers later, the interview will be recorded, but we certainly guarantee you full anonymity with all the data. The data will solely be used for scientific purposes. Well, then let us begin with the first question. I now switch on the tape-recorder.

We will start with the meaning of integration and participation.

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A) When we talk about a person with SCI participating in society, what do you think is meant by this?

→ specific aims 1 and 2

B) When we talk about a person with SCI being integrated into society, what do you think is meant by this?

[▶ Interviewer: If the interviewee remarks that there is no difference between this and the first question, the interviewer will ask:

Do you therefore think that integration and participation are the same?]

[▶ Interviewer: If the interviewee answers 'yes', the interviewer will say:

Ok, we have now found out that you do not see any difference between integration and participation. So we will only refer to participation from now on.]

→ specific aims 1 and 2

C) Do you feel that you are taking part in society?

[▶ Interviewer: wait for answer!]

Does this apply to all areas of your life or only to some?

[▶ Interviewer: If answer is «only to some» and concrete areas are not mentioned ask:

In which areas is this the case and in which not?]

→ specific aims 1 and 2

Why is this so, do you think?

→ specific aims 3 and 2

[▶ Interviewer: Pose the following question only to those who see a difference between integration and participation:

Do you feel socially integrated?]

[▶ Interviewer: wait for answer!]

Does this apply to all areas of your life or only to some?

[▶ Interviewer: If the answer is «only to some» and concrete areas are not mentioned then ask:

In which areas is this the case and in which not?]

→ specific aims 1 and 2

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Why is this so, do you think?

→ specific aims 3 and 2

D) When you think about the time in the clinic shortly after your spinal cord injury what positively or negatively influenced your later participation in society?

[▶ Interviewer: If only negative influences are mentioned, ask:

Were there any factors that facilitated (helped) your later participation?

[▶ Interviewer: wait for answer!]

Was there something or someone that pushed you to keep going?]

[▶ Interviewer: If only positive influences are mentioned, ask:

Were there any factors that hampered your later participation?

[▶ Interviewer: wait for answer!]

Was there something that held you back?]

[▶ Interviewer: Pose the following question only to those who see a difference between integration and participation:

And what about integration? Were there any additional factors that influenced that?]

E) When you think about the time shortly after your discharge from the clinic, what positively or negatively influenced your later participation in society?

[▶ Interviewer: If only negative influences are mentioned, ask:

Were there any factors that facilitated your later participation?]

[▶ Interviewer: wait for answer!]

Was there something or someone that pushed you to keep going?]

[▶ Interviewer: If only positive influences are mentioned, ask:

Were there any factors that hampered your later participation?]

[▶ Interviewer: wait for answer!]

Was there something that held you back?]

[▶ Interviewer: Pose the following question only to those who see a difference between integration and participation:

And what about integration? Were there any additional factors that influenced that?]

- F) Finally, when you think about your current situation, what positively or negatively influences your participation in society?**

[▶ Interviewer: If only negative influences are mentioned, ask:

Are there any factors that help you to take part in society?]

[▶ Interviewer: If only positive influences are mentioned, ask:

Is there anything that hampers your participation?]

Is there anything you would like to change in your environment in order to facilitate your participation?

[▶ Interviewer: Pose the following question only to those who see a difference between integration and participation:

And what about integration? Were there any additional factors that influenced that?]

→ specific aims 3 and 4

- G) Now in general, could you mention any additional factors which positively or negatively influence the participation of people with SCI?**

[▶ Interviewer: Pose the following question only to those who see a difference between integration and participation:

And what about integration? Would you name any additional factors important with respect to that?]

→ specific aims 3 and 4

- H) What do you personally do in order to take part in society? Do you apply, for example, certain strategies or do you have a specific philosophy concerning your personal integration?**

[▶ Interviewer: Pose the following question only to those who see a difference between integration and participation:

And what about integration?]

→ specific aim 4

- I) Could you mention where and how you developed these strategies?**

→ specific aims 4 and 5

- J) Have these strategies changed over time?**

→ specific aims 4 and 5

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K) What would you advise other people living with SCI to do in order to improve their participation?

[▶ Interviewer: wait for answer!]

[▶ Interviewer: Pose the following question only to those who see a difference between integration and participation:

And what about integration? Do you have any additional ideas regarding that?]

What advice would you give to their relatives and friends?

[▶ Interviewer: Pose the following question only to those who see a difference between integration and participation:

And what about integration? Do you have any additional ideas regarding that?]

→ specific aims 5 and 4

L) In conclusion, do you think that you now take more or less part in society than before your injury?

[▶ Interviewer: Pose the following question only to those who see a difference between integration and participation:

Does the same hold true for integration?]

Now, we would like to ask you to complete the following questionnaire concerning personal information. You can either fill it in yourself and put it in the attached envelope, or I can ask the questions if you prefer. Again, I would like to stress that the information will be anonymous and used only for scientific purposes.

[▶ Interviewer: Questionnaire with demographics and injury related aspects]

Finally, please would you tell us what you liked and disliked about the interview? I'll show you all the questions again.

[▶ Interviewer: Hand out questions.]

I) What did you particularly like about the questions?

II) What did you dislike?

III) Do you have any suggestions how the questions can be improved?

IV) Did you understand the differentiation between integration and participation?

V) Are any important aspects missing?

We thank you very much for your participation in the interview! If you like we will inform you about the results of the study.

[▶ Interviewer: Make a note accordingly.]

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If you have any further ideas or comments please do not hesitate to contact Dr. Jan Reinhardt from Swiss Paraplegic Research or Jane Horsewell from ESCIF, who are the leaders of the study.

[▶ Interviewer hand out paper sheet with contact information]

2.4 Standardized personal record



Personal Record

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Interviewer
Interview number
Date of interview





INJURY CHARACTERISTICS:

Date of injury:					
	D	M	Y		
Injury etiology:					
	Traffic accident	<input type="checkbox"/>	Other traumatic cause	<input type="checkbox"/>	
	Sports	<input type="checkbox"/>	Non-traumatic spinal cord dysfunction	<input type="checkbox"/>	
	Assault	<input type="checkbox"/>	other:	<input type="checkbox"/>	
	Fall	<input type="checkbox"/>	_____		
Level of injury:	_____				
	If you do not know exactly just mark one of the following:				
	<input type="checkbox"/> paraplegia				
	<input type="checkbox"/> quadriplegia				
	<input type="checkbox"/> do not know				
Completeness of injury	<input type="checkbox"/> complete				
	<input type="checkbox"/> incomplete				
	<input type="checkbox"/> do not know				

SOCIO-DEMOGRAPHIC DATA:

Date of birth:					
	D	M	Y		
Gender:					
Years of formal education:	_____				

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Highest level of education:					
<input type="checkbox"/> elementary/primary school, <input type="checkbox"/> high/secondary school, <input type="checkbox"/> apprenticeship, <input type="checkbox"/> university					
Current marital status:					
	Never married	<input type="checkbox"/>	Divorced	<input type="checkbox"/>	Other
	Currently married	<input type="checkbox"/>	Widowed	<input type="checkbox"/>	
	Separated	<input type="checkbox"/>	Cohabiting	<input type="checkbox"/>	
Living situation:					
	How many persons live in your household?	_____		Number of children: _____	
	Do you have children?	<input type="checkbox"/> yes <input type="checkbox"/> no			
Current occupation: (select the single best option):					
	Paid employment	<input type="checkbox"/>	Keeping house/House maker	<input type="checkbox"/>	
	Self-employment	<input type="checkbox"/>	Retired	<input type="checkbox"/>	
	Non-paid work, such as volunteer/charity	<input type="checkbox"/>	Unemployed (health reason)	<input type="checkbox"/>	
	Student	<input type="checkbox"/>	Unemployed (other reasons)	<input type="checkbox"/>	
			Other	<input type="checkbox"/>	
			Unknown	<input type="checkbox"/>	
Kind of occupation:					
Country of origin:					
Complications:					
	Did you have any complications in the year 2006?	Yes No	<input type="checkbox"/> <input type="checkbox"/>	Kind of complications:	