

Promoting patient participation in rehabilitation
– caring for the patient's perspective

PhD dissertation

Randi Steensgaard

Health
Aarhus University
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'Researchers work on the epistemological assumption that the purpose of academic research and discourse is not just to describe, understand and explain the world but also to change it (...).'

(Coghlan & Brannick 2001)

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I will conclude by quoting the Danish philosopher Kierkegaard: *‘If One Is Truly to Succeed in Leading a Person to a Specific Place, One Must First and Foremost Take Care to Find Him Where He Is and Begin There’*. This has been my guide as a nurse, as a PhD student and as a person. I am grateful to have so many people in my professional and personal life, who met me where I was, leading me and supporting me. Thank you.

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List of papers

Paper I

Steensgaard, R.; Kolbaek, R.; Borup Jensen, J; Angel, S.

"Promoting patient participation in rehabilitation by engaging nurses in research"

Nursing Inquiry. (Submitted)

Paper II

Steensgaard, R.; Kolbaek, R.; Angel S.

"Promoting patient participation – Nurses as participants in the patient's rehabilitation"

Journal of Clinical Nursing. (Submitted)

Paper III

Steensgaard, R.; Kolbaek, R.; Kasch H.; Angel, S.

"Nurses struggle for patient participation in rehabilitation - A path littered with obstacles".

Journal of Disability and Rehabilitation. (Submitted)

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Abbreviations

SCI – Spinal cord injury

WHO – World Health Organization

Definitions

Action research:

'A democratic and participative orientation to knowledge creation. It brings together action and reflection, theory and practice, in the pursuit of practical solutions to issues of pressing concern. Action research is a pragmatic co-creation of knowing with, not on about, people.'

(Bradbury, 2015, p. 1)

Co-researchers:

Four nurses and four nursing assistants working at the Spinal Cord Injury Centre of Western Denmark

Patient participation, definition developed in the study:

'Patient participation consists of dialogue and knowledge sharing between the patient and the health professional. Involving the patient's wishes, needs, preferences and knowledge about own situation enables the health professional to target the rehabilitation process. A patient's participation can be more or less active and the contribution of the health professional corresponds to the patient's needs. This does not mean that everything is possible, but it is a consensus-seeking approach.'

(Co-researchers, supervisors and I, 27 January 2016)

Introduction

In this dissertation, I will present a comprehensive summary of a study on how nurses can support their patients' participation in the rehabilitation process towards a meaningful life with a spinal cord injury (SCI).

Patient participation is recognised worldwide as a prerequisite for the quality of care, treatment and rehabilitation (Eldh, 2019; A. Kitson, Marshall, Bassett, & Zeitz, 2013; McCormack, Dulmen, Eide, Skovdahl, & Eide, 2017; Melin, Persson, Taft, & Kreuter, 2018; Sahlsten, Larsson, Sjöström, & Plos, 2008). Benefits like patient safety, lower costs and higher quality of healthcare have political attention and have motivated health services to enhance patient participation (World Health Organization, 2011; Coulter & Ellins, 2006; Weingart et al., 2011; World Health Organization, 2001). However, it is difficult to achieve individualised patient participation due to highly contextual and varying needs of participation from patient to patient and for the individual patient during hospitalisation (Angel, 2010; Angel & Frederiksen, 2015; Eldh, 2019; Van De Velde, Bracke, Van Hove, Josephsson, & Vanderstraeten, 2010). This may be one of the reasons why health professionals still struggle to interpret and implement the results, despite a growing body of literature on patient participation worldwide (Légaré et al., 2018). Even though health professionals ascribe this to the need for more tools and knowledge (*Fire anbefalinger til styrket patientinddragelse*, 2014; Joseph-Williams et al., 2017; Légaré et al., 2018), it has also been suggested that the attitudes and approach of health professionals play a decisive role in the efforts of involving patients in healthcare and rehabilitation (Angel & Frederiksen, 2015; Goodridge et al., 2019; Longtin et al., 2010; Scheel-Sailer, Post, Michel, Weidmann-Hügler, & Baumann Hölzle, 2017).

This study explores how the patient's participation in rehabilitation can be facilitated. I will provide insight into how involvement of health professionals, in this case nurses, can contribute to support patient participation. Given the involving nature of action research, I have worked closely with nurses and supervisors in a process of knowledge generation in the local context of a spinal cord injury rehabilitation unit to shed light on some of the challenges but also possibilities for supporting patients in rehabilitation. Due to the severity of the situation and lifelong consequences of a spinal cord injury, the patient's participation is a highly complex issue and determines how well the patient is prepared for life after discharge (Angel, 2010; Lindberg, Kreuter, Taft, & Person, 2013). Accordingly, exploring patient participation in this setting is not just highly relevant to the patient group involved; it may be useful in other complex and less complex rehabilitation settings.

Content of dissertation

Synthesising and summarising an action research study in a dissertation of this size can be challenging. In this comprehensive summary, I will elaborate on some of the aspects that were left little or no space in the articles due to publisher restraints. Therefore, besides providing a background to the context together with the relevance of the study leading to the aim and research questions, I will unfold the processes and phases of the study more extensively in the section on methodological framework and methods. A central aspect of undertaking action research is the close involvement of others. Therefore, the participants' roles are outlined and followed by the ethical considerations and implications. The next two sections will summarise the findings presented in the three papers and discuss the overall findings in a shared discussion. Finally, I will consider the methodological consequences of the choices made in this study and conclude with future perspectives on how this study adds to the body of literature on patient participation in rehabilitation and what should be explored further.

Background

In the following, I will argue why patient participation is crucial for rehabilitation after a spinal cord injury, just as I will elaborate on a possible strategy for working with improving patient participation in rehabilitation.

Patient participation as a critical element of spinal cord injury rehabilitation

Patient participation is a key component of rehabilitation where the purpose is to attain and maintain *'maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life'* (Concept Paper WHO Guidelines on Health-Related Rehabilitation, 2012; World Health Organization, 2011). Accordingly, patient participation is also a central aspect in the World Health Organisation's (WHO) framework 'The International Classification of Functioning, Disability and Health' (ICF) which is a leading guide to determine the health and disability of the individual and at population level (World Health Organization, 2001, 2011). This framework is often applied in the international community of rehabilitation including spinal cord injury rehabilitation (Haas et al., 2016; Ruoranen, Post, Juvalta, & Reinhardt, 2014; Van De Velde et al., 2018). It is a bio-psycho-social framework that has moved away from being a 'consequences of disease' classification to becoming a 'components of health' classification that takes into account contextual factors, such as personal and environmental circumstances (World Health Organization, 2001). The contextual factors play a decisive role in how the patient copes with the situation, is motivated or feels confident that there is a possible future ahead (Melin et al., 2018). Consequently, persons of the same

gender, age and level of injury may not necessarily get the same outcome from SCI rehabilitation (Steensgaard & Bjørnshave Noe, 2014; Bickenbach et al., 2013). Nevertheless, the need for assistance to re-interpret and convert wishes and routines according to the new life situation may be present in any case (Kirkevold, 2014). Therefore, successful rehabilitation depends on substantial understanding of the patient's situation as a whole (Melin et al., 2018; Scheel-Sailer et al., 2017; Wade, 2015). Accordingly, rehabilitation should be planned in line with what matters to the patient in order to enable the individual to reach full inclusion and participation in life (Lindberg, Kreuter, Person, & Taft, 2013; WHO Regional Office for Europe, 2013; World Health Organization, 2011).

Currently, there is no consensus on how to define patient participation (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016; Wade, 2015). Although the ICF framework has also been criticised for providing a poor definition of patient participation together with an unclear differentiation between participation and activity (Ruoranen et al., 2014; Van De Velde et al., 2018), the framework is still the most used tool for guiding both mono and inter-professional work in rehabilitation organisation (Ruoranen et al., 2014; Van De Velde et al., 2018). With this being the case and the inter-professional collaboration being regarded as another essential component of rehabilitation (Singh, Küçükdevic Ayse I., Grabljevec, & Gray, 2018), it is important that every profession brings a highly qualified set of skills to the collaboration to support patients and their families (Singh et al., 2018). Therefore, it is problematic that the nurse's role in rehabilitation is poorly described in general (Christiansen & Feiring, 2017; Kirkevold, 2010; Loft et al., 2017; Portillo & Cowley, 2011; Pryor, Walker, O'Connell, & Worrall-Carter, 2009) as well as in SCI rehabilitation (Pellatt, 2003). Despite the demand for specialised nursing skills and a promising position of being the person at the bedrock of the rehabilitation process, Pellatt argues that nurses have a low profile and position in the spinal cord injury rehabilitation setting (Pellatt, 2003). The unclear role and position represent a challenge which nurses need to face to contribute sufficiently to the collaboration (Melin et al., 2018).

According to Lindberg et al. (2013), the patients emphasise a need for health professionals to be the facilitators and promoters of patient participation. With this call from the patients and patient participation being a core element in nursing care (Castro et al., 2016; A. Kitson et al., 2013; Morgan & Yoder, 2012), nurses have the opportunity to pursue and occupy this important area of rehabilitation.

Strategy for changing practice to achieve patient participation

The patients are the experts of their own bodies and situations (Castro et al., 2016; Lindberg et al., 2013). Therefore, their perspective is central to successful spinal cord injury (SCI) rehabilitation. Nevertheless, patient

participation is challenging within SCI rehabilitation (Scheel-Sailer et al., 2017) (as well as in other healthcare settings (Angel & Frederiksen, 2015)) and patients may often feel alone in their fight for a meaningful life (Angel, 2010; Angel, Kirkevold, & Pedersen, 2009, 2011). Comments like: 'we do it already' or 'the patient is not ready to participate' hinders a mutual understanding between the health professional and the patient on how to involve the patient's routines, preferences, beliefs and needs (Eldh, Ekman, & Ehnfors, 2006; Freil, Wandel, Pedersen, Jönsson, & Nyborg, 2014; Joseph-Williams et al., 2017; Longtin et al., 2010).

The complex situation of a patient with SCI and examples of unsuccessful implementation of patient participation (Elwyn, Frosch, & Kobrin, 2016; Jangland & Gunningberg, 2017) call for a different approach to patient participation. Several studies argue that involving the health professionals is a promising way of dealing with the barrier of implementation and changing practice (Jangland & Gunningberg, 2017; Johansson Jørgensen, 2017; King, Taylor, Williams, & Vanson, 2013).

According to Waterman et al. (2007) and Montgomery, Doulougeri and Panagopoulou (2015), a suitable way of involving health professionals is by applying the methodology of action research. It differs from traditional research by combining the act of changing practice with research while involving participants actively in the study (Meyer, 2000; Waterman et al., 2007). The involving nature of this methodology is a key point and prerequisite as the Norwegian philosopher and action researcher Olav Eikeland states social research should be:

'cultivated in practical contexts, letting the "natives" themselves start "dialectical gatherings" in order to map their social, intellectual, organisational, relational, emotional, economic, etc. topographies, enabling them to experiment, learn, deliberate, choose, act, and cooperate more wisely' (Eikeland, 2008, p. 49).

Following the precept of Eikeland (2008) in this study, we wanted to develop practical knowledge in a rehabilitation setting with the involvement of nurses who worked and experienced the everyday practice of SCI rehabilitation. Thereby, we could shed light on the possibilities and challenges of patient participation. Enabling the nurses to experiment and learn more about their own position and on how to act could potentially strengthen their position in the inter-professional collaboration and, more importantly, provide them with skills, competences and options to change nursing to support the patient's ability to participate in rehabilitation.

Issues leading to the aim

Sustaining a SCI is a comprehensive and far-reaching event for the person and his family and routines and lifestyle will most likely have to be reinterpreted and adjusted to maintain values and important aspects of the patient's existence. Patient participation may be a path and a tool in rehabilitation to awaken the patient's ability to move forward and hopefully learn to live a meaningful life with a disability. Patients call for health professionals to facilitate and promote patient participation and nurses can play a decisive role in this matter. However, as many attempts have been made to implement or apply patient participation in nursing care and rehabilitation with a varying success, it may be appropriate to address the problem differently. No prior attempt has been made to involve the nurses from a practical context in an experimental process exploring their ability to take on a supporting role as facilitators of patient participation. Therefore, with this dissertation and three related articles, I propose to make a contribution to the scientific community and the body of knowledge on how to support the patient's participation in the SCI rehabilitation process towards a meaningful life.

Aim and research questions

The aim of the study was to strengthen the patient's participation in rehabilitation to support his path towards a meaningful life after a spinal cord injury:

- By exploring how nurses could support the process of rehabilitation by using new methods and by enhancing patient participation.
- While exploring the potentials of prototypes as an organisational method to make changes in rehabilitation.

The research questions I wished to explore were:

1. How can nurses, through increased patient participation, accompany and support the patient with a spinal cord injury towards a meaningful life?
2. How can 'prototypes' as a methodological tool contribute to patient participation?
3. How can action research guide nurses to enhance patient participation?

Methodological framework

With the known challenges of implementing initiatives to enhance patient participation from prior studies (Jangland & Gunningberg, 2017; Joseph-Williams et al., 2017; Légaré et al., 2018), the aim of this study was to strengthen patient participation in rehabilitation, not only by exploring the complexity of patient participation in rehabilitation but also by proposing new methods to create changes and practice-oriented solutions.

The German-American psychologist Kurt Lewin (1890–1947) was the first to emphasise the need to work with the group dynamics rather than the individual to effect change (Burnes, 2004; Lewin, 1946). Furthermore, he described that there was a need for the individuals to be involved, engaged and committed leading to learning and behavioural change (Bargal, 2006; Burnes, 2004; Lewin, 1946). Inspired by Lewin's thoughts on social change, I did not just want to add to the body of knowledge from my own unilateral point of view or analysis, I wanted to explore the knowledge that can be developed in collaboration with those who have hands-on experience. Therefore, action research became the methodological approach for this study.

Action research belongs to a large family of methods and methodological approaches (Bradbury, 2015), all with a scientific approach to real-life problems. It has many overlapping elements with mode 2 research (Kildedal & Laursen, 2012; Svensson & Nielsen, 2006) which legitimises a broader field of methods of knowledge development (Laursen, 2012). Due to the complexity of society and organisations, it is argued that mode 2 research is more robust than the traditional mode 1 research, where participants act as informants or consumers of the gained knowledge, which still strives to overcome the transfer problem between scientific knowledge and practice. The argument is that with staff as co-producers of knowledge, it becomes more targeted and useful to specific situations and practices (Svensson & Nielsen, 2006).

The definition of action research provided by Hilary Bradbury in the SAGE handbook of Action Research (Bradbury, 2015) is presented in the definition section. This definition contains key elements of action research and therefore key elements of this study, that is the *democratic and participative orientation, action and reflection, practical solutions, co-creation of knowing with, not about, people* (Bradbury, 2015).

The content and key elements were included in the present study where the *democratic and participative orientation* led to the participation of four nurses and four nursing assistants. They were involved in an open and equal, shared dialogue throughout the processes of the four phases. Their position and role are further elaborated on in the section 'The participants and their roles and functions'.

It was prudent to learn more about how nurses could strengthen the patient's participation in rehabilitation to support his path towards a meaningful life after a spinal cord injury. The wish to learn more and translate the knowledge into changed behaviour and practice went through a process of *action and reflection*.

Starting out as prototypes, the actions resulted in *practical solutions* in the form of four nursing initiatives. These are further elaborated on in the 'Prototype testing and evaluation' section.

This action research study was based on the understanding that we needed to enter a setting of *co-creation of knowing with, not about, people* to find solutions to enhancing patient participation. Hence, the action research methodology had the function of enabling the nurses to act upon their reflections both in terms of the specific situation with the patient and together with their nursing and inter-professional colleagues in the organisation. The methods for co-creation of knowledge is the recurring theme of the design and method section.

This study was conducted within the dialogical and pragmatic tradition of action research. In this tradition, dialogical processes bring the participants' understanding and knowledge into a shared critical reflection with an organisational change perspective (Frimann & Bager, 2012). The democratic element is paramount in this understanding (Greenwood & Levin, 2007). Dewey described democracy as being more than a form of government (Dewey, 2015). He argues that democracy is a free, equal and flexible reciprocal referring of one's own actions to those of others, creating an environment of mutual inspiration which results in a "*mode of associated living, of conjoint communicated experience*" (Dewey, 2015, p. 81).

Accordingly, based on the pragmatic philosophy of John Dewey (1859–1952) (Dewey, 2015; Greenwood & Levin, 2007), the scientific knowledge in this study was developed during reflections and dialogues combined with action in continuous circles. Thus, learning and acting were interrelated central aspects that, in the movement where reflections are converted into action, could lead to the development of new knowledge, experience and insight. Accordingly, learning is not equal to practising a skill but it is something that also involved an understanding of the terms of meaning and value under which it was practised (Dewey, 2015). The design in which learning was connected to reflection, dialogue and action will be presented next.

Design

The design of this study relied on the use of different methods related to action research to promote the intended reflection, dialogue, learning, action for change and knowledge development. With inspiration from Lewin (Bargal, 2006; Lewin, 1946), who was the first to provide a spiral process, and from Coghlan (Coghlan, 2019) who further developed the model in his work, the study was designed and conducted in four overall phases. The phases are construction, planning, taking action and evaluating (Coghlan, 2019). They served as a structure for the study. Coghlan also described a pre-phase where the context and purpose are explored according to the requirement of the particular study and how this requirement manifests itself in the local context (Coghlan, 2019). The pre-phase elements of this study were literature search (see Appendix I for search strategy) and dialogues with staff and managers to understand if the general area of interest was relevant in the local context. However, the local motivation and need to change was not in fact explored till the construction phase together with the co-researchers. Among other things, this led to the development of a definition of how patient participation was preferred to be in the rehabilitation setting (see definition in definition paragraph). Thereby, the desired future state was also indicated as Coghlan recommends (Coghlan, 2019).

The four phases of this study are described in Table 1. However, as described by Coghlan (2019), there are many cycles of varying duration and it is difficult to place activities definitively in specific phases. Therefore, experimenting actions occurred in all four phases concurrently with the co-researchers' shared reflective dialogues. Furthermore, the transition from, for example, the constructing phase to the planning phase was fluid and happened both in and in-between phases.

I designed the study considering that the participant could alter through the phases as outlined in Table 1. The different participants and their roles and functions are further elaborated on in the section 'The participants and their roles and functions'. Table 1 also shows the timespans together with the methods.

Table 1. The four phases, their aims, participants, activities and timespans

Phase	Aim	Participants	Activities	Methods	Timespan
1: Constructing	To identify the shared meanings and challenges related to the issues of patient participation	Patients Co-researchers Supervisors PhD student	Reflection Dialogue (Action)	A. Case studies B. Creative workshops C. Consecutive meetings	October 2015 – May 2016
2: Planning	To collaborate on planning actions to address the identified issues	Co-researchers Supervisors PhD student	Reflection Dialogue (Action)	B. Creative workshops C. Consecutive meetings	May 2016 – November 2016
3: Acting	To intervene and act upon identified issues while learning from the consequences	Patients Co-researchers Supervisors PhD student	Reflection Dialogue Action	B. Creative workshops C. Consecutive meetings D. Testing of four prototypes	October 2016 – November 2017
4: Evaluating	To evaluate the actions and discuss how they solved the issues of patient participation	Co-researchers Supervisors PhD student	Reflection Dialogue (Action)	B. Creative workshops C. Consecutive meetings E. Prototype evaluations	September 2016 – February 2018

Methods

The methods, consisting of A) Case studies, B) Creative workshops, C) Consecutive meetings and D) & E) Testing and evaluation. Inspired by Dewey and his pragmatic learning philosophy (Dewey, 1988, 2015), we focused on providing a setting where collective, collaborative learning could occur. This together with trying out new procedures pointed towards participation in a democratic social practice both in clinical practice and during reflective meetings and creative workshops.

A) Case studies

According to Freil et al. (2014) and Joseph-Williams et al. (2017), a problem with patient participation is that health professionals believe they already involve patients to a satisfactory level. To learn how to strengthen the patient's participation in rehabilitation to support his path towards a meaningful life after a spinal cord injury, we needed to start by exploring current practice. This is in line with Dewey who states that one should start with already existing traits and common features of the group, such as common experiences and undertakings to make changes or remove less appropriate or unwanted aspects of society (Dewey, 2015). Skills to reflect critically on practice was a way for the nurses to gain access to the profound knowledge they already had embedded in their habits (Dewey, 1988). Accordingly, during the constructing phase, we explored cases of patient participation in clinical practice to achieve a solid platform for reflection and discussion. The cases consisted of a synthesis of observations, log-books and interviews. We had nineteen cases in total of which eleven were complete cases with log-books, interviews and observations. Patients were aged 23–76, seven women and twelve men, of whom seven had sustained paraplegia and eleven tetraplegia (one unknown).

Over a period of two months (19 days in total), I went along with the all co-researchers in their practice, if the patient had agreed to participate. Inspired by Spradley (1980), I did observations and I used a guided notebook for my observations and thoughts. I had points to pay attention to such as: What happened? How was the atmosphere? How was the dialogue and collaboration? What did the patient say and do? What did the nurse say and do? How did the patient participate, who set the agenda and how were the activities negotiated?

The co-researcher performed her planned activities with the patient, and afterwards the co-researcher wrote her reflections related to patient participation in her personal log-book. The co-researchers were asked to describe the situation with the patient in detail. To guide their reflection, their personal log-books contained prompting questions like: What went well? How was the atmosphere? How was the dialogue? What did the patient do and what did you do? Furthermore, the co-researchers were asked to describe the collaboration,

dialogue and participation. Later the same day, the patients were interviewed by me about their experiences of the collaboration and the opportunities they had to participate and contribute to the process of rehabilitation, both in terms of the specific situation and in general. As Kvale and Brinkmann (2009) suggest, the interviews were semi-structured with a question guide. All interviews were later transcribed verbatim.

B) Creative workshops

The first workshop followed up on the identification of issues of patient participation in clinical practice. This workshop and the rest of the workshops were aimed at engaging learning processes and co-creating knowledge using creative methods as suggested by Borup Jensen (2019). The reason was that art has multiple functions in the process of learning and on the development of skills to reflect (Fredens, 2018). Moreover, sensory perception through art strengthens the imagination, observational skills and the ability to express oneself more profoundly (Borup Jensen, 2014). Furthermore, different artistic disciplines can be attained by different senses. However, they all have the ability to reveal dimensions of practice to which one has become blind due to habits and non-reflective behaviour (Borup Jensen, 2014). Therefore, we chose a creative approach in content and structure inspired by the creative approaches of Titchen, Dewing and McCormack (McCormack & Dewing, 2013; McCormack et al., 2017; Angie Titchen & McCormack, 2010) and Borup Jensen (Borup Jensen, 2014; Borup Jensen & Rina Dahlerup, 2019). Moreover, McCormack and Titchen argue that critical creativity enables access to spiritual and emotional intelligence along with bodily and artistic knowledge (Titchen & McCormack, 2009; Angie Titchen & McCormack, 2010). As Peter Reason expressed it, people are not disembodied minds but embodied acting beings (Reason, 2006).

In the context of nursing, Martinsen argues that emotion is the key to understanding a suffering person and allows the nurse to participate in his/her world (Martinsen, 2006). Therefore, to learn together, it was necessary to gain access to the individual embodied knowledge together with the senses and emotions linked to understanding the patient's perspective in order to support his or her participation. Accordingly, the methods of the workshops were to trigger reflection, analysis and knowledge development. To do that we listened to music, we drew, painted (Picture 1), role-played, looked at art and did physical exercises. The effect of the creative activities is further elaborated on in the findings section.

Picture 1. Photograph (brought with permission) from one of the exercises at workshop one



C) Consecutive meetings

Just as the idea of the workshops was to trigger reflection and dialogue in order to enhance knowledge production on how to support patient participation, the consecutive meetings were held throughout the study for much the same reason. All together we conducted 19 meetings. Furthermore, they worked as a process guideline and provided overview: how far were we in the phases, what was next and what had we experienced in terms of difficulties, challenges but also successes and “aha” experiences. To move away from ready-made knowledge and habits (Dewey, 1988), we focused our reflections at the meetings on responding to the co-researchers’ experiences of situations involving patient participation. We did not seek consensus but let the group explore incidences that the co-researchers found confusing or difficult to interpret in line with Dewey’s thoughts (Dewey, 1988). Therefore, the reflection and dialogue sought to explore problems, breakdowns and to be a fertile setting for new ideas and experiences that could be developed and tested.

D) & E) Prototype testing and evaluation

The reflective meetings and creative workshops led to the development of four prototypes of nursing initiatives that were to be tested and evaluated for their potential to support patient participation. The method of prototyping was developed by Midtlab¹ for innovative projects to create small adjustments to work procedures with the potential to have great significance on daily practice. Hence, trying new ways of working during short periods of time, in small defined parts of the organisation, on a small scale, involving small rather than large groups of people should facilitate change in a fast and smooth way. The prototypes

¹ Midtlab was Central Region Denmark’s Innovation department in 2014

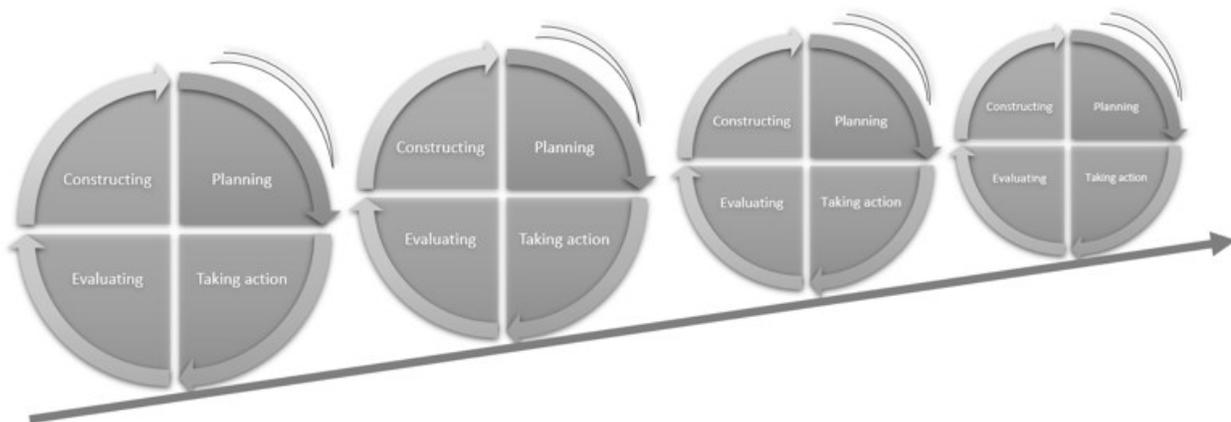
were always to be evaluated and only when assessed to improve practice should they be implemented (Duvald, Jensen & Astrup, 2015; Jensen, Jensen, Digman, & Bendix, 2008; MidtLab, n.d.).

We had successfully used prototypes at the rehabilitation centre before in a large inter-professional development project in 2013–2014. The use of prototypes had great appeal to the health professionals, who recommended and preferred (92%) this to be the centre’s future approach when working with development of practice. The health professionals also found the method manageable and clear (81%) (Hoffmann, Hansen, & Steensgaard, 2015). (Unpublished report)

By choosing prototypes as a method in the present study, we build on our knowledge and experience from the development project at the rehabilitation centre and explore the method further.

The number of prototypes was not predetermined. They emerged and were developed during meetings and workshops. Furthermore, they came from our experiences of testing the previous prototypes meaning that they informed each other and the experiences from the first prototype led to the next (Figure 1). This was very much like the iterative processes described by Coghlan (2019). The structure and form were the same in all four prototypes (Table 2 and Appendices E–H). Despite having a pre-defined form and the end goal of enhancing patient participation, the prototypes turned out to have the capacity to work as independent initiatives. Still, they had overlapping functions and could inform each other and a clinical pathway with continued focus on eliciting the patient’s perspective.

Figure 1. Prototypes 1–4. The spiral processes and their interrelatedness



Prototype – Name	
Background and purpose	<ul style="list-style-type: none"> ▪ Description of the purpose, briefly and concisely: ▪ What needs to be done differently? ▪ Why do we need to make this change? ▪ How does this prototype improve conditions for patients or staff?
Participants	Who and how many people participate? (What professions, which patients?).
When	<ul style="list-style-type: none"> ▪ When in the clinical pathway? ▪ Time frame (date, time) ▪ For how long is the prototype to be tested?
Where	<ul style="list-style-type: none"> ▪ Location of the prototype testing
Task	<p>What should be done, when and by whom:</p> <ul style="list-style-type: none"> ▪ How are participants informed (or if patients: have they been asked if they wish to participate)? ▪ How and where do we document this in the electronic patient journal? ▪ Co-researchers' tasks: Specific tasks are outlined here. ▪ Researcher's tasks: Specific tasks are outlined here.
Duration	Period for testing the prototypes (date, time)
Evaluation	<p>Plan for evaluation:</p> <ul style="list-style-type: none"> ▪ How is the prototype to be evaluated? ▪ Who will perform the evaluation? ▪ When is the prototype to be evaluated? ▪ What are the signs and parameters for changes in practice? <p>The evaluation must contain pros and cons together with an overall evaluation as well as recommendations.</p>
Adjustment and implementation (if not rejected)	The evaluation of the prototype is presented to the participants and to the management who decide how the results should affect the clinical practice.
Guide to prototype	<ul style="list-style-type: none"> ▪ Prompting questions ▪ Structure of the prototype ▪ Any supportive information to help the co-researchers

Table 2. Guideline to the form and content of prototypes

As suggested in the guide and in the literature on innovative initiatives (Dahler-Larsen, 2013, 2016), all prototypes were evaluated. We conducted a written evaluation with open questions assessing the substance, the applicability as well as the pros and cons of the prototypes. In line with Dahler-Larsen (2013, 2016), the written evaluation was followed up by a participatory evaluation where the co-researchers critically commented on and discussed the evaluation.

Summing up, the different methods assisted each other in a sense, as thinking, reflection and action were connected in four overall phases to enhance patient participation. On the basis of the evaluations, we

ended up with four nursing initiatives to enhance patient participation in rehabilitation on the path towards a meaningful life. They are further elaborated on in the findings section.

The participants and their roles and functions

As it appeared from the definition (Bradbury, 2015), participation is a central aspect of action research. However, in action research there are many names for the participants, just as there are different degrees of involvement (Block-Poulsen & Kristiansen, 2018; Bradbury-Huang, 2010; Reason & Bradbury, 2008). As presented in Table 1, the recurring participants were the co-researchers, the supervisors and me. Nevertheless, patients were also involved in the study. In the following, I will elaborate on how the different participants were involved in the study.

Co-researchers

According to Eikeland, participants in action research are not subjects of investigation but those who hold the acquired experience. Therefore, by establishing communities of inquiry within organisations, they are fully-fledged members of the research group. They just bring another type of knowledge to the inquiry (Eikeland, 2006). With this approach, the participating nurses and nursing assistants were named co-researchers in this study. The co-researchers held an active role and profoundly contributed to the knowledge development throughout the action research process from the construction phase to the evaluation. The central position of co-researchers is described by, for example, Block-Poulsen & Kristiansen (2018), Greenwood & Levin (2007) and Hummelvoll et al. (2015).

On entering the study, the co-researchers had varying levels of experience and knowledge about practice, the patient group, the organisation and the culture (see Table 3). Their role and position provided them with a right and a duty to engage in critical dialogue, action and change of practice. They took on this role with curious, enquiring, critical and exploring minds in reflective dialogues and actions. This brought their knowledge into play. Not only did they contribute to the development of practice, they were also committed to change the structure of the workshops to learn more and to improve the outcomes. Together with the supervisors and me, they acted as members of the research team.

Table 3. The co-researcher characteristics (anonymised)

Co-researcher	Education	Age (28–56)	Years of experience (1–20)	Years of experience in SCI rehabilitation (0.3–19)
Lise	Nursing assistant	54	9	9
Annett	Nursing assistant	56	19	19
Rikke	Nursing assistant	39	14	14
Tine	Nursing assistant	32	11	8
Hanne	Nurse	46	20	0.3
Line	Nurse	39	9	9
Maja	Nurse	26	1	1
Ann	Nurse	28	5	1.5

Patients

The patients who participated were admitted at the centre at the time of the study. They were assigned to a team of health professionals and one member of that team was one of the co-researchers. None of the patients participated in all four phases as the phases spanned a longer period than the admission time of the individual patient.

The patients had all sustained spinal cord injury which is damage to the spinal cord leading to varying degrees of sensory, motor and autonomic dysfunction. The severity of the impairment depended on the level of injury and whether the lesion was complete or incomplete. The injuries were either traumatic e.g. falls, road traffic accidents or sports or occupational injuries or non-traumatic, pathological: e.g. tumours or infectious disease. The physical severity depended on where on the spinal cord the injury was located. A cervical injury is generally referred to as a tetraplegia with paralysis of body, arms and legs. An injury below the cervical level is referred to as paraplegia with paralysis of legs and lower body (Bickenbach, Officer, Shakespeare, & von Groote, 2013). Both patients with tetraplegia and paraplegia participated in the study. For both groups, their injuries had brought about a life-changing situation affecting most aspects of their lives. Hence, it had impact on physical, psychological, social and existential areas of the individual's life.

Accordingly, persons with a spinal cord injury are exposed to a higher risk of other physical impairment, isolation, anxiety, depression and low quality of life (Angel, 2010; Angel & Frederiksen, 2015; Chen; Boore, 2005; Dickson; Allan O'Carroll, 2008; Erosa, Berry, Elliott, Underhill, & Fine, 2014; Geisler; Coleman; Benzel; Ducker; Hurlbert; McDonald; Sadowsky, 2002).

Depending on the phase, the patients participated differently (Table 1). Some were interviewed and some participated in the testing and evaluation of the prototypes by providing oral feedback to the co-researchers.

Consumer

One of the patients who participated in the initial construction phase volunteered to be a member of the advisory board (explained below) after discharge and for the remainder of the study, taking on a consulting role as recommended in the INVOLVE programme (Roberts, Turner, George', & Ward, 2012). As in other studies (Brett et al., 2014; Pii, Schou, Piil, & Jarden, 2019), we experienced numerous benefits from involving a consumer. The consumer participant contributed with his experiences, from being a patient at the ward and participating in the study's first phase. Furthermore, he was in the process of adjusting to life with a spinal cord injury and he could share his thoughts, concerns and experiences important to him and potentially others in similar situations. He participated actively in the meetings of the advisory board and when he was unable to attend in person, he gave written feedback to the items on the agenda.

Researcher – PhD student

When conducting action research, the researcher takes on a role that differs from the traditional role of a researcher. In action research, the researcher interacts with practice and bridges practice and academia. Moreover, the researcher may have more than one role in the organisation where the study is conducted (Westlander, 2006). During this study period, I continued working as a clinical nurse specialist and thereby, I was an insider action researcher and I had a dual role (Coghlan, 2019). According to Coghlan (2019), conducting action research within one's own organisation may have advantages but may also cause dilemmas regarding the research and one's personal role (Coghlan, 2019). This means that what may be beneficial in terms of in-depth knowledge about the organisation, culture, people, structure and dynamics may in turn be an obstacle, if the researcher is unaware of how this affects the research, the role of a researcher and the ability to maintain an appropriate distance to the object of study (Coghlan, 2019). Therefore, just as being an insider action researcher strengthened the study in terms of in-depth knowledge about formal and informal structures, roles and positions of the health professionals and managers (Coghlan, 2019), it also gave rise to considerations about how I affected the study. Consequently, I paid attention to this point throughout the study. Therefore, with a log-book of my own, I continually wrote down my reflections on my pre-understanding throughout the entire study relating to observations, workshops and the subsequent analysis.

What became a critical and important part of being an insider action researcher was my profound knowledge about the co-researchers as women. Consequently, I addressed them in different ways and I was able to look out for them and adjust my support to their individual needs.

The research context and organisational anchoring

According to Coghlan (2019), it is important to identify cultural, political and structural aspects that can act as potential drivers or inhibitors of a change within organisations. These factors are crucial to understand the results of action research (Coghlan, 2019). Therefore, the context and organisational anchoring of the study is elaborated on here.

Spinal Cord Injury Centre of Western Denmark

The study took place at the Spinal Cord Injury Centre of Western Denmark which is one of two Danish centres providing highly specialised rehabilitation after spinal cord injury. Approximately 100 patients are admitted a year, and the centre has 35 beds and an out-patient facility to which patients are referred to life-long follow up. The centre is part of the Department of Neurology, Central Regional Hospital Viborg, Denmark. The centre employs more than 100 inter-professional staff, including occupational therapists, physiotherapists, doctors, secretaries, psychologists, social workers, nurses and nursing assistants (Nursing assistants have shorter training than nurses. Nevertheless they are called nurses in this dissertation for reader-friendliness).

As described in the next section, I have worked at the centre for many years. Therefore, I had thorough knowledge about the structure and the culture at the centre. I continued in my position as a clinical nurse specialist during the study and thereby, I continued my collaboration with all health professionals and managers.

Organisational anchoring

According to Huges (2008) and Kjerholt and Toftdahl Sørensen (2014), it is important to have an organisational anchoring as lack of support from management can become a key barrier to obtain legitimacy and a mandate for participants and retain change after the end of a study (Huges, 2008; Kjerholt & Toftdahl Sørensen, 2014). Therefore, I addressed both the nursing and inter-professional managers at the centre for support. I actively worked to obtain and maintain close collaboration with the nursing managers and an advisory board was established to strengthen the study's position within the organisation.

Nursing managers

The head nurse and daily nursing managers supported the study verbally and in their organisation of nursing duties. They coordinated the duty schedule with a priority for co-researchers to be able to participate in meetings and workshops during their working hours. They provided space on staff meetings, inter-professional teaching and allowed all the nurses outside the project to participate in a one-day workshop to learn about the approach and initiatives developed in the study. Despite a positive approach of the nurse managers, a shortage of time to care for patients continuously caused discussions within the nursing group about which nursing tasks were 'a must' and which were expendable. The findings of this study were not spared in this respect. I will elaborate further on this issue in the findings and discussion section as well as in paper three.

Advisory board – function and functionality

The advisory board consisted of a representative from the co-researchers, a consumer, the supervisors and representatives from the nursing and inter-professional managers.

Terms of reference were made and the aim of the board was to support the project and to secure the management's support of the changes. Furthermore, the board contributed with coordination of the project in accordance with the day-to-day running of the centre. The advisory board was positive and actively participated at board meetings. However, the board members did not engage in changing the overall structures of the rehabilitation organisation to pave the way for the nursing initiatives and a more involving approach.

Pre-understanding of an insider action researcher

According to Brydon-Miller (2008), the person undertaking action research must critically reflect on own values, position in relation to the institution, power and privileges to understand how these factors may influence interactions and research practice (Brydon-Miller, 2008). According to Coghlan (2019), the researcher's role and pre-understanding are important aspects for the transparency of the study and the findings. I find these aspects interrelated when it comes to this study: my indignation was also part of my pre-understanding just as both elements affected my role in the study.

Although it is not possible to outline all aspects of one's pre-understanding (Coghlan, 2019), I will present some of the important incentives to undertake this study on a personal level. Furthermore, I will illustrate how my personal beliefs, experience, knowledge and motivations for choosing this methodological approach guided the study and affected my role.

Indignation

A person suffering a SCI has a changed life ahead of him or her with obstacles that can be difficult to overcome, affecting his/her life satisfaction and quality of life (Dickson; Allan; O'Carroll, 2008; Erosa et al., 2014).

However, it is possible to assist the patient in the process of rehabilitation to reduce disability and achieve quality of life (Birkenbach et al. 2013.). In my experience of caring for patients with SCI, the transition from hopelessness and despair to hope and belief in a possible future is complex and difficult. Even though, I have cared for patients who felt or gained a sense of meaning and who were confident when they were discharged from the rehabilitation centre, I have also experienced devastated and depressed patients who could not find the drive or motivation to pursue a meaningful life with a disability. In those situations, I have sometimes felt helpless and inadequate and had a burning wish to be able to do more. Experiences like that and the clash with my experience of task-oriented nursing performed at the centre led me to wondering how nurses could support their patients to a greater extent.

Pre-understanding

An insider action researcher brings pre-understanding to the project, including the lived experiences of being a member of the organisation (Coghlan, 2019). Thus, due to familiarity and taking certain situations for granted, it may be challenging to see things critically and facilitate change (Dewey, 1988). Therefore, attentive awareness is crucial (Coghlan & Shani, 2015).

Working as a nurse at the rehabilitation centre since 2006 has provided me with an in-depth knowledge of the routines and the organisation. I have cared for many patients and I have worked together with all professions in teams. In 2013, I was appointed as a clinical nurse specialist and my work concentrated primarily on development projects and teaching (both in nursing and inter-professional subjects). I had extensive knowledge of the organisation and a friendly collegial relationship with the staff and managers, and I hoped this would be an advantage. Nevertheless, on several occasions, I also engaged in frank, intensive and passionate professional discussions on potential improvement of the rehabilitation provided at the centre. Even though these discussions were conducted in a respectful tone, I did not know in advance how my colleagues and the managers would react to the outcome of this study, as I had previously experienced some reluctance in a project that changed the rehabilitation organisation.

Action research was an obvious choice of research methodology for this study, mainly due to the aim and research question but also due to my pre-understanding. It was my understanding that changing nursing practice was highly dependent on those who were to perform the task. They should be driven by motivation

and personal knowledge from experience rather than from findings presented by me. As is known from action research, the involvement of staff in research is decisive to solve real-life problems (Greenwood & Levin, 2007; Svensson & Nielsen, 2006). That was my intention. The nurses and I were equally dependent on each other and equally important in our wish to change rehabilitation nursing. I would not be able to do the study without my co-researchers and vice versa.

My indignation was my drive to initiate the study. However, along the way, the changed behaviour of my co-researchers became a driver as well. It was rewarding to see their dedication, involvement and effort to provide better nursing and to bridge their new knowledge with nursing practice.

Ethical considerations

The study received the approval of the Head of the Department of Neurology and the Danish Data Protection Agency (journal no. 1-16-02-503-15). The study did not fall under the jurisdiction of the Danish Health Research Act but was performed in accordance with the Helsinki II Declaration (*World Medical Association. Declaration of Helsinki – Ethical principles for medical research involving human subjects*, n.d.) and the Ethical Guidelines for Nursing Research (Dansk Sygeplejeetisk Råd, 2014).

This meant that in every way, the study worked from the principles of autonomy, beneficence (doing good) and non-maleficence (not causing harm). According to Brydon-Miller (2008), action research takes it one step further and embodies the values of ethics due to the participatory democratic process (Brydon-Miller, 2008). However, to succeed in providing a democratic process requires profound ethical considerations beyond the formal guidelines and may entail ethical dilemmas (Laursen, 2019). As described by Morton (1999), dilemmas cannot always be anticipated before initiating a study due to the innovative and iterative process. Therefore, ethical considerations, reflections and discussions were conducted throughout this study in the research team, with the supervisors and with the advisory board. Since the study involved two groups, namely patients and nurses, I had thorough considerations about how to protect both groups.

Ethical considerations concerning the co-researchers

Formal arrangements were made to provide an ethical safety net for the co-researchers. I made an agreement with the regional clinic for occupational medicine to provide psychological support for the co-researchers if they found it necessary. The co-researchers actively and voluntarily contacted me to join the study, they gave written consent to participate and were able to withdraw from the study at any time. Anonymity was a challenge because the entire ward knew who the co-researchers were. However, in the dissertation and the

papers, the co-researchers have been anonymised. Even so, they are mentioned in the acknowledgements with written permission.

One thing is formal demands and another is the day-to day ethical responsibility towards the participants. It was my duty to look out for the co-researchers. They participated with honesty and openness which might put them in a vulnerable position in relation to each other and to their self-image when their new experiences and realisations opened their eyes to their nursing prior to the study. Hence, meetings and workshops were organised to foster trust, dialogue, openness, confidentiality and integrity. Timeframes and workloads were extensively coordinated with the nurse managers and adjusted according to the co-researchers' levels of surplus energy, psychological as well as physical.

A dilemma occurred during the study concerning the co-researchers' sense of responsibility. It came out in their statements how they were afraid of letting the study down and not being able to convey and implement their new insights in rehabilitation practice. They undertook the responsibility of changing nursing. Not just their own, but entire wards. When I became aware of their concern, I emphasised that their task was to participate actively to the extent they could within the constraints of the way in which rehabilitation was organised at the centre.

Ethical considerations concerning the patients

Patients who were involved in the study were informed both verbally and in writing about the study and asked to participate by the co-researchers. The patients were asked twice: the day before and on the morning of the event. As a member of the patient's team, the individual co-researcher was well informed about the patient's condition and state of mind. Therefore, on several occasions, we postponed or cancelled a planned day (phase one), if the patient was not well and fit to participate. Patients, too, gave informed consent and were able to withdraw their consent at any time without it affecting their care and rehabilitation. Even during prototype testing where the patients did not contribute with any recorded material but only with their immediate responses to the prototypes, they were asked to give informed consent. Furthermore, I had made an arrangement with a local psychologist to provide support in case the patients felt harm. No patients availed themselves of this service.

The consumer and previous patient on the advisory board was a constant voice throughout the study to make sure that we maintained our focus on the patient's perspective. The co-researchers also had an ethical responsibility towards their patients. As recommended by Brydon-Miller (2008), critical dialogue in the research group on ethical matters was embedded throughout the study.

Analysis method, analysis and interpretation

As in other action research projects (Nielsen, 2004, 2012), I shared the scientific realisation processes with the co-researchers. Accordingly, their analysis and interpretations were imbedded systematically within the processes of the four phases of the study.

In practical terms, this meant that shared analyses of e.g. sections of interviews with patients or of the experiences during prototype testing in actions were conducted in workshops and at meetings. The creative elements described in the methodology section and in article one (Appendix A) were applied to get an analytic approach to the experiences and to open up for further interpretations. During our dialogues, the individual interpretations from e.g. log-books and written evaluations were tested and qualified by the group in dialectical relationships as described by Greenwood and Lewin (2007), where the co-researchers' local, practical, tacit knowledge was combined with the professional, scientific or theoretical knowledge which was introduced by one of the supervisors or me. The analysis and interpretations performed by the research team (co-researchers, supervisors and me) led to the four nursing initiatives. They were implemented at the rehabilitation centre without further adjustment or interpretation. Nevertheless, the processes of the study provided more empirical data to explore. To obtain a deeper understanding of the meaning of patient participation and a more universal understanding of the nurses' options to support the patients' participation, I performed an analysis inspired by the philosophy of Paul Ricoeur (1913-2005) (Ricoeur, 1973a, 1976) as I will elaborate on in the following section.

Preparing the material for interpretation

The empirical material consisted of different sources such as log-books, interviews, meetings, workshops and written evaluations. To systematically and transparently bring out central findings from the large material, I used the same analytical approach regardless of the source. According to Ricoeur (1976), all social phenomenon of a semiotic character can be analysed by using the text model (Paul Ricoeur, 1976). Therefore, the recorded and verbatim transcribed interviews and dialogues from the workshops and meetings were turned into text and gathered with the rest of the data into one document. This prepared the text for analysis and paved the way for a first overall interpretation of the empirical material from all four phases of the study. This is what Ricoeur (1976) calls the naïve interpretation.

On the basis of careful consideration, I chose to perform in-depth analysis of the empirical material from phases one and four. The analysis of the first constructing phase produced an in-depth interpretation of the issue of patient participation as it played out in practice. Furthermore, it unveiled how this was articulated

in the interactions and dialogues leading to the development of possible solutions in the form of prototypes. The analysis of phase four produced an interpretation of the obstacles and opportunities connected to testing the prototypes and working with the four nursing initiatives and a changed approach to patient participation. The empirical material which underwent full analysis comprised of 180 pages. After the analysis of the material from phases one and four, I checked for confirmation or discrepancy in phases two and three. The data from phases two and three did not provide any further information in relation to the aim despite units of texts confirming the findings.

Analysing the empirical material as text

The intention of using the text model was not to understand the actual events, the involved persons or to shed light on the co-researchers' intentions. Rather, it was to explore the meaning of the events and what the text said about the notion of patient participation in a more universal matter in line with the thoughts of Ricoeur (1973a).

According to Ricoeur, to explore the meaning, you first have to distance yourself from what was said and the intention behind. As the speech was fixed into text, it was loosened from the event and authors (Ricoeur, 2002). This methodological distancing turned the text into an object that could be explored in a dialectic process, not to explore what was behind the text, but instead to achieve an understanding of what the text was about and how it pointed '*towards a possible world*' (Ricoeur, 1976, p. 87,) (Ricoeur, 1973a, 1973b). An example of this was when the actual event of e.g. a workshop (speech, action, interaction and dialogue) was transcribed into text. Then it was loosened from the co-researchers' intentions as they had emerged at the workshop. Accordingly, what had happened now appeared as a text that was open to my interpretation. Hence, the distancing was not just something to conquer, it was also a condition for interpreting (Ricoeur, 1973b). In this study, what the text said about the patients' need for participation in rehabilitation and how this could be supported.

Despite being circular and interrelated, the text analysis consisted of three stages where an understanding of the text as a whole (naïve interpretation) was succeeded by an explanatory, mediating stage (structure analysis) and completed by a likely interpretation and a deeper understanding (critical interpretation) (Ricoeur, 1973a, 1976, 2002).

Naïve interpretation

In this first stage of the analysis, the text was read and re-read to appropriate an immediate and overall understanding. The text was read with an open mind and the interpretation was close to what was said.

At this stage, I remained open to the text knowing that my pre-understanding did play a role (Ricoeur, 1973a, 1976). As the authors, e.g. the co-researchers or patients were no longer present to reply to my questions to the text, I tried to grasp the meaning by stepping back and asking the text: what is emerging here? What is my immediate interpretation of this? An example of this was the analysis of the texts from the first phase where I tried to grasp the meaning of patient participation. How did it take place at the centre and how did the co-researchers and patients talk about the participation and its meaning to the patients' rehabilitation? The naïve surface interpretation of the text was not just to rephrase and repeat what was said but to guess the meaning (Ricoeur, 1976). This led to a subjective, naïve construction of a text, which was followed by the more objective structure analysis to confront and argue for or against the interpretation.

Structure analysis

The structure analysis worked as a settlement of the subjective appropriation in the naïve interpretation and as a movement towards a possible objective interpretation (Ricoeur, 1973a). Accordingly, in this process, the analytical step was to follow the movement from meaning (what the text said) to reference (what the text said something about)(Ricoeur, 1976). According to Ricoeur, this leads to the disclosure of the world itself in front of the text and it thereby provides access to a deeper sense of the underlying intention of the text (Ricoeur, 1973a, 1976).

The structure analysis was vital to get from the surface understanding of the naïve interpretation to the explanation and a deeper understanding (Ricoeur, 1976). The empirical material was read sentence by sentence and successive sentences carrying the same unit of meaning were gathered into themes (Ricoeur, 1976). However, the movement from the first naïve interpretation to the critical interpretation was not linear and not just one quote led to the themes. Nevertheless, in the following, I will illustrate the procedure and movement from "what is said" to "what is talked about" and to the reduction into units and themes (Ricoeur, 1976) as it was applied in this study.

The first example is from the evaluating phase where one of the co-researchers said:

'This is where the code for the patient's drive, his motivation, energy, problems, doubts and frustrations may come to the surface. Here the pieces of the puzzle are inspected to see what will fit, and maybe a few of the pieces are positioned, but that is not the aim. The aim must be to find the pieces and start the puzzle.'

(Co-researcher Hanne, Evaluation of prototype 2)

In the structure analysis, I explored what was being talked about and elaborated on in the quote or paragraph by adding explanation. The structure analysis was as follows:

Through conversations between the patient and nurse, the nurse achieves knowledge about the patient as a person. She learns what interests or aspects from his life were important and what could motivate the patient in the process of rehabilitation. Furthermore, the nurse obtains knowledge about how the situation affects the patient's strength to participate. The metaphor of a puzzle provides a language for the patient's situation and for what the patient's situation called for from the nurse. It was not to take over and do the puzzle for him but to arrange for the patient to do it himself with the support of the nurse. Hence, knowledge about the person enabled the nurse to target her participation and facilitate the patient's participation by tailoring it to his life and situation.

This and other paragraphs and units of meaning were combined into the theme

Participation paves the way for a tailored rehabilitation process.

The second example is of a quote from meeting 16 also in the evaluating phase. The quote is from one of the co-researchers, but two different places in the dialogue with the rest of the co-researchers:

'... why is it not (...) equally valid to go in and say: we have a conversation today; it is an integrated part of the treatment. You might just as well look at it like that (...)

- and

'You are also thinking, well (...) it is part of the rehabilitation process here at VCR, it is part of the package, (...), why is it then that we have to put in so much effort to try to (...) get it changed instead of just being able to say to the patient: today (...) you and I are having a conversation ...'

(Co- researcher Lise, Meeting 16)

The structure analysis was as follows:

A conversation between a patient and a nurse without performing other practical tasks is important to rehabilitation. However, it is not viewed as equally legitimate to other elements of nursing and rehabilitation. As presented here, the nurses find it to be an integral part of rehabilitation to understand the patient's perspective. This illustrates a discrepancy in understanding between those who have reflected on their practice in a learning environment and tested the effect of another approach and the colleagues at the rehabilitation centre. Therefore, the co-researchers called for conversations to be as valid as other aspects of rehabilitation nursing and rehabilitation in general. It is not specified to whom the statement was addressed. It might be to patients, inter-professional colleagues, nursing colleagues or managers.

Once again, the two quotes are examples that represent parts of the text leading to the theme that can be retrieved in the text as a whole: **The call for nursing to include the patient's perspective.**

The comprehensive process of explanation in the structure analysis was finalised in a critical interpretation and an in-depth understanding.

Critical interpretation

The critical interpretation aimed at identifying the most likely interpretation among competing interpretations and to refute shallow meanings (Ricoeur, 1973a) of what was needed to support the patient's participation in rehabilitation. At this stage, the naïve interpretation was either confirmed, supported, modified or rejected (Ricoeur, 1973a). In the present study, the naïve interpretation was not rejected but it was modified as the critical interpretation pointed more to the need for a re-instatement of caring in rehabilitation nursing than I had initially understood. The critical interpretation and the themes were discussed in the light of other literature or theories. This is dealt with in the discussion section and in papers II and III.

Findings

The aim of this study was to strengthen the patient's participation in rehabilitation to support his/her path towards a meaningful life after a spinal cord injury. The findings that strive to fulfil this aim were presented in papers I, II and III. First, in this section, a summary of the findings presented in paper I (Appendix A) outlines the methodological implications of applying action research to the work with enhancing patient participation. Afterwards, I will present a summary of papers II (Appendix B) and III (Appendix C) showing the interrelatedness of the findings outlining the complexity of supporting the patient's participation in rehabilitation. A more profound exposition is to be found in the three papers which are all included in the dissertation as Appendices I-III.

Action research as a means to enhance patient participation

One of the main findings this study brings to the scientific community is the effect of involving the nurses in finding solutions to enhance patient participation.

As presented in paper I, (Appendix A), we saw several signs of change following the methodological approach: the co-researchers explored their practice through the four phases, and apart from developing four supporting nursing initiatives, they indicated that their perception of themselves as health professionals had changed as well as their nursing practice and engagement in patient participation.

In practical terms, we could see how the co-researchers changed patterns and became more analytical towards their practice. Moreover, this was followed by an eagerness to act and a drive to involve the patients' perspective not only in nursing but also in rehabilitation in general. This was seen in a suggested change to the

structure of inter-professional meetings with the patients. A change that was later implemented at the centre. Furthermore, the co-researchers suggested two other initiatives to enhance the patients' clinical pathway. These have not yet been implemented at the centre. Hence, their newly found drive provided the co-researchers with competences and skills to address patient participation, not only on an individual level, but also on an organisational level.

In the paper, we argue that the methodology of action research played a decisive role. With a setting where it was possible for the co-researchers to withdraw from their daily work, they had the opportunity to reflect on their nursing and collaborate on the four prototypes. The combination of conducting meetings at the centre in the afternoon at a time when the workload for the remaining nurses was small and the workshops away from the centre provided a conducive environment and mindset for the co-researchers.

The use of creative artistic methods opened up for a new language and triggered reflection. This was seen in the use of metaphors e.g. in their drawings. They got a language for the patient's situation, for the patient's perspective and for what the patient brings to rehabilitation in terms of routines, networks and life experiences. Furthermore, they gained a language for and thoughts on what kind of support the patient might need during rehabilitation to obtain a meaningful future life. Using the different accessories (music, bodily exercises, painting), the co-researchers expressed how they felt compelled to learn more about their patients using their senses and listening more carefully to their perspective.

Picture 2.



Picture 3.



The paintings are from the workshop in November 2016. As an introduction to the exercise, the co-researchers were asked to paint how they perceived patient participation at that moment in time (*Picture 2*) and how they would like it to have a different impact in the future (*Picture 3*). By putting the canvas on the edge, the co-researcher illustrated a shaky ground beneath your feet by a physical representation of a tilted horizon.

I found that the study points to the potentials of creative activities as a way to encourage critical reflection, developing language for and actions in nursing to support patient participation.

Another central method was the development and testing of the prototypes. The use of prototypes provided the co-researchers with a simple and well-known method to test new initiatives. Combined with the learning and knowledge developing aspects, the prototypes provided a systematic structure for action and the co-researchers expressed that they found the method both appropriate and effective in testing solutions to enhance patient participation. However, the challenge of implementing the solution to the larger group remained.

The four prototypes were developed, tested and modified into four nursing initiatives as a result of the work within all four phases. A short description of the initiatives is provided here (Table 4). The guides and prompting questions were not adjusted so they are referred to in Appendices E–H together with full descriptions of the prototypes.

Table 4. A short presentation of the four nursing initiatives

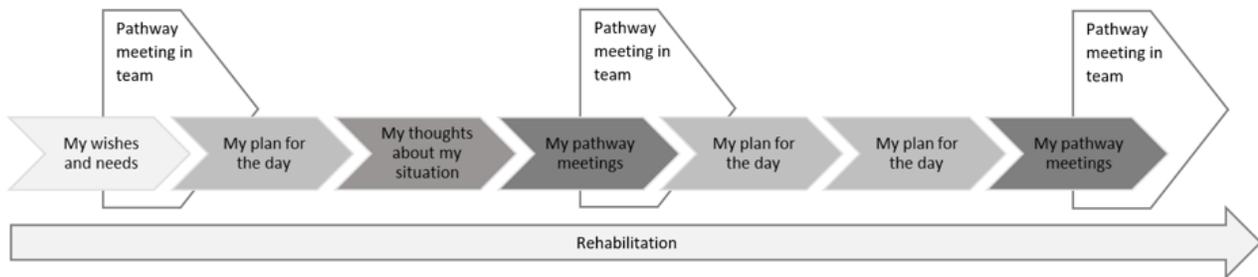
The four mediating tools (can work separately or together in the individual clinical pathway)	
My wishes and needs	<p>Held within the first two weeks of admission</p> <p>Aim Knowledge about</p> <ul style="list-style-type: none"> ▪ the patient’s needs and wishes for the admission and for the future ▪ the patient’s preferences and experiences in life <p>Prepare patient for the first interdisciplinary clinical pathway meeting</p> <p>Setting Up to one hour’s conversation with primary nurse in a private room with no interruptions</p> <p>Prompting questions – see Appendix E</p> <p>Documentation The conversation is planned and subsequently documented in the electronic patient journal in relation to the topic it involves (bladder, bowel, psychosocial)</p>
My plan for the day	<p>Held no later than one week after admission and continually throughout the admission every time there were changes to the patient’s wishes, needs and self-sufficiency</p> <p>Aim To plan a clinical pathway where the starting point is the patient’s needs, preferences and wishes for daily life at the rehabilitation centre To align expectations to the clinical pathway and the different roles of patient and different staff To strive towards continuity, structure and prepare an overview of activities for the day and the clinical pathway To make sure the patient can be as active and participate in line with his resources and energy To plan the patient’s activities and need for nursing assistance when the primary nurse is not present</p> <p>Setting Up to 30 minutes conversation with primary nurse in a private room with no interruptions</p> <p>Prompting explanations/questions – see Appendix F</p> <p>Documentation The conversation is documented in a shared day and night care plan using the letters HPU to indicate how the nurse or team-member should assist the patient:</p> <ul style="list-style-type: none"> H: Help P: practice U: unassisted <p>In the comments field of the electronic patient journal, write down important points such as philosophy, way of life, normal pattern on an ordinary day, physical and psychological factors, job and hobbies related to the planning of the rehabilitation on a daily basis and also in the longer term</p>

<p>My thoughts about my situation</p>	<p>Held after two months</p> <p>Aim To support</p> <ul style="list-style-type: none"> ▪ The patient’s understanding of his situation and himself through a coherent narrative of his life and what has happened ▪ Coherence between past, present and the patient’s wishes and hopes for the future <p>Setting Up to one hour’s conversation with primary nurse in a private room with no interruptions</p> <p>Instructions</p> <ul style="list-style-type: none"> ▪ Follow the patient’s narrative ▪ Think of your role as a facilitator to self-understanding. The goal is not to gain knowledge. ▪ Avoid leading or value-laden words ▪ Ask open-ended questions <p>Prompting explanations/questions – see Appendix G</p> <p>Documentation The conversation is planned and subsequently documented in the electronic patient journal. Only if there is relevant new knowledge about topics like e.g. bladder, bowel, psychosocial is anything written down)</p>
<p>My pathway meetings</p>	<p>Held one to two weeks before the second and third clinical pathway meetings</p> <p>Aim</p> <ul style="list-style-type: none"> ▪ To prepare the patient for the clinical pathway meetings where all team members and relatives draw big lines and plans for the pathway together with the patient ▪ To help the patient reflect on his situation to prepare the basis for his active participation in the clinical pathway meetings ▪ To support adjustments to the clinical pathway to ensure that they take their starting point in the patient’s wishes, needs and preferences ▪ To focus on the patient’s physical, psychological and social functional capabilities in combination with health and contextual parameters ▪ To support the patient in his current situation and considerations about the future <p>Setting Up to one hour’s conversation with primary nurse in a private room with no interruptions</p> <p>Prompting questions – see Appendix H</p> <p>Documentation The conversation is planned and subsequently documented in the electronic patient journal in an interdisciplinary status update (topics decided by patient and nurse together)</p>

The nursing initiatives worked separately and could stand alone. However, they were developed to support the patient’s varying and varied needs for participation and therefore placed consecutively, aiming for a coherent rehabilitation process. In Figure 2, it is illustrated how the initiatives appear in the clinical pathway. "My plan for the day" appears several times to show that this initiative is ongoing as the patient’s needs and demands fluctuate and change during the rehabilitation process. The pathway meetings are three meetings held in every

clinical pathway by the inter-professional team together with the patient and one of his/her relatives. They were known as conferences before the study, but they were changed to support a more involving approach of the clinical pathway.

Figure 2. The four nursing initiatives as they appear in the clinical pathway of SCI rehabilitation.



The four nursing initiatives may provide answers to both the concrete clinical practice as well as the wider community of rehabilitation nursing working to enhance patient participation due to their link between the person's life and the rehabilitation pathway more than to the specific injury or illness.

In short, I wished to explore how action research could guide nurses to enhance patient participation including the use of prototypes as an organisational method to make changes in rehabilitation. Concluding on the impact of the methods and methodology, I found that by involving the nurses directly in the research and the development of practical solutions to the complex issue of involving the patient's perspective in rehabilitation, they came up with workable new methods. At the same time, they showed drive and an eagerness to act to change practice. Therefore, I propose greater involvement of nurses when the task is to solve practice-oriented problems.

Supporting patients with SCI through participation

Another of the main findings was related to the research question of how nurses, through increased patient participation, could accompany and support the patient with a spinal cord injury towards a meaningful life. This was explored in paper II *'Promoting patient participation – Nurses as participants in the patient's rehabilitation'*.

We found the co-researchers changed their perception of and approach to patient participation in rehabilitation during the process of reflecting, acting in practice and engaging themselves in dialogue to develop a nursing practice.

Moreover, in a more general sense, we found that nurses' engagement and participation in their patients' rehabilitation was of great importance to learn about the patients' preferences, wishes and needs. By participating in the rehabilitation and accompanying the patient, the nurses are more attentive to their patients' needs and consequently adjusted their nursing care to the wishes of the patient – also when it came to the wish for participation. Accordingly, patient participation can become a direct consequence of the nurses' engagement and participation in their patients' rehabilitation and lives.

The findings were synthesised into four themes:

- 1) Patient participation changes the approach of nurses and enhances rehabilitation,*
- 2) Nurse participation in the patient's rehabilitation enables collaboration and companionship,*
- 3) Nurse participation reinstates caring in nursing, and*
- 4) Participation paves the way for a tailored rehabilitation process.*

The themes were clarified and discussed in paper II, and we concluded that tailoring patient participation to the individual depended on nurses being able to meet their patients in person-to-person relationships. When the nurses really engaged with their patients and participated actively in their rehabilitation, they were able to reinstate caring in their nursing. This, together with four nursing initiatives, led to a collaborative process that paved the way for caring nursing, tailored to the individual person with SCI.

However, as revealed in paper III, *'Nurses struggle for patient participation in rehabilitation – A path littered with obstacles'*, it was not without difficulties to develop an approach in nursing that supported the patient's path towards a meaningful life. This paper presents the possibilities and obstacles experienced by the co-researchers in their efforts to establish patient participation in rehabilitation.

The co-researchers tested the prototypes of the four nursing initiatives and on the basis of their evaluation, the following central themes emerged:

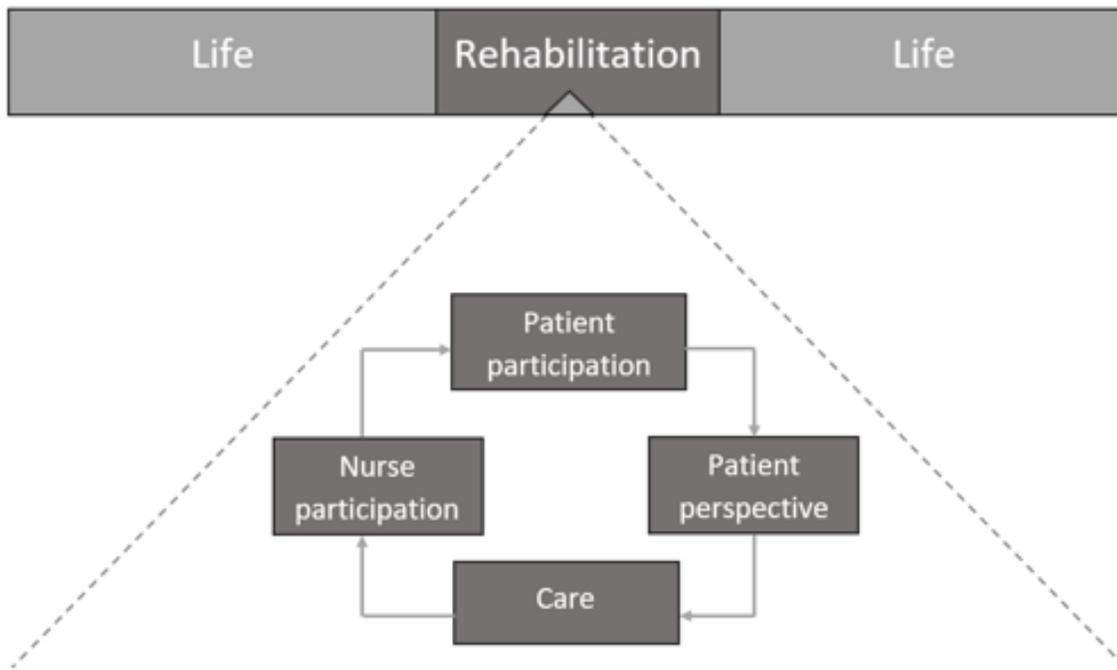
- 1) Recognising the impact of the patient's perspective for patient participation,*
- 2) Struggling to be attentive to the patient's perspective,*
- 3) Searching for time to elicit the patient's perspective, and*
- 4) The call for nursing to include the patient's perspective.*

The analysis revealed that the co-researchers recognised the impact of the patient's perspective for patient participation. Nevertheless, they experienced difficulty in imbedding the patient's perspective in their everyday practice. Hence, they were struggling to be attentive to the patient's perspective and they found it

unfamiliar and difficult to find personal calmness to pay full attention to the patient's narrative. Furthermore, finding time and space for a conversation with the patient without being disturbed or having to perform practical tasks was another challenge. Moreover, it clashed with existing nursing practice and the organisation of the rehabilitation at the centre. Hence, the co-researchers had to find time to elicit the patient's perspective through alternative and less appropriate solutions. Accordingly, the co-researchers called for a change to the conditions and setting to ensure that the nursing would include the patient's perspective in rehabilitation.

Summing up as illustrated in Figure 3, we found that **patient participation** was crucial for patients to achieve autonomy and independence in life. When patients participated in rehabilitation, the collaborative process could be adjusted to the patient's life, state of mind and energy to engage actively in the process. **Nurses participating actively** in the patient's rehabilitation proved to be a prerequisite for the collaborative process of rehabilitation. When nurses engaged and were attentive to the patient's situation, they were able to get to grips with the **patient's perspective** and organise their nursing to support the patient's participation. To end the circle, the aspect of **caring** emerged as a consequence of nurse participation. When the nurses learned about the patient's perspective, they were able to understand how the patient wished to participate. This awakened their urge to care for the patient. In the end, **rehabilitation** could be viewed as a part of life, as a small section, a paragraph. How it was organised was crucial to the value of the patient's path towards a meaningful life post injury. Therefore, the efforts to change rehabilitation practice made the nurses call for a stronger emphasis on caring for the person in rehabilitation nursing which in turn will enhance the patient's participation and path towards a meaningful life with a spinal cord injury.

Figure 3. The elements of the findings and the interconnectedness between patient participation, the patient's perspective, care and the nurse's participation in the patient's rehabilitation process.



Discussions

In this section, I will discuss the collected findings of the study. A more comprehensive discussion is presented in the three papers (Appendices A–C). Finally, I will discuss the methodological considerations connected to the methodology, design and methods of this dissertation.

Discussion of findings

In the present study, the nurses experienced how their engagement and interest in the patient as a person increased their desire to learn more about the patient and his needs, leading to attunement of the caregiver. In 2016, Castro et al. (2016) developed a definition of patient participation based on a content analysis of a literature review. Accordingly, patient participation was defined as something that *‘revolves around a patient’s rights and opportunities to influence and engage in the decision making about his care through a dialogue attuned to his preferences, potential and a combination of his experiential and the professional’s expert knowledge’* (Castro et al. 2016, p. 1929).

Hence, they found that the nurses' caring was adjusted to meet the patient's preferences and potential through dialogue. This is aligned with the central position of conversation in the four nursing initiatives developed in this study. However, it appears that this definition revolves around decision making. As if patient participation primarily concerns conscious decisions. The risk of a unilateral focus on active decision making may be enhanced further by the growing focus on goal-setting in rehabilitation, generally viewed as a key component of successful rehabilitation (Bovend'Eerd, Botell, & Wade, 2009; Cao, Walker, & Krause, 2014; Levack et al., 2016; Scobbie, Wyke, & Dixon, 2009). This emphasis on goals-setting may also contain an integrative expectation of the patients to be active participants in specific, measurable, achievable, realistic and timely (so-called smart goals) decisions and activities – which in isolation is a good idea (Bovend'Eerd et al., 2009; Cao et al., 2014; Levack et al., 2016; Scobbie et al., 2009). However, together with the focus on decision making, the trend may colour the determination of the quality and content of the patients' participation in their rehabilitation. This comprises a potential conflict with the very purpose of rehabilitation which, according to WHO, is met when it is adjusted to the patient's life not only in terms of what activities and functionalities the patient can gain but to all aspects of the person's life (*Concept Paper WHO Guidelines on Health-Related Rehabilitation*, 2012).

For rehabilitation to be tailored to the patient's life, the nurses cannot only bring their professional knowledge to enhance the patient's participation as stated by Castro et al. (2016). Even though, the nurses bring professional knowledge about the disability, the possibilities of training the skills and functionalities, they do not contribute sufficiently to the patient's rehabilitation unless the care is tailored to the life of the disabled. Therefore, the findings of this study suggest that exploring the patient's perspective is an integral element of patient participation, and the nurses must not just enter the dialogue with their professional knowledge alone but supplement it with an attentive caring approach to tailor the rehabilitation process to the patient's life.

In Eldh et al.'s study, they explored how patients expressed non-participation as 'Not understanding', 'Not being in control', 'Not being accountable' and 'Lacking a relationship' (Eldh, Ekman, & Ehnfors, 2006, 2008). These non-participating aspects would also affect rehabilitation where elements like control and mastery of injury, according to the systematic review of Li and Chien (2017), affect active rehabilitation engagement and the quality of rehabilitation aiming at 'maximum independence' and 'full inclusion' (Officer & Posarac, 2011). This supports the interrelatedness between participation and rehabilitation tailored to the patient's perspective and needs. Accordingly, patient participation may be viewed as a precursor to rehabilitation (Officer & Posarac, 2011). The close connection between participation and rehabilitation is also evident in the present study. We experienced that the patient's perspective came about by patient

participation, which in turn emerged through nurse participation in the patient's life and rehabilitation in a collaborative process. This urged the nurses to care for the patient and the process seemed to be self-perpetuating.

The close connection between patient participation and care which is centred on the patient's perspective is outlined in several studies (Castro et al., 2016; Kitson et al., 2013; Melin et al., 2018; Scholl, Zill, Härter, & Dirmaier, 2014). This approach has been conceptualised as patient-centred care (LaVela et al., 2017), person-centred care (McCormack et al., 2017), patient-centredness (Scholl et al., 2014) and patient empowerment (Castro et al., 2016) among others, aiming at enhancing the person's autonomy, self-determination, independence, empowerment and health (Castro et al., 2016; Jesus, Bright, Kayes, & Cott, 2016; Kitson & Athlin, 2014; LaVela et al., 2017; McCormack et al., 2017; Melin et al., 2018).

Therefore, Kitson and her colleagues developed a framework for person-centred care. They argue that care is under pressure due to a mechanistic and depersonalised approach to the basics of care (termed the "task and time" driven culture) leaving the patients with insufficient care for their fundamental needs (Kitson, Conroy, Wengstrom, Profetto-McGrath, & Robertson-Malt, 2010; Kitson et al., 2013; Kitson & Athlin, 2014). In line with the findings of Kitson and Athlin (2014), this study also highlighted the difficulties that the nurses experienced in terms of having the time and calmness to spend undisturbed time with the patient without doing practical tasks. This issue is also recognised in SCI rehabilitation. Accordingly, Melin et al. (2018) stress the need for time to communicate with the patient to enhance patient participation. In line with our findings, Melin et al. (2018) suggest that the lack of time decreases the nurses' attentiveness to the patients' wishes and needs.

During this study, we allocated time to communicate with the patients. Thus, our four nursing initiatives were to guide and support the nurses at the rehabilitation centre to structure meetings and allocate time with the patients. The initiatives were adjusted to the clinical pathway and as far as possible to the organisation of the other work processes within the centre. Therefore, despite the challenges to adapt to the changes, I argued for the involvement of nurses in the development of their practice. By involving the nurses, they did not just develop practice-oriented solutions customised to the local conditions, they also achieved real-life experiences during the testing of the initiatives which led to their engagement and commitment to pay even more attention to the patient's situation. In addition, they transform their knowledge and realisations into methods targeting change not only of their own nursing but of rehabilitation at an organisational level. Our findings agree with those of other studies outlining how involvement of staff in action research in healthcare changes practice as well as the people involved (Bergdahl, Benzein, Ternstedt, & Andershed, 2011;

Friesen-Storms, Jolanda Moser & van der Loo, Sandra Beurskens, Bours, 2014; Montgomery et al., 2015; Tutton, 2005; Waterman et al., 2007).

Hence, we can confirm that collective learning, critical reflection and joint action lead to changes within the organisation and the people involved in the study as described in action research literature (Nielsen & Nielsen, 2006; Nielsen & Svensson, 2006).

An interesting prospect is to utilise action research in mentoring or training programmes for newly employed nurses to increase their reflection and application of nursing initiatives to enhance patient participation. Melin et al. (2018) and Siösteen et al. (2005) argue that length of employment affects the staff's ability to perceive patients' problems and need for help. However, we had three co-researchers who had less than two years of experience within SCI rehabilitation. We did not detect any difference in their ability to reflect on or learn about the patient's perspective compared to the rest of the group.

Though there is overall increased political willingness to move in the direction of person-centred care and participation, there is a lack of transformation from policy and research into clinical practice (Castro et al., 2016; McCormack et al., 2017). In this study, research took place in practice and thereby the transformation difficulties were limited. Nevertheless, the nurses still called for a stronger focus on caring to enhance patient participation for the rehabilitation process to point towards a meaningful life. They developed practice-oriented solutions to the issues. Now they urge the organisation to change accordingly.

Methodological considerations

In the following, I elaborate on some considerations regarding the methodology and methods of this study to clarify the connection between the choices and consequences (Reason, 2006). I will especially argue how the prototyping method was accompanied by other methods to strengthen the action research process and the outcome.

Considerations about the method of prototyping

Initially, I wanted to explore the scope of prototypes and their feasibility as a method for nurses to change practice towards more patient participation (research question two). Prototypes were a promising choice: firstly, because they had been used at the centre before; secondly, because they were well-known and accepted by the co-researchers; thirdly, I was familiar with the method as a feasible way to change practice and to involve health professionals from development to evaluation; and finally, I had discovered a gap of knowledge in the theoretical foundation of the method, even though it had been developed and used in several Danish hospital wards (Digmann, Nørgaard Andersen, Ingerslev, & Høj Jørgensen, 2016; Duvald, Jensen,

& Astrup, 2015; Johansson Jørgensen, 2017; Toppenberg, Grøn, Honoré, & Dam, 2013). These were four plausible arguments for applying the method of prototypes in this study where involvement and change of practice were central aspects.

With the “fail fast and learn fast” aspect as a key component of the method, it was in line with the thoughts of Dewey who stated that one should not be afraid of failures, as they provide insight and knowledge from which to learn: ‘*We learn from our failures when our endeavours are seriously thoughtful*’ (Dewey, 2015, p. 308). We wished to learn from our failures as we tested the four prototypes, and to adjust them into nursing initiatives tailored to the clinical practice. However, the last part of Dewey’s quote became path-breaking for this study: we needed not just to act, but to act on something we had thought seriously about as pointed out by Dewey.

As described in the literature, an unclear definition and understanding of the content of patient participation may contribute to discrepancy between what the patients expect and what is expected of them (Angel & Frederiksen, 2015; Freil et al., 2014; Jørgensen & Rendtorff, 2018; Joseph-Williams et al., 2017). Therefore, to obtain a deeper understanding of the nature of patient participation at the rehabilitation centre and to avoid developing prototypes on assumptions and stereotype understandings that would prove untrue, we needed to learn more. Hence, the need for combining prototypes with other methods became clear during the first phase where the co-researchers betrayed a hazy understanding of the notion and content of patient participation. Being “seriously thoughtful” in this study came in the form of reflection, shared dialogue combined with action instead of just action.

Combining prototypes with other methods is also found in other studies using prototypes. This was the case in the local development project at the rehabilitation centre in Viborg in 2014. Here, the prototypes were accompanied by training, discussions and inter-professional teamwork activities (Hoffmann et al., 2015) (unpublished work).

Another example is the large study at Aarhus University Hospital, where prototypes were tested at all 18 participating wards to establish a patient-involving hospital. Notably, the prototypes were not the sole initiative to enhance patient involvement. They were accompanied by teaching and process activities (Johansson Jørgensen, 2017).

Having taken the explorative steps in the construction phase, we had moved away from the original aspect of prototypes with their lightness and short distance from thought to action. Therefore, the prototypes went from being a main method to a method predominately used in the action phase supplemented by other methods to underpin the learning, dialogical aspect and competence development.

Finally, instead of just solving local problems in the form of changed work procedures (Jensen et al., 2015; MidtLab, n.d.), I wanted the knowledge that was developed and the findings of the study to have a scientific quality and a rigour to be recognised and usable in other healthcare settings. This is further elaborated on in the next section.

Summing up, the study became more than merely a test of four isolated prototypes to change work procedures in order to promote patient participation. The study included methods to support nurses in transforming and achieving the competences to change their nursing practice in a broader sense. By combining prototypes with action research in this study, the prototypes became the known element with a light, yet clear and foreseeable structure of the actions, and action research became the methodological framework to provide the reflection, learning and competence development. Therefore, this study cannot claim that prototypes alone will improve patient participation. However, the combination of prototypes and other action research methods may have the potential to enhance patient participation and support caring in nursing that can be tested and adjusted to other healthcare settings. This is also elaborated on in the next section where the consequences of applying action research are considered.

Considerations about the methodology of action research

In action research, the criteria for quality differ from other empirical research paradigms (Duus, 2012; Reason, 2006). The social complexity that this type of research tries to address (mode II, as mentioned in the Methodological framework and methods section) limits the opportunity to create solutions and results that can be transferred directly to other contexts (Duus, 2012; Greenwood & Levin, 2007). Therefore, transparency is crucial for others to be able to evaluate how to apply the results of this type of research (Laursen, 2019; Reason, 2006).

I considered the issue of transparency while conducting the present study and while writing this dissertation, wanting to highlight the steps taken to achieve a correlation between the intention of the research and the outcome. This is what Duus describes as an aspect of validity. Accordingly, validity is how good we are at doing and researching what we say we do and how the results of our research match our intentions (Duus, 2012). As described in the previous section, the use of prototypes deviated from the intention. However, related to the four characteristic dimensions of action research outlined by Reason (2006), I will clarify how well these dimensions are met and how they correspond to the 'systematic evidence for the claims we make' (Reason, 2006).

The dimensions include how *democracy and participation* occur in the study and if the *practical purpose is worthwhile* to both the participating individuals and the wider community. Furthermore, there is the dimension of an *emergent developmental form*, and the choices made within the *many ways of knowing*. All dimensions should be considered in performing, developing and articulating the results to the broader public after the inquiry (Reason, 2006).

In this dissertation, the *democratic* values behind the study are outlined and discussed in the section on methodological framework where Dewey's understanding provides the foundation for the approach of this study. I have elaborated on how and to what degree the co-researchers have *participated*. It was considered how to facilitate a setting where the co-researchers could communicate as freely and openly as possible about their practice. Therefore, it was decided not to engage patients as co-researchers. Consequently, by choosing not to involve patients more actively led to outcomes predominantly from the staff perspective.

The *practical purpose* was described in the four prototypes (see Appendices E–H) and they were evaluated by the co-researchers to be *worthwhile* to nurses and patients with spinal cord injury. Therefore, they were turned into four nursing initiatives to be used in all clinical pathways at the rehabilitation centre. Even more, the co-researchers expressed that their personal growth and competence development were worth their while.

To determine if the study was worthwhile to the *wider community* corresponds somewhat to the term 'travelling capacity' used by Hummelvoll et al. (2015). It concerns how the local knowledge can attain value and rigour to be recognisable and usable in other settings and communities (Hummelvoll et al., 2015; Reason, 2006). In this study, it is too early to discuss the prospects of travelling capacity of the results of the action research processes. However, the choice of applying Ricoeur's text model provided an opportunity to systematically and analytically process the empirical data in the same manner. Accordingly, the knowledge generated in the action research process was addressed uniformly, and the in-depth analysis included a critical interpretation pointing to something more universal than the individual experiences.

Despite various possible interpretations of a text, not all interpretations are equally probable (Ricoeur, 1973a). I was very aware of this, and during the analysis, I was very strict keeping to the structure of the text model. In close dialogue with my supervisors, I went through the analysis over and over again in a cyclical process from naïve and structure analysis to critical analysis. In the articles and the discussion section, the findings were associated and discussed in relation to research from other healthcare settings. Thereby, it was possible to assess the present research on patient participation vis-à-vis other research results and to some extent outline how this study might potentially impact *the wider community*.

The findings of the analysis did not take precedence over the findings generated in the action research process, but they helped my acquisition of the central themes within the study. Furthermore, they were able to contribute to the discussion regarding patient participation e.g. by suggesting a change of perspective to nurse participation.

The *emergent developmental form* concerns the emergent process of inquiry where a deeper understanding of the area of interest evolves over time. This means that quality in action research depends on how well the study adapts to emerging knowledge, learnt skills and changes in practice over time (Reason, 2006). The changed role of prototypes was a consequence of the emergent developmental process.

Consequently, we became aware of the need to explore the concept of patient participation to a greater extent and the need to add methods to support reflection and learning. Furthermore, we experienced how powerful the artistic and creative methods were as outlined in article one and the findings section. Therefore, with backing from theory and the literature (Borup Jensen, 2014; Borup Jensen & Rina Dahlerup, 2019; Fredens, 2018; McCormack & Dewing, 2013), we continued to explore the potentials of this approach. Despite the nurses being unaccustomed and somewhat reluctant to begin with, they participated actively in the creative tasks. In this case, the artistic creative methods worked as catalysts for the *emergent development* of the methods to support patient participation and of the co-researchers' skills and approach. However, it is worth considering that the co-researchers' openness and the vigorous creative methods may have been somewhat different, if I had not been an insider action researcher who knew practice and the participants well and was able to link the two.

The fourth and final dimension described by Reason is *many ways of knowing* (Reason, 2006). With reference to Heron, Reason suggests four ways of knowing: experiential, presentational, proportional and practical (Reason, 2006). In this study, we touched upon the experiential knowing in the shared reflection sessions where we explored the experiences of the co-researchers in relation to patient participation, their understanding of the patient's situation and their own nursing practice. We gained access to the presentational knowing via the artistic methods. Through a critical view on everyday common sense, proportional knowing was sought in meetings and workshops by bringing in theoretical perspectives and aspects. The practical knowing and knowledge in action were developed by the co-researchers as they tested and reflected on new initiatives in their own practice to meet the challenges of patient participation.

Summing up, this study touched upon all four dimensions of action research. However, there is an issue Reason does not address and that is the influence of the researcher. According to Duus, transparency and validity also concern how well the content of the study is exposed including how the researcher influences and

participates in the study (Duus, 2012). Researcher participation is inevitable and it is therefore important to explicate the study to others in a way so it is possible to assess what the researcher contributed to the results (Duus, 2012). Hence, considerations were made about which elements of the study to elaborate on to be transparent about my participation as an insider action researcher. This was dealt with in the sections on the researcher's role and on indignation and pre-understanding.

Nyman et al. (2016) described how she felt as if she were at a messy frontline, struggling, feeling distressed when she conducted an action research study (Nyman, Berg, Downe, & Bondas, 2016). Fortunately, I did not have that experience. Instead, the managers and the other health professionals at the centre were supportive and encouraging. Nielsen and Nielsen (2005) argue that the dialogical tradition often takes place in single wards and too often focuses on providing changes within the existing settings of the organisation instead of challenging or overrunning it (Nielsen & Nielsen, 2005). Despite my close professional relationships with inter-professional and nursing colleagues as well as managers due to my insider position, I have still done my best to critically analyse and discuss the results even when they induced or suggested a change within the organisation. Nevertheless, I did not overrun the organisation and maybe my insider position did somehow prevent me from being sufficiently critical to push for wide-ranging organisational change. However, I did not find myself in a position where I had the mandate to do so.

Conclusion

The overall aim of this study was to strengthen the patient's participation in rehabilitation to support his path towards a meaningful life after a spinal cord injury.

To reach this aim, I conducted a study with the methodological approach of action research where the involvement of nurses as co-researchers led to the development of knowledge and four practice-oriented solutions to promote patient participation.

These four solutions were developed into in four nursing initiatives which all revolved around the connection between the patient's life and the rehabilitation pathway. They contained consecutive conversations between the patient and the nurse and led to a care and rehabilitation process that was tailored to the patient's prior routines and current wishes and needs. In this study, the nurses experienced how they could actively accompany the patient in his/her rehabilitation when they provided participatory care. By doing so, the patient was able to unfold his personal perspective which in return could lead to a targeted rehabilitation. Learning the patient's perspective induced the nurses to change their approach regarding their role and responsibility towards the patient and the collaborative process of rehabilitation. Nevertheless, even

after identifying the patient's perspective as a crucial cornerstone in rehabilitation nursing, nurses found it difficult to achieve the necessary calmness and presence to utilise it in the current structures and conditions.

Constant interruptions and lack of opportunities to set aside or hand over other tasks to colleagues and pay full attention to their patients pushed the nurses to find alternative solutions to make the time to elicit the patients' perspective and support their participation. The nurses called for a structure and organisation of rehabilitation where conversations with patients were viewed as equally important to other elements of the patient's rehabilitation.

I found the methodological approach, with prototypes as a component alongside others, appropriate to enable the nurses to explore their practice, develop solutions and utilise their skills, attitudes and actions in practice both when it came to promoting patient participation in rehabilitation and when it came to their practice more generally.

In summary, this study provides insight into elements of rehabilitation nursing that may enhance the patient's participation and support his/her path towards a meaningful life with a spinal cord injury.

Implications for practice and future perspectives

Patient participation is just as challenging now as it was before this study was conducted. The complexity of the patient's situation combined with the complexity of rehabilitation is an immutable reality and it demands continuous flexible rehabilitation nursing to adjust the clinical pathway to the individual patient's needs. Nevertheless, the implication of our study on how to address this complexity is elaborated on here together with the future perspectives.

Clinical implications

The findings of this study suggest that the caring element in rehabilitation is necessary to trigger nurses' participation and thereby enhance the patient's participation. Our four nursing initiatives can provide a structure for this to occur and may be useful in rehabilitation settings other than SCI due to the person-centred approach. However, it would still need to be adjusted to the local conditions and the nurses who are to use the initiatives must be provided with conditions and organisational support, including the understanding that communication with the patient must be treated as equally important to other aspects of rehabilitation.

This study provides insight into the potentials of using action research as a methodology to change practice and to develop competences and skills. The co-researchers achieved a reflective, analytic approach to their practice together with the drive and skills to act on their observations. Nursing assistants and nurses, both

experienced and newly appointed, were able to reflect and contribute to the development of practice in our study. Hence, our findings illustrate the potentials of the involving methods of action research to enhance the quality of patient participation and thereby the quality of rehabilitation.

Future research

Just as I saw potential in the methods of action research, we also identified some obstacles when the co-researchers were to disseminate the results and implement the new initiatives, using their newly acquired skills and knowledge. This indicates a need to explore how the organisation can be geared to accommodate this bottom-up approach and retain and support the changes following action research.

Another aspect which we did not pursue to the full was the involvement of patients in the action research process. In our study, we had a consumer participant on the advisory board, and the patients participated in the construction phase and the action phase. Their immediate reactions to the four prototypes were taken into account during the co-researchers' assessments and evaluations.

In a discussion paper, Eldh (2019) argues for more patient involvement in deciphering the notion of patient participation within a particular setting either for a particular group of patients or the individual patient (Eldh, 2019). Furthermore, Ehde et al. (2013) recommend the involvement of patients in the early stage of research with the aim of developing, testing and sustaining rehabilitation interventions (Ehde et al., 2013). They suggest action research as a possible way of achieving that on account of its embedded involving structure. This recommendation is supported by other studies that have shown promising results in improving patient involvement in healthcare by involving patients and relatives (Gustavsson & Andersson, 2019; Zøylner, Lomborg, Christiansen, & Kirkegaard, 2019). Therefore, it would be interesting and relevant to explore how the patients would design rehabilitation to meet their needs, beliefs, values and demands.

Finally, the very important inter-professional collaboration in rehabilitation could be a next step for improving patient participation in a more comprehensive way. We did experience some challenges due to the organisation of rehabilitation and it might have benefited the study if the inter-professional colleagues had played a more central role. This would be interesting to pursue in a more fundamental re-organisation of rehabilitation where the starting point of all the initiatives would be the patient and his perspective and needs.

References

- Angel, S. (2010). Patient participation during rehabilitation after spinal cord injury. *Tidsskrift for Sygeplejeforskning*, 1, 20–25.
- Angel, S., & Frederiksen, K. N. (2015). Challenges in achieving patient participation: A review of how patient participation is addressed in empirical studies. *International Journal of Nursing Studies*, 52(9), 1525–1538. <https://doi.org/10.1016/j.ijnurstu.2015.04.008>
- Angel, S., Kirkevold, M., & Pedersen, B. D. (2009). Getting on with life following a spinal cord injury: Regaining meaning through six phases. *International Journal of Qualitative Studies on Health and Well-Being*, 4(1). <https://doi.org/10.3402/qhw.v4i1.4999>
- Angel, S., Kirkevold, M., & Pedersen, B. D. (2011). Rehabilitation after spinal cord injury and the influence of the professional's support (or lack thereof). *Journal of Clinical Nursing*, 20(11–12), 1713–1722. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/21323775>
- Bargal, D. (2006). Personal and intellectual influences leading to Lewin's paradigm of action research. *Action Research*, 4(4), 367–388. <https://doi.org/10.1177/1476750306070101>
- Bergdahl, E., Benzein, E., Ternstedt, B.-M., & Andershed, B. (2011). Development of nurses' abilities to reflect on how to create good caring relationships with patients in palliative care: an action research approach. *Nursing Inquiry*, 18(2), 111–122. <https://doi.org/10.1111/j.1440-1800.2011.00527.x>
- Bickenbach, J., Officer, A., Shakespeare, T., & von Groote, P. (Eds.). (2013). *International Perspectives on Spinal Cord Injury*. Geneva: World Health Organization (WHO).
- Block-Poulsen, J., & Kristiansen, M. (2018). *Inddragelse i forandringsprocesser: Aktionsforskning i organisationer*. Aalborg: Aalborg Universitetsforlag. [Involvement in processes of change: Action research in organisations]
- Borup Jensen, J. (2014). Musik, kunst og æstetisk læring. In G Duus, K. Kildedal, E. Laursen, & D. Tofteng (Eds.), *Aktionsforskning - en grundbog* (pp. 159–170). Frederiksberg: Samfundslitteratur. [Music, art and aesthetic learning]
- Borup Jensen, J. (2019). Design af aktionsforskningsprojekter - et æstetisk, samskabende blik på vidensudvikling. In M. S. K. Sunesen (Ed.), *Aktionsforskning indefra og udefra* (pp. 61–84). Frederikshavn: Dafolo. [Design of action research projects – an aesthetic, co-creative glance on knowledge development]
- Borup Jensen, J., & Rina Dahlerup. (2019). *Det vi ved om æstetiske læreprocesser*. Frederikshavn: Dafolo. [What we know about aesthetic processes of learning]
- Bovend'Eerdt, T. J., Botell, R. E., & Wade, D. T. (2009). Writing SMART rehabilitation goals and achieving goal attainment scaling: a practical guide. *Clinical Rehabilitation*, 23(4), 352–361. <https://doi.org/10.1177/0269215508101741>
- Bradbury-Huang, H. (2010). What is good action research?: Why the resurgent interest? *Journal of Action Research*, 1(8), 93–109.

- Bradbury, H. (2015). Introduction: How to Situate and Define Action Research. In H. Bradbury (Ed.), *The SAGE handbook of action research* (pp. 1–13). London: SAGE Publication.
- Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., & Suleman, R. (2014). Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 17(5), 637–650. <https://doi.org/10.1111/j.1369-7625.2012.00795.x>
- Brydon-Miller, M. (2008). Ethics and Action Research: Deepening our Commitment to Principles of Social Justice and Redefining Systems of Democratic Practice. In P. Reason & H. Bradbury (Eds.), *The SAGE handbook of action research* (2nd ed., pp. 199–210). Londo: SAGE Publications.
- Burnes, B. (2004). Kurt Lewin and the Planned Approach to Change: A Re-appraisal. *Journal of Management Studies*, 41(6), 977–1002. <https://doi.org/10.1111/j.1467-6486.2004.00463.x>
- Cao, Y., Walker, E. A., & Krause, J. S. (2014). Environmental barriers and subjective health among people with chronic spinal cord injury: A cohort study. *The Journal of Spinal Cord Medicine*. <http://www.maneyonline.com/doi/abs/10.1179/2045772314Y.0000000275>
- Castro, E. M., Van Regenmortel, T., Vanhaecht, K., Sermeus, W., & Van Hecke, A. (2016, December 1). Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient Education and Counseling*, Vol. 99, pp. 1923–1939. <https://doi.org/10.1016/j.pec.2016.07.026>
- Chen, H; Boore, J. (2005). Considering the physiological and psychological consequences of spinal cord injury. *British Journal of Neuroscience Nursing*, 1(5), 225–232.
- Christiansen, B., & Feiring, M. (2017). Challenges in the nurse’s role in rehabilitation contexts. *Journal of Clinical Nursing*, 26(19–20), 3239–3247. <https://doi.org/10.1111/jocn.13674>
- Coghlan, D. (2019). *Doing action research in your own organization* (5th ed.). London: SAGE Publications Ltd.
- Coghlan, D., & Shani, A. B. (Rami). (2015). Developing the Practice of Leading Change Through Insider Action Research: A Dynamic Capability Perspective. In H. Bradbury (Ed.), *The SAGE handbook of action research* (pp. 47–54). London: Sage Publication.
- Coulter, A., & Ellins, J. (2006). *Patient-focused interventions A review of the evidence*. Picker Institute Europe. The Health Foundation (Report)
- Dahler-Larsen, P. (2013). *Evaluering af projekter: og andre ting, som ikke er ting*. Odense: Syddansk Universitetsforlag. [Evaluation of projects: and other things which are not things]
- Dahler-Larsen, P. (2016). *Vejledning om at evaluere innovative tiltag*. København: Center for Offentlig Innovation. [Instructions on evaluation of innovative initiatives]
- Dansk Sygeplejeetisk Råd. *De Sygeplejeetiske Retningslinjer(2014)*. Dansk Sygeplejeetisk Råd (2nd ed.). Retrieved from: https://dsr.dk/sites/default/files/479/sygeplejeetiske_retningslinjer_2014.pdf [The nursing ethical guidelines]

- Dewey, J. (1988). Construction and criticism. In J. A. Boydston (Ed.), *John Dewey - The later work 1925-1953* (pp. 125–145). Illinois: Southern Illinois University.
- Dewey, J. (2015). *Democracy and Education*. Sheba Blake Publishing. [United States of America]
- Dickson, R; Allan, A; O'Carroll, D. (2008). Biographical disruption and the experience of loss following a spinal cord injury: an interpretative phenomenological analysis. *Psychology & Health (Psychol Health)*, 23(4), 407–425.
- Digmann, A., Nørgaard Andersen, P. B., Ingerslev, K., & Høj Jørgensen, J. (2016). *På tværs: grænsekrydsende ledelse og samarbejde*. Gyldendal public. [Crosswise: Crossing bounds in management and cooperation]
- Duus, G. (2012). Validitet. In Duus, G. M. Husted, K. Kildedal, E. Laursen, & D. Tofteng (Eds.), *Aktionsforskning - en grundbog* (pp. 113–129). Frederiksberg C: Samfundslitteratur. [Validity]
- Duvald, I. , Jensen, K. E. & Astrup, P. W. (2015). *Prøvehandling - en let innovationsmetode*. Gyldendal Buisness. [Prototypes – an Easy Method for Innovation]
- Ehde, D. M., Wegener, S. T., Williams, R. M., Ephraim, P. L., Stevenson, J. E., Isenberg, P. J., & MacKenzie, E. J. (2013). Developing, testing, and sustaining rehabilitation interventions via participatory action research. *Archives of Physical Medicine and Rehabilitation*, 94(1 Suppl), S30-42. <https://doi.org/10.1016/j.apmr.2012.10.025>
- Eikeland, O. (2006). Condescending ethics and action research: Extended review article. *Action Research*, 4(1), 37–47. <https://doi.org/10.1177/1476750306060541>
- Eikeland, O. (2008). *The Ways of Aristotle: Aristotelian Phronêsis, Aristotelian Philosophy of Dialogue, and Action Research*. Bern: Peter Lang. International Academic Publishers
- Eldh, A. C. (2019). Facilitating patient participation by embracing patients' preferences—A discussion. *Journal of Evaluation in Clinical Practice*. 1-4. <https://doi.org/10.1111/jep.13126>
- Eldh, A. C., Ekman, I., & Ehnfors, M. (2006). Conditions for Patient Participation and Non-Participation in Health Care. *Nursing Ethics*, 13(5), 503–514. <https://doi.org/10.1191/0969733006nej898oa>
- Eldh, A. C., Ekman, I., & Ehnfors, M. (2008). Considering patient non-participation in health care. *Health Expectations*, 11(3), 263–271. <https://doi.org/10.1111/j.1369-7625.2008.00488.x>
- Elwyn, G., Frosch, D. L., & Kobrin, S. (2016). *Implementing shared decision-making: consider all the consequences*. 11 (114). <https://doi.org/10.1186/s13012-016-0480-9>
- Erosa, N. A., Berry, J. W., Elliott, T. R., Underhill, A. T., & Fine, P. R. (2014). Predicting quality of life 5 years after medical discharge for traumatic spinal cord injury. *British Journal of Health Psychology*, 19(4), 688–700. <https://doi.org/10.1111/bjhp.12063>
- Fire anbefalinger til styrket patientinddragelse*. (2014). Danske Patienter, Lægeforeningen, Dansk Sygeplejeråd. Retrieved from <https://www.danskepatienter.dk/politik/nyhedsarkiv/fire-anbefalinger-til-styrket-patientinddragelse>. [Four recommendations to strengthen patient participation]
- Fredens, K. (2018). *Læring med kroppen forrest*. Copenhagen: Hans Reitzels Forlag. [Learning, leded by the

body]

- Freil, M., Wandel, A., Pedersen, L., Jönsson, A. B. R., & Nyborg, M. (2014). *Læger og sygeplejerskers forståelse af patientinddragelse*. København. [Doctors and nurses understanding of patient participation]
- Friesen-Storms, Jolanda Moser, A., & van der Loo, Sandra Beurskens, Bours, J. G. (2014). Systematic implementation of evidence-based practice in a clinical nursing setting: a participatory action research project. *Journal of Clinical Nursing*, 24, 57–68.
- Frimann, S., & Bager, I. (2012). Dialogkonferencer. In Duus, G. M. Husted, K. Kildedal, E. Laursen, & D. Toftend (Eds.), *Aktionsforskning - en grundbog* (pp. 193–204). Frederiksberg C: Samfundslitteratur. [Dialogue Conference]
- Geisler, FH; Coleman, WP; Benzel, E; Ducker, T; Hurlbert, RJ; McDonald, JW; Sadowsky, C. (2002). Spinal cord injury. *Lancet (LANCET)*, 359, 417–425.
- Goodridge, D., Mcdonald, M., New, L., Scharf, M., Harrison, E., Rotter, T., ... Penz, E. D. (2019). Building patient capacity to participate in care during hospitalisation: A scoping review. *BMJ Open*, Vol. 9. <https://doi.org/10.1136/bmjopen-2018-026551>
- Greenwood, D., & Levin, M. (2007). *Introduction to Action Research Social Research for Social Change* (2. edition). California: SAGE Publication Inc.
- Gustavsson, S. M., & Andersson, T. (2019). Patient involvement 2.0: Experience-based co-design supported by action research. *Action Research*, 17(4), 469–491. <https://doi.org/10.1177/1476750317723965>
- Haas, B., Playford, E. D., Ahmad, A. Q., Yildiran, T., Gibbon, A. J., & Freeman, J. A. (2016). Rehabilitation goals of people with spinal cord injuries can be classified against the International Classification of Functioning, Disability and Health Core Set for spinal cord injuries. *Spinal Cord*, 54(4), 324–328. <https://doi.org/10.1038/sc.2015.155>
- Hoffmann, D., Hansen, R., & Steensgaard, R. (2015). Evaluering ad projekt 44 – Patientinddragelse og sammenhængende patientforløb.. Viborg. [Evaluation of project 44 - Patient participation and coherent clinical pathway] (Unpublished. Can be retrieved by contacting raneil@rm.dk)
- Huges, I. (2008). Action Research in Healthcare. In H. Bradbury & P. Reason (Eds.), *The SAGE handbook of action research* (pp. 381–393). London: SAGE Publication.
- Hummelvoll, J. K., Eriksson, B. G., & Cutcliffe, J. R. (2015). Local experience – central knowledge? - Methodological and practical implications for knowledge development in local mental health care settings. *Nordisk Sygeplejeforskning*, 5(03), 283–295.
- Jangland, E., & Gunningberg, L. (2017). Improving patient participation in a challenging context: a 2-year evaluation study of an implementation project. *Journal of Nursing Management*, 25(4), 266–275. <https://doi.org/10.1111/jonm.12459>
- Jensen, K. E., Jensen, J. P., Digman, A., & Bendix, H. W. (2008). *Principper for offentlig ledelse. Fra best practice til next practice*. København: Børsens Forlag. [Principles for public management. From best practice to next practice]

- Jesus, T. S., Bright, F., Kayes, N., & Cott, C. A. (2016). Person-centred rehabilitation: What exactly does it mean? Protocol for a scoping review with thematic analysis towards framing the concept and practice of person-centred rehabilitation. *BMJ Open*, 6(7). <https://doi.org/10.1136/bmjopen-2016-011959>
- Johansson Jørgensen, M. (2017). *Det brugerinddragende hospital - Evalueringsrapport*. Retrieved from <https://danskepatienter.dk/vibis> [The user involving hospital - Evaluation report]
- Jørgensen, K., & Rendtorff, J. D. (2018). Patient participation in mental health care - perspectives of healthcare professionals: an integrative review. *Scandinavian Journal of Caring Sciences*, 32(2), 490–501. <https://doi.org/10.1111/scs.12531>
- Joseph-Williams, N., Lloyd, A., Edwards, A., Stobbart, L., Tomson, D., Macphail, S., ... Thomson, R. (2017). Implementing shared decision making in the NHS: lessons from the MAGIC programme. *BMJ (Clinical Research Ed.)*, 357, j1744. <https://doi.org/10.1136/BMJ.J1744>
- Kildedal, K., & Laursen, E. (2012). Professionsudvikling - udvikling af professionel praksis gennem aktionsforskning. In Gitte Duus, M. Husted, K. Kildedal, E. Laursen, & D. Tofteng (Eds.), *Aktionsforskning - en grundbog* (pp. 81–96). Frederiksberg C: Samfundslitteratur. [The development of the profession - development of professional practice through action research]
- King, E., Taylor, J., Williams, R., & Vanson, T. (2013). *The Magic Programme: Evaluation*. London.
- Kirkevold, M. (2010). The Role of Nursing in Rehabilitation of Stroke Survivors an Extended Theoretical Account. *Advances in Nursing Science*, 33(1), 27–40.
- Kirkevold, M. (2014). Sygeplejerskens roller og funktioner i rehabiliteringsprocessen. In S. Angel & L. Aadal (Eds.), *Rehabiliterende sygepleje - Fra begreb til praksis* (pp. 131–159). København: Munksgaard. [The Nurse's role and function in the Process of Rehabilitation]
- Kitson, A., Conroy, T., Wengstrom, Y., Profetto-McGrath, J., & Robertson-Malt, S. (2010). Scholarly Paper: Defining the fundamentals of care. *International Journal of Nursing Practice*, 16(4), 423–434. <https://doi.org/10.1111/j.1440-172X.2010.01861.x>
- Kitson, A. L., & Athlin, M. (2014). Anything but Basic: Nursing's Challenge in Meeting Patients' Fundamental Care Needs. *Journal of Nursing Scholarship*, 46, 331–339. <http://dx.doi.org/10.1111/jnu.12081>
- Kitson, A., Marshall, A., Bassett, K., & Zeitz, K. (2013). What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing*, 69(1), 4–15. <https://doi.org/10.1111/j.1365-2648.2012.06064.x>
- Kjerholt, M., & Toftdahl Sørensen, O. (2014). Implementeringsbarrierer i klinisk praksis – Hvordan kan de forstås og håndteres? In B. Hølge-Hazelton (Ed.), *Forsknings- og udviklingskultur i klinisk praksis* (pp. 49–65). Roskilde: Region Sjælland. [Implementation barriers in clinical practice - How can they be understood and Managed]
- Kvale, S., & Brinkmann, S. (2009). *InterView - Introduktion til et håndværk* (2.). København: Hans Reitzels Forlag. [Interview - An introduction to a craft]
- Laursen, E. (2012). Aktionsforskningens produktion af viden. In Gitte Duus, M. Husted, K. Kildedal, E. Laursen, &

- D. Tofteng (Eds.), *Aktionsforskning - en grundbog* (pp. 97–112). Frederiksberg: Samfundslitteratur. [The production of knowledge in action research]
- Laursen, E. (2019). Etik og aktionsforskning. In M. S. K. Sunesen (Ed.), *Aktionsforskning indefra og udefra* (pp. 163–184). Frederikshavn: Dafolo. [Ethics and action research]
- LaVela, S. L., Heinemann, A. W., Etingen, B., Miskovic, A., Locatelli, S. M., & Chen, D. (2017). Relational empathy and holistic care in persons with spinal cord injuries. *Journal of Spinal Cord Medicine, 40*(1), 30–42. <https://doi.org/10.1080/10790268.2015.1114227>
- Légaré, F., Adekpedjou, R., Stacey, D., Turcotte, S., Kryworuchko, J., Graham, I. D., ... Donner-Banzhoff, N. (2018). Interventions for increasing the use of shared decision making by healthcare professionals. *Cochrane Database of Systematic Reviews, 7*, CD006732. <https://doi.org/10.1002/14651858.CD006732.pub4>
- Levack, W. M., Weatherall, M., Hay-Smith, J. C., Dean, S. G., McPherson, K., & Siegert, R. J. (2016). Goal setting and strategies to enhance goal pursuit in adult rehabilitation: summary of a Cochrane systematic review and meta-analysis. *European Journal of Physical and Rehabilitation Medicine, 52*(3), 400–416.
- Lewin, K. (1946). Action Research and minority problems. *Journal of Social Issues, 2*(4), 34–46.
- Li, Y., Bressington, D., & Chien, W. T. (2017). Systematic Review of Psychosocial Interventions for People With Spinal Cord Injury During Inpatient Rehabilitation: Implications for Evidence-Based Practice. *Worldviews on Evidence-Based Nursing, Vol. 14*, pp. 499–506. <https://doi.org/10.1111/wvn.12238>
- Lindberg, J., Kreuter, M., Taft, C., & Person, L.-O. (2013). Patient participation in care and rehabilitation from the perspective of patients with spinal cord injury. *Spinal Cord, 51*(11), 834–837. <https://doi.org/10.1038/sc.2013.97>
- Loft, M. I., Poulsen, I., Esbensen, B. A., Iversen, H. K., Mathiesen, L. L., & Martinsen, B. (2017). Nurses' and nurse assistants' beliefs, attitudes and actions related to role and function in an inpatient stroke rehabilitation unit-A qualitative study. *Journal of Clinical Nursing, 26*(23–24), 4905–4914. <https://doi.org/10.1111/jocn.13972>
- Longtin, Y., Sax, H., Leape, L. L., Sheridan, S. E., Donaldson, L., & Pittet, D. (2010). Patient participation: Current knowledge and applicability to patient safety. *Mayo Clinic Proceedings, 85*(1), 53–62. <https://doi.org/10.4065/mcp.2009.0248>
- Martinsen, K. (2006). *Care and vulnerability*. Oslo: Akribes.
- McCormack, B., & Dewing, J. (2013). Action Research: Working with Transformational Intent. *Klinisk Sygepleje, 32*(03), 4–14.
- McCormack, B., Dulmen, A. M. van, Eide, H., Skovdahl, K., & Eide, T. (Eds.). (2017). *Person-centred healthcare research*. Hoboken: Wiley-Blackwell
- Melin, J., Persson, L.-O., Taft, C., & Kreuter, M. (2018). Patient participation from the perspective of staff members working in spinal cord injury rehabilitation. *Spinal Cord, 56*(6), 614–620. <https://doi.org/10.1038/s41393-018-0061-7>

- Meyer, J. (2000). Qualitative research in health care. Using qualitative methods in health related action research. *BMJ (Clinical Research Ed.)*, 320(7228), 178–181.
- MidtLab. (n.d.). Prøvehandlinger. Retrieved from MidtLab website: <http://preview.www.midtlab.dk/om-midtlab/ordforklaring/provehandlinger/>. Accessed: December 2019. [Prototypes]
- Montgomery, A., Doulougeri, K., & Panagopoulou, E. (2015). Implementing action research in hospital settings: a systematic review. *Journal of Health, Organisation and Management*, Vol. 29, pp. 729–749. <https://doi.org/10.1108/JHOM-09-2013-0203>
- Morgan, S., & Yoder, L. H. (2012). A concept analysis of person-centered care. *Journal of Holistic Nursing : Official Journal of the American Holistic Nurses' Association*, 30(1), 6–15. <https://doi.org/10.1177/0898010111412189>
- Morton, A. (1999). Ethics in Action Research. *Journal of Systemic Practice and Action Research*, 12(2), 219–222.
- Nielsen, K. A. (2004). Aktionsforskningens videnskabsteori. In L. Fuglsang & P. B. Olsen (Eds.), *Videnskabsteori i Samfundsvidenskaberne: På tværs af fagkulturer og paradigmer* (2nd ed.) (pp. 517–547). Frederiksberg: Roskilde Universitetsforlag. [Philosophy action research]
- Nielsen, K. A. (2012). Aktionsforskningens historie - på vej til et refleksivt akademisk selskab. In *Aktionsforskning: en grundbog* (pp. 19–36). [The history of action research - on the way to a reflective Academic society]
- Nielsen, K. A., & Nielsen, S. B. (2005). Kritisk Utopisk Aktionsforskning - Demokratisk naturforvaltning som kollektiv dannelsesproces. In T. bechmann Jensen & G. Christensen (Eds.), *Psykologiske og Pædagogiske Metoder: Kvalitative og Kvantitative Forskningsmetoder i Praxis* (pp. 155–181). Roskilde: Roskilde Universitetsforlag. [Critical utopian action research – Democratic nature management as a collective process of formation]
- Nielsen, K. A., & Nielsen, S. B. (2006). Methodologies in Action Research. In K. A. Nielsen & L. Svensson (Eds.), *Action and Interpretive Research* (pp. 63–88). Maastricht: Shaker Publishing.
- Nyman, V., Berg, M., Downe, S., & Bondas, T. (2016). Insider Action research as an approach and a method – Exploring institutional encounters from within a birthing context. *Action Research*, 14(2), 217–233. <https://doi.org/10.1177/1476750315600225>
- Officer, A., & Posarac, A. (Eds.). (2011). Rehabilitation. In *World Report on Disability* (pp. 93–134) Geneva: World Health Organization (WHO). https://www.who.int/disabilities/world_report/2011/chapter4.pdf?ua=1
- Pellatt, G. C. (2003). Perceptions of the nursing role in spinal cord injury rehabilitation. *British Journal of Nursing*, 12(5), 292–299. <https://doi.org/10.12968/bjon.2003.12.5.11175>
- Pii, K. H., Schou, L. H., Piil, K., & Jarden, M. (2019). Current trends in patient and public involvement in cancer research: A systematic review. *Health Expectations*, 22(1), 3–20. <https://doi.org/10.1111/hex.12841>
- Portillo, M. C., & Cowley, S. (2011). Working the way up in neurological rehabilitation: the holistic approach of

nursing care. *Journal of Clinical Nursing*, 20(11–12), 1731–1743. <https://doi.org/10.1111/j.1365-2702.2010.03379.x>

- Pryor, J., Walker, A., O'Connell, B., & Worrall-Carter, L. (2009). Opting in and opting out: a grounded theory of nursing's contribution to inpatient rehabilitation. *Clinical Rehabilitation*, 23(12), 1124–1135. <https://doi.org/10.1177/0269215509343233>
- Reason, P. (2006). Choice and Quality in Action Research Practice. *Journal of Management Inquiry*, 15(2), 187–203. <https://doi.org/10.1177/1056492606288074>
- Reason, P., & Bradbury, H. (2008). Introduction. In P. Reason & H. Bradbury (Eds.), *The SAGE handbook of action research* (Second). London: Sage Publication.
- Ricoeur, P. (1973). *Filosofiens kilder* (P. Kemp, Ed.). København: Vintens Forlag. [Sources of philosophy]
- Ricoeur, P. (1973b). The Hermeneutical Function of Distanciation. *Philosophy Today*, 17(2), 129–141. <https://doi.org/10.5840/philtoday197317233>
- Ricoeur, P. (1976). *Interpretation Theory: discourse and the surplus of meaning*. Texas Christian University Press.
- Ricoeur, Paul. (2002). Tekstmodellen - meningsfuld handling betragtet som tekst. In M. Hermansen & J. D. Rendtorff (Eds.), *En Hermeneutisk Brobygger - tekster af Paul Ricoeur* (pp. 49–74). Aarhus: Klim. [A hermeneutic bridge-builder - texts of Paul Ricoeur]
- Roberts, L., Turner, K., George, S., & Ward, D. (2012). *Briefing notes for researchers: public involvement in NHS, public health and social care research*. Retrieved from <http://www.invo.org.uk/wp-content/uploads/2012/04/INVOLVEBriefingNotesApr2012.pdf>
- Ruoranan, K., Post, M. W. M., Juvalta, S., & Reinhardt, J. D. (2014). Participation and integration from the perspective of persons with spinal cord injury from five European countries. *Journal of Rehabilitation Medicine*. <https://doi.org/10.2340/16501977-1911>
- Sahlsten, M. J. M., Larsson, I. E., Sjöström, B., & Plos, K. A. E. (2008). An Analysis of the Concept of Patient Participation. *Nursing Forum*, 43(1), 2–11. <https://doi.org/10.1111/j.1744-6198.2008.00090.x>
- Scheel-Sailer, A., Post, M. W., Michel, F., Weidmann-Hügler, T., & Baumann Hölzle, R. (2017). Patients' views on their decision making during inpatient rehabilitation after newly acquired spinal cord injury - A qualitative interview-based study. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 20(5), 1133–1142. <https://doi.org/10.1111/hex.12559>
- Scholl, I., Zill, J. M., Härter, M., & Dirmaier, J. (2014). An integrative model of patient-centeredness - A systematic review and concept analysis. *PLoS ONE*, Vol. 9. <https://doi.org/10.1371/journal.pone.0107828>
- Scobbie, L., Wyke, S., & Dixon, D. (2009). Identifying and applying psychological theory to setting and achieving rehabilitation goals. *Clinical Rehabilitation*, 23(4), 321–333. <https://doi.org/10.1177/0269215509102981>
- Singh, R., Küçükdevic Ayse I., Grabljevec, K., & Gray, A. (2018). The Role of Interdisciplinary Teams in Physical and Rehabilitation Medicine. *Journal of Rehabilitation Medicine*, 50, 673–678.

- Siösteen, A., Kreuter, M., Lampic, C., & Persson, L. O. (2005). Patient-staff agreement in the perception of spinal cord lesioned patients problems, emotional well-being, and coping pattern. *Spinal Cord*, 43(3), 179–186. <https://doi.org/10.1038/sj.sc.3101693>
- Spradley, J. (1980). *Participant Observation*. Harcourt Brace College Publishers. New York.
- Steensgaard, R., & Bjørnshave Noe, B. (2014). Borgere med rygmarvsskade. In S. Angel & L. Aadal (Eds.), *Rehabiliterende sygepleje - Fra begreb til praksis* (p. 272). København: Munksgaard. [Citizens with a spinal cord injury. In Rehabilitation Nursing - From concept to Practice]
- Svensson, L. & Nielsen, K. A. (2006). Action Research and Iterative Research. In K. A. Nielsen & L. Svensson (Eds.), *Action Research and Interactive Research: Beyond Practice and Theory* (pp.13–44). Maastricht: Shaker Publishing.
- Titchen, A., & McCormack, B. (2009). A Methodological Walk in the Forest: Critical Creativity and Human Flourishing. In K. Manley, B. McCormack, & V. Wilson (Eds.), *In International Practice Development in Nursing and Healthcare*. Blackwell Publishing Ltd.
- Titchen, Angie, & McCormack, B. (2010). Dancing with stones: Critical creativity as methodology for human flourishing. *Educational Action Research*, 18(4), 531–554. <https://doi.org/10.1080/09650792.2010.524826>
- Toppenberg, M., Grøn, U., Honoré, H., & Dam, B. (2013). Don't get it perfect – get it going. *Tidsskrift for Dansk Sundhedsvæsen*, 89(4), 16–21.
- Tutton, E. M. M. (2005). Patient participation on a ward for frail older people. *Journal of Advanced Nursing*, 50(2), 143–152. <https://doi.org/10.1111/j.1365-2648.2005.03373.x>
- Van De Velde, D., Bracke, P., Van Hove, G., Josephsson, S., & Vanderstraeten, G. (2010). Perceived participation, experiences from persons with spinal cord injury in their transition period from hospital to home. *International Journal of Rehabilitation Research*, 33(4), 346–355. <https://doi.org/10.1097/MRR.0b013e32833cdf2a>
- Van De Velde, D., Coussens, M., De Baets, S., Sabbe, L., Vanderstraeten, G., Vlerick, P., ... De Vriendt, P. (2018). Application of participation in clinical practice: Key issues. *Journal of Rehabilitation Medicine*, Vol. 50, pp. 679–695. <https://doi.org/10.2340/16501977-2363>
- Wade, D. (2015). Rehabilitation – a new approach. Part two: the underlying theories. *Clinical Rehabilitation*, 29(12), 1145–1154. <https://doi.org/10.1177/0269215515601175>
- Waterman, H., Marshall, M., Noble, J., Davies, H., Walshe, K., Sheaff, R., & Elwyn, G. (2007). The Role of Action Research in the Investigation and Diffusion of Innovations in Health Care: The PRIDE Project. *Qualitative Health Research*, 17(3), 373–381.
- Weingart, S. N., Zhu, J., Chiappetta, L., Stuver, S. O., Schneider, E. C., Epstein, A. M., ... Weissman, J. S. (2011). Hospitalized patients' participation and its impact on quality of care and patient safety. *International Journal for Quality in Health Care : Journal of the International Society for Quality in Health Care / ISQua*, 23(3), 269–277. <https://doi.org/10.1093/intqhc/mzr002>
- Westlander, G. (2006). Researchers role in Action Research. In L. Svensson & K. Aagaard Nielsen (Eds.), *Action*

Research and Interactive Research. Beyond practice and theory (pp. 45–62). Maastricht: Shaker Publishing.

WHO Regional Office for Europe. (2013). *Exploring patient participation in reducing health-care-related safety risks*. Copenhagen. World Health Organization.

World Health Organization. (2001). *International Classification of Functioning, Disability and Health*. Geneva: World Health Organization.

World Health Organization. (2011). *World Report on Disability* (A. Officer & A. Posarac, Eds.). Geneva: World Health Organization.

World Health Organization. (2012). *Concept Paper WHO Guidelines on Health-Related Rehabilitation*. Geneva: World Health Organization.

World Medical Association. *Declaration of Helsinki – Ethical principles for medical research involving human subjects*. (n.d.). Retrieved from <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/> (Accessed: 15 October 2019)

Zøylner, I. A., Lomborg, K., Christiansen, P. M., & Kirkegaard, P. (2019). Surgical breast cancer patient pathway: Experiences of patients and relatives and their unmet needs. *Health Expectations*, 22(2), 262–272. <https://doi.org/10.1111/hex.12869>

Summary

The patient's participation in rehabilitation is decisive to tailor the rehabilitation to the individual as well as complex and complicated due to the patient's varied and varying needs for participation.

Most people sustaining spinal cord injury experience permanent disability together with extensive changes in the opportunities for living the life they had imagined and wanted. The need for and effect of patient participation is well documented, but there is a lack of knowledge on how health professionals can promote patient participation in practical terms. This led to the aim of this study which was to explore how nurses, through enhanced patient participation, could accompany and support the patient with a spinal cord injury towards a meaningful life.

Four nurses and four nursing assistants (named co-researchers) working at the Spinal Cord Injury Centre of Western Denmark participated in an action research study over a two-year period. Through four phases: construction, planning, testing and evaluation, four nursing initiatives were developed, tested and evaluated. They worked individually but together they aimed at creating time and space for the patient's participation throughout the entire rehabilitation pathway.

This study showed how nurses can play a decisive role in adjusting rehabilitation to important elements of the patient's life in a way that points towards the patient's future life with a spinal cord injury. Furthermore, facilitating conditions for the patients to express their values, routines, wishes and needs, the nurses too had the opportunity to increase their knowledge about the patient's perspective leading to a more targeted rehabilitation process. However, even with tailored nursing initiatives, it proved to be difficult to comply with the wish for better patient participation due to a lack of calmness, time and space.

Using a learning, reflective, dialogue-based and creative design, the co-researchers demonstrated an analytical approach to their own practice together with motivated, engaged and caring nursing, pointing towards a patient-centred approach adjusted to the rehabilitation pathway.

The promising results of the methodological approach were substantiated as the co-researchers insisted on participating and accompanying in the patient's rehabilitation focusing on bringing forth the patient's perspective in the spinal cord injury rehabilitation. This indicates that nurses have the ability and potential to find solutions to practice-oriented problems when they are provided with the supporting conditions and terms. However, a comprehensive organisational change may be a prerequisite for the rehabilitation to change accordingly.

Dansk resumé

Patientens deltagelse i rehabiliteringen er afgørende for tilrettelæggelse af et forløb, der er målrettet og individuelt tilpasset. En rygmarvsskade har gennemgribende indvirkning på de vilkår og muligheder for at leve det liv man ønsker sig og vellykket deltagelse i rehabiliteringen har stor betydning for hvor godt patienten føler sig hjulpet. Patientens ønske om deltagelsens form og indhold varierer imidlertid igennem rehabiliteringsforløbet, ligesom det er forskelligt fra person til person. Det øger kompleksiteten og udfordrer de sundhedsprofessionelle i deres tilrettelæggelse af patientforløb der sikre patientens kontinuerlige deltagelse. Derfor blev formålet med dette studie at undersøge hvordan sygeplejersker, gennem øget patientdeltagelse, kunne ledsage og støtte patienten med en rygmarvsskade mod et meningsfuldt hverdagsliv.

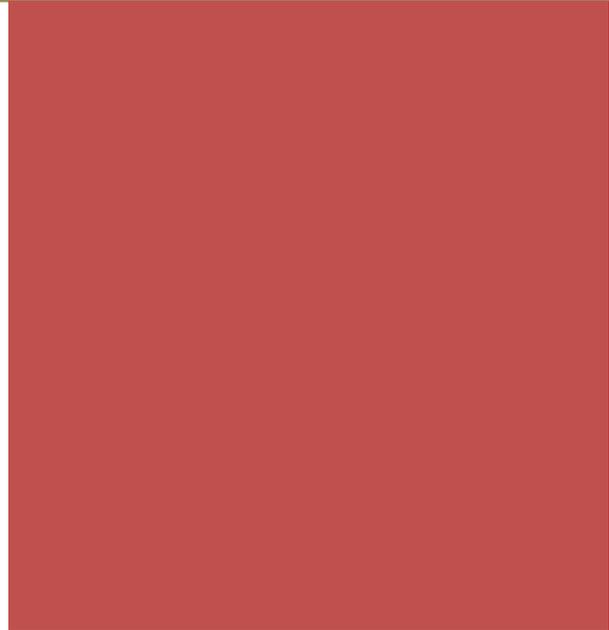
Fire sygeplejersker og fire social- og sundhedsassistenter, ansat på Vestdansk Center for Rygmarvsskade, deltog i et toårigt aktionsforskningsstudie. Gennem fire faser; konstruktion, planlægning, afprøvning af aktioner og evaluering, blev der udviklet fire sygeplejefaglige tiltag, der, udover at fungere individuelt, tilsammen stillede mod at skabe tid og mulighed for patientens deltagelse igennem hele rehabiliteringsforløbet.

Dette studie viser, at sygeplejefagligt personale kan spille en aktiv rolle i forhold til at tilrettelægge rehabilitering der søger at tilvejebringe, for patientens vigtige elementer, på en måde, så de kan videreføres i det liv der skal leves med en rygmarvsskade. Ved at etablere et rum hvor patienten kunne ytre sine værdier, rutiner, ønsker og behov, fik det sygeplejefaglige personale øget kendskab til patientens perspektiv og præferencer. Det medførte en mere målrettet motiveret, engageret og omsorgsfuld patientcentreret rehabiliterende sygepleje.

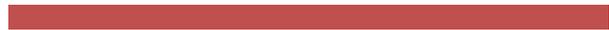
Med afsæt i lærende, reflekterende, dialogbaserede og kreative processer udviste medforskerne et analytisk blik på deres egen praksis, der resulterede i en anden tilgang til eget virke, til sygeplejen og rehabiliteringen. Konkluderende kan det siges, at sygeplejefagligt personale, der engagerer sig og deltager i patientens rehabilitering på en måde der inviterer patienten til at dele sit perspektiv medfører en omsorg for patienten og deraf et ønske om at støtte patientens deltagelse. Med et undersøgende, reflekterende og lærende miljø udviklede medforskerne sygeplejefaglige initiativer, der kunne understøtte denne proces og potentielt skabe et sammenhængende patientforløb. Alligevel viste det sig vanskeligt at efterleve ønsket om en mere patientinddragende rehabilitering. Dette indikerer, at sygeplejefagligt personale selv kan finde frem til løsninger når de har de rette vilkår. Der er dog behov for villighed til at justere praksis og den overordnede organisering så den skaber plads til de løsninger der udvikles.

Appendices

- A) Paper I**
- B) Paper II**
- C) Paper III**
- D) Declarations of authorship paper I, II, III**
- E) Prototype 1**
- F) Prototype 2**
- G) Prototype 3**
- H) Prototype 4**
- I) Literature search strategy**
- J) Patient information**
- K) Approval Danish Data Protection Agency**



**Appendix A:
Paper I**



Promoting patient participation in rehabilitation by engaging nurses in action research

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Abstract

Using a combination of interviews, observations and log-books, a research team consisting of eight nurses, a PhD student and two PhD supervisors explored the roots of the problems related to patient participation. The two-year study took place at a rehabilitation facility for patients who had sustained a spinal cord injury. The initial identification of problems was followed by creative workshops and reflective meetings to explore possibilities and obstacles to meet the challenges they had identified. This led to the development and testing of four new initiatives in rehabilitation nursing that could potentially enhance patient participation. This study suggested that critical reflection skills shed light on both the notion of patient participation and other aspects of nursing rehabilitation. As nurses were actively involved in the research, the knowledge development on promoting patient participation stemmed from practice and the solutions were therefore practice-oriented. In addition, the personal and professional development experienced by the involved nurses pointed to a secondary gain of an analytical and reflective approach to complex issues in rehabilitation in general.

Introduction

Due to a wide range of documented positive outcomes, patient participation is regarded as a perquisite within good quality care, treatment and rehabilitation (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016; Coulter & Ellins, 2006; Stacey et al., 2017). Consequently, patient participation has been reported to empower patients to take control over their bodies and their situations during rehabilitation (Castro et al., 2016). Furthermore, it can potentially increase patient safety, reduce healthcare costs (Goodridge et al., 2019;

Weingart et al., 2011), improve the quality of life (Kwok, Pan, Lo, & Song, 2011) and bridge the knowledge of the patient and the knowledge of the health professional leading to better health solutions (Castro et al., 2016). Therefore, it is not surprising that patient and professional organisations, national policies and hospital managements emphasise the need for health professionals to change practice and increase patient involvement (*Fire anbefalinger til styrket patientinddragelse*, 2015; WHO, 2001; Freil, Wandel, Pedersen, Jönsson, & Nyborg, 2014; Jørgensen, 2019; Region Midtjylland, 2014). However, due to varying needs for participation from patient to patient and for the same patient over time in their recovery process, patient participation is a complex issue (Eldh, 2019; Longtin et al., 2010). Despite being a prerequisite for high-quality rehabilitation (Lindberg, Kreuter, Taft, & Person, 2013; Van De Velde, Bracke, Van Hove, Josephsson, & Vanderstraeten, 2010), this complexity is also evident in the rehabilitation after a severe, life-changing event such as a spinal cord injury (Chen, H; Boore, 2005; Dickson, R; Allan, A; O'Carroll, 2008; Geisler, FH; Coleman, WP; Benzel, E; Ducker, T; Hurlbert, RJ; McDonald, JW; Sadowsky, 2002; Williams & Murray, 2015).

Even though patient participation is described as an ultimately good and a central part of nursing and healthcare (Angel & Frederiksen, 2015; Castro et al., 2016; Jangland & Gunningberg, 2017), it is challenged by health professionals' attitudes, the organisation of healthcare and the severity of the patient's illness (Angel & Frederiksen, 2015; Longtin et al., 2010). Therefore, inaccurate assumptions of how the patient would like or is able to participate together with time constraints, lack of tools, unsupportive behaviour and attitudes on behalf of some health professionals increase the complexity of the patient's participation even more (Angel & Frederiksen, 2015; Joseph-Williams et al., 2017; Longtin et al., 2010). This complexity and accompanying challenges indicate that genuine patient participation requires changes in practices, tools, approaches and mind-sets of health professionals as well as alignment with the needs of the patient.

After a two-year period of implementation, Jangland and Gunningberg's (2017) study showed that improved patient participation in one clinical setting could not be transferred and implemented in another setting. It failed despite meticulous efforts including a wide range of initiatives, such as implementation of an adjusted tool and information/discussion sessions. However, it is worth bearing in mind that the study did not engage the staff in learning and reflection activities that could adjust the content and course of action, nor did it seem as if they involved the staff in decisions and knowledge development about the context-specific problems related to patient participation.

This indicates a need for local development of solutions matching the context and staff to enable them to promote patient participation.

A way to change clinical practice is through action research which draws on participatory, bottom-up approaches to induce change. Within cyclical processes of reflection and learning, action research involves participants in a combination of research and action to develop solutions that make sense to the professionals who experience specific problems related to their practice (Coghlan, 2019; Greenwood & Levin, 2007). Therefore, the shared process of a researcher and participants from a practical setting may produce knowledge about the nature of the problem, leading to changes of the social culture within the organisation where the study is conducted (Greenwood & Levin, 2007; Laursen, 2012; Nielsen & Nielsen, 2006; Svensson & Nielsen, 2006).

In healthcare, action research has been used to improve quality of care, enhance staff knowledge and skills, bring changes to clinical practice, improve staff job satisfaction and well-being, among other things (Montgomery, Doulougeri, & Panagopoulou, 2015) and has become increasingly popular in healthcare research worldwide (Cordeiro & Soares, 2018; Meyer, 2000; Montgomery et al., 2015). Therefore, we wanted to explore the potentials of applying the methodology of action research in promoting patient participation in SCI rehabilitation. Accordingly, the aim was to gain insight into how an action research process could engage the nurses in developing care that promotes patient participation.

Methodology and method

The study was organised to meet documented challenges to patient participation: lack of ownership, too little focus on culture and detachment from management (Angel & Frederiksen, 2015; Jangland & Gunningberg, 2017; Joseph-Williams et al., 2017). Inspired by the thinking of John Dewey (Dewey, 2015; Greenwood & Levin, 2007), we combined dialogues, reflections and actions to collectively learn how to solve the problems related to patient participation in a meaningful way.

Participants

To do so, four nurses and four nursing assistants volunteered to be involved in the two-year action research project. As co-researchers they were engaged in the community of inquiry with highly valued contribution to the knowledge development (Eikeland, 2006). Their experiences within nursing (1–20 years) and in SCI rehabilitation (0.3–19 years) varied, just as their ages (26–56 years). The co-researchers collaborated continuously with the PhD supervisors and the PhD student. The PhD student had worked at the rehabilitation centre since 2006 and therefore took the position as an insider action researcher as described by Coghlan and Shani (Coghlan & Shani, 2015). On the positive side, this dual role entailed profound knowledge of the

organisational culture and politics. On the potentially negative side, there was also a risk that the duality and pre-understanding could affect the PhD student's ability to secure sufficient distance to see things critically and enable change (Coghlan & Shani, 2015). This issue was attended to carefully throughout the entire study by close supervision.

Setting and context

The eight co-researchers came from a group of 50 nurses and nursing assistants who were employed at the Spinal Cord Injury Centre of Western Denmark where the study was conducted. The rehabilitation centre has 35 beds and in addition to the nursing staff, the health professionals comprise physiotherapists, occupational therapists, doctors, psychologists and social workers.

An advisory board for the study was recruited from among the staff at the rehabilitation centre, consisting of inter-professional managers (a doctor and a physiotherapist), PhD supervisors, nursing managers, a consumer representative and a co-researcher representative. This group was expected to pave the way for organisational support of the study and of the co-researchers.

Ethical Considerations

The appointment of the co-researchers gave rise to a number of ethical considerations. With respect to their contribution and central position (Eikeland, 2006), we wanted to make sure that they were taken care of in case they felt vulnerable. Arrangements were made to intervene, if necessary, with assistance from the regional clinic for occupational medicine and the psychologist at the centre.

The study was conducted in accordance with the Helsinki II Declaration (*World Medical Association. Declaration of Helsinki – Ethical principles for medical research involving human subjects*, n.d.) and the Ethical Guidelines for Nursing Research (Dansk Sygeplejeetisk Råd, 2014). Furthermore, it received the approval of the management at the Department of Neurology, Central Region Hospital, Denmark. The co-researchers are anonymised in this paper. The Danish Data Protection Agency approved the study (journal no. 1-16-02-503-15).

Design

This action research study was conducted in four phases (Table 1): construction, planning, action and evaluation (Coghlan, 2019; Greenwood & Levin, 2007; Lewin, 1946).

Phase	Aim	Participants	Activities	Methods	Timespan
1: Constructing	To identify the shared meanings and challenges related to the issues of patient participation	Patients Co-researchers Supervisors PhD student	Reflection Dialogue (Action)	A. Case studies B. Creative workshops C. Consecutive meetings	October 2015 – May 2016
2: Planning	To collaborate on planning actions to address the identified issues	Co-researchers Supervisors PhD student	Reflection Dialogue (Action)	B. Creative workshops C. Consecutive meetings	May 2016 – November 2016
3: Acting	To intervene and act upon identified issues while learning from the consequences	Patients Co-researchers Supervisors PhD student	Reflection Dialogue Action	B. Creative workshops C. Consecutive meetings D. Testing of four prototypes	October 2016 – November 2017
4: Evaluating	To evaluate the actions and discuss how they solved the issues of patient participation	Co-researchers Supervisors PhD student	Reflection Dialogue (Action)	B. Creative workshops C. Consecutive meetings E. Prototype evaluations	September 2016 – February 2018

Table 1: The action research process of the study; the activities, the participants and the timespan

The activities comprised theoretically and personally based reflection on patient participation in clinical practice. Here, new insights emerged as the co-researchers realised and reflected on how they affected and related to their patients and their clinical pathways. Consequently, actions occurred in all four phases concurrently with the co-researchers sharing reflective dialogues. In this way, the methodological approach played out in practice where knowledge and skills were developed through a conscious and critical movement between experience and reflection (Dewey, 2015). Hence, the movement between reflection, dialogue and action was underpinned and supported by case studies, meetings, workshops and actions.

Case studies

The nurses were involved in the initial identification of the problems of patient participation to counter the potentially prejudiced assumptions that could colour and affect the approach to patient participation as described in previous studies (Angel & Frederiksen, 2015; Goodridge et al., 2019; Longtin et al., 2010). To attain critical awareness of own habits, the first step was to actually identify the habits. This was based on the thoughts of Dewey, where new insights, knowledge and skills can be developed through a dynamic movement between experience, critical awareness of habits and reflection (Dewey, 2015). For the co-researchers to identify their own professional habits and reflect on the way in which they supported patient participation at the outset, the first phase included exploration and reflection on 19 cases comprising 1) interviews with patients, 2) log-books written by co-researchers and 3) the PhD student observations.

The cases were generated in the following way: When a patient had volunteered to participate, the PhD student accompanied the co-researcher on her rounds, making observations and writing field notes. The co-researcher planned activities with the patient, and afterwards she wrote her reflections related to patient participation in a personal log-book to combine practical action with written reflection. Later the same day, the patient was interviewed by the PhD student about his experiences of the collaboration with the co-researcher and the opportunities he felt that he had to participate and contribute to the process of rehabilitation.

Meetings

The successive meetings which continued throughout the study allowed the co-researchers to share reflections on the consequences experienced during acting, reorganising and restructuring their habits, collective social action and their perception of patient participation in line with Dewey's theory (Dewey, 2015; Greenwood & Levin, 2007). The co-researchers, PhD supervisors and PhD student acted as discussion partners to support a transforming educational process.

The trusting approach and setting allowed the dialogue to be open and constructive while still critical and explorative. Meetings were planned to interfere as little as possible with the tasks of clinical practice and took place at the end of day shifts when most co-researchers were most likely to participate.

Creative workshops

Three workshops were conducted to create space for further exploration of the co-researchers' experiences, habits and clinical practice related to patient participation and to develop actions to address the challenges of patient participation. The co-researchers, the two PhD supervisors and the PhD student participated in the full-day workshops which took place away from the ward and were facilitated by an experienced action researcher.

To foster a safe environment for reflection and personal honest conversation, the workshops facilitated a learning environment which supported processes in which the researcher and the co-researchers could collaborate in a companionship as described by Greenwood, Levin and Titchen et al. (Greenwood & Levin, 2007; A. Titchen & McCormack, 2009; Angie Titchen, 2018). We wanted to create a shared understanding and to interrupt and challenge the unquestioned practice that was taken for granted. This was supported by creative art-based activities, materials and exercises which worked as catalysts for reflection and access to experiences on both a personal and group level.

The creative approach paved a path for the emotions embedded in the experience to improve perception of the practice and helped getting around readymade and old habits by creating interruptions (Borup Jensen, 2014, 2019; Borup Jensen & Rina Dahlerup, 2019; Dewey, 1980, 1988; Fredens, 2018; McCormack & Dewing, 2013). Therefore, restful music was played during the workshops which featured creative elements such as listening to and analysing music and pictures, drawing and painting.

Actions

The case studies, meetings and workshops were constantly linked to the central element of action in practice. In that sense, action played a part throughout the study and not just while testing prototypes in phase three (Illustrated in Table 1).

Nevertheless, four practice-oriented solutions were developed and tested during phase three where the generated knowledge was pooled into four prototypes of nursing initiatives (Information box).

Information box:

The four prototypes
The prototypes may be characterised as four independent conversations between the primary nurse and the patient. Together they provide knowledge about the patient and a relative who assisted the nurses in adjusting the clinical pathway to the patient's needs, preferences and wishes for the future.

Because these initiatives were developed in practice, their content was closely linked to the patient's clinical pathway. Furthermore, they were characterised by the co-researchers' newly discovered urge to learn more about the patient's perspective to promote patient participation. The four initiatives were tested in a prototype approach, which is a simple change method comprised of a test of small interventions on a defined section of the organisation to gain knowledge about consequences and perspectives of the change to fail fast and learn fast. The intention was that only positively evaluated outcomes were to be implemented into the organisation (

Duvald, Jensen, & Astrup, 2015; Jensen, Jensen, Digman, & Bendix, 2008; MidtLab, n.d.; Toppenberg, Grøn, Honoré, & Dam, 2013). Accordingly, four prototypes were developed and tested by the co-researchers in the action phase. They were evaluated during the evaluation phase when they had experienced the consequences for both patients and themselves. The co-researchers provided written evaluations and after adjustments, the prototypes were converted into four nursing initiatives that were implemented in the entire nursing practice at the centre.

Results

The developed methods were to support the exploring of patient participation in the local context followed by iterative processes of experimenting with actions to enhance patient participation. Their implications and prospects to support patient participation are outlined here:

Identifying the problems related to patient participation in the local context

The co-researchers expressed how their view of patient participation was affected by using this combined method. In isolation, the logbooks contained more or less detailed descriptions of what had happened during the care session. However, their reflections on the situations as they had just occurred combined with the discussions in the group afterwards changed the co-researchers' views on patient participation. In dialogue, co-researchers reflected on and demonstrated how they had obtained a critical awareness of how they interacted with their patients to ensure that patient participation was an integrated part of rehabilitation. In meeting one, three different co-researchers highlighted how their views on patient participation had changed:

Rikke:

'... then suddenly, you do something that you actually questioned previously or you become aware that (...) then you have a little chat about something or other outside the door. I think it would be a good idea, if we all had somebody come around with us once in a while.'

Tine:

'I think that I have realised how important background is for the approach to patient participation. I mean when you come round with me, how quick it was to get to grips with the patient's narrative at the point where the patient is at, also in relation to what one should offer, how the person is at receiving, what approach I should use to encourage the patient to participate. I think that may have been what I have realised most of all by having you around with me.'

Maja:

'(...) we are thinking about patient participation in a completely different way after we have become part of this [project].'

(Co-researcher Rikke, Tine, Maja, meeting one)

These quotes illustrate a change in perception of the concept of patient participation. The co-researchers had become more conscious of how they performed their care and aware of aspects that they had not thought about before. This new awareness combined with new knowledge seemed to motivate them to learn more and to change their practice.

Successive reflections on patient participation in rehabilitation

Successive meetings formed a platform for occasional collective reflections and new insights, both about the situation and about how to reflect. Supported by reflective dialogues, the co-researchers developed an explorative and critical approach to their own practices and world views they took for granted, or to which habit had “turned them blind”. The nurses raised questions like:

- ‘How does it affect a patient sitting naked in front of a big mirror during morning routines while waiting for the co-researcher to return, after taking care of other things outside the bathroom?’
- ‘Is it appropriate to have conversations about the patient’s thoughts and concerns about her future life with a spinal cord injury while she is on the toilet?’

These examples, along with others, led to the realisation that conversations with patients had to take place where both were comfortable and ready to open up about issues of such a personal nature.

The meetings were not consensus-seeking but rather explorative in a respectful tone. What cannot be conveyed in the quotes is the light-hearted tone and laughter that went with the discussions. Nevertheless, they illustrate how the co-researchers did not just support each other’s statements but also challenged them and thereby generated new knowledge:

Rikke: ‘That was a really good idea.’

Maja: ‘Yes, I thought so too.’

Annett: ‘Well, I am going to turn the issue on its head.’

Lise: Oh no! (laughter)

Annett: Well, yes because I am looking at the patient. We all know when we get a patient described before arrival, (...) then there is a brief description of this patient. After all, it is not always that it turns out how we expect. But now you have already started putting the picture together: you have an age, you may even have an education, then you have an injury and a range of issues, but it does not mean that it is like that; we have some cold facts, but our documentation does not say everything about the patient.’

(Co-researchers Rikke, Maja, Lise, Annett, Workshop 1)

Exploring how to support patient's participation

The use of art-based creative methods seemed to lead to an increased sensitivity to and understanding of the need to gain access to the patient's perspective in order to tailor rehabilitation to the individual. For example, the co-researchers were asked to use drawing to express how they viewed their patients' experience of their situation and how their support of their patients' participation could unveil a future life with a SCI. The co-researchers engaged in exploring their patients' situation and the prospects of improved patient participation through painting and the use of the materials:

'Ann: We're often approached by a patient who feels on shaky ground, so how do we convey that in a painting: by placing the canvas on one of the corners (...)

Hanne: Doing that, you express what a challenge it is. It also makes me think about balance, because it won't take much for it to tumble over. It would be completely different, if you place the canvas normally, that is horizontally! Establishing balance is also about the right amount, it's about laying the foundations for participation at the right time. We need to be there at the right time to establish the right balance.'

(Co-researchers Ann and Hanne, workshop, November 2016)



Placing the canvas on a corner, the co-researcher created a physical representation of a tilted horizon, illustrating the shaky foundation of the patients' lives. This invited the other co-researchers to explore the patient's perspective, and they wondered how it would feel when your horizon changes and your balance disappears, and when and how they as nurses could act in relation to the tilted life situation as displayed in the picture.

The use of metaphors in their drawings provides a new depth or a new perspective. Other metaphors used were the illustration of a backpack (which was a metaphor for lived life, routines, motivations and preferences which the patients brought with them to rehabilitation) and a window to the outside world symbolising the life to come (which is small in the first drawing and bigger in the last drawing (the red square)). The different accessories (music, bodily exercises and painting) supported the co-researchers in articulating their reflections on and thoughts about their patients' situation, and they realised that they needed to include their patients' prior lives, preferences and needs to see a possible future. During this process, we produced prototypes with starting points in the patient's prior routines and wishes for the life ahead.

Learning from the consequences of actions to enhance patient participation

During the two-year period, the co-researchers developed a drive to act upon and change elements of rehabilitation to include the patient's perspective. Having had their eyes opened, they started noticing inferior work procedures and they displayed an urge to act and felt empowered to speak up. Consequently, they articulated how they had achieved a stronger and more confident position both within the inter-professional group and within the nursing team. They became advocates for the patient's perspective in inter-professional and nursing collaborations. A specific result was a change in the structure and content of the meetings (conferences) where the patient, a close relative and members of the inter-professional team participated to plan the rehabilitation pathway. Besides changing the name from the formal 'conference' to the more inclusive 'pathway meeting', the content also became more involving.

However, even before the conferences had changed to clinical pathway meetings, one of co-researcher took matters into her own hands. She displayed a confidence and power to act when she saw the opportunity to involve the patient's perspective. Contrary to normal procedure, she started the meeting by focusing on the patient's views, experiences and preferences. Afterwards she shared her experience and the positive feedback from the patient, his relatives and inter-professional colleagues with the rest of the co-researchers who provided positive feedback to reinforce the different path and approach:

'... then I thought: you will take charge here. And I did and I just let Martin start by telling how he was, how his life had been and what he wanted to achieve by being here (...) It was really good. He had been dreading it. Honestly, he could not praise it enough – it was such a good experience.'

(Co-researcher Annett, Meeting 10)

The co-researchers expressed how they were more confident in their assessments of a patient's situation due to their newly acquired professional confidence as well as the knowledge they had obtained performing the nursing initiatives. Accordingly, they argued more profoundly on their reflections and supported their patients in voicing concerns and thoughts important to the clinical pathway at meetings of the patient's team.

The co-researchers described how the positive experiences of taking charge in conference or standing up for the patient's perspective in the planning of the clinical pathways affected them both personally and professionally. This was emphasised in a mail from a co-researcher after the final meeting on completion of the project:

*'It was a fantastic meeting (...), and in particular a very touching evening (...)
What an experience it was to see and hear how much this project has meant for all of us, both professionally and personally!'*

(Co-researcher Tine, after closing meeting)

During the project, the co-researchers expressed and shared insecurity, vulnerability and prior blind spots regarding their professional knowledge and views on rehabilitation and nursing. They also shared their excitement and their experiences of the importance of involving the patient's perspective in rehabilitation with their colleagues. They acted as ambassadors of change and gradually introduced the nursing initiatives to their colleagues. They also highlighted the obstacles they met in the process of changing nursing rehabilitation to elicit more patient participation.

Discussion

In this study, reflection combined with dialogue and linked to creative processes seemed to provide a space and a language to articulate professionally what nursing is or can be. The co-researchers were able to transfer their shared processes of learning into changed perceptions and knowledge of what had to change in rehabilitation nursing to promote patient participation. Furthermore, when the prototypes were tested with patients, the co-researchers saw and felt the consequences of their actions as described by Dewey (Dewey, 2015). It seemed as if the experience and the reflection connected to the action enhanced their motivation to change their practice and urged them to meet the patient's needs, wishes and demands in rehabilitation.

The creative methods seemed to enhance their reflections and provided a language for the co-researchers to address their patients' needs and to respond to these with caring nursing. This is supported by other studies describing how art and artistic forms of expression have multiple functions during the process of learning and on the development of skills to reflect (Fredens, 2018). Accordingly, Borup Jensen (2014) describes how through art, the sensory perception strengthens the imagination, observational skills and the ability to critically reflect and express oneself more profoundly in an exchange of experiences (Borup Jensen, 2014). By addressing different senses, the co-researchers' experiences were laid bare and became open to interpretation and discussion. The link between art and care may be found in the strong urge to access emotions and senses to perform nursing tasks and to care for a person as argued by Martinsen (Martinsen, 2006).

According to McCormack and colleagues, this is exactly the potential of using creative action research methods in nursing. Senses are awakened together with bodily experiences and emotions connected to performing nursing care. They argue that this can lead to transformation of nurses and generate new knowledge (McCormack & Dewing, 2013; Angie Titchen & McCormack, 2010). Hence, we found creative methods suitable for expanding awareness, developing knowledge and nursing skills and raising awareness of

the patient's perspective. Supporting the nurses in supporting their patients is another point highlighted by McCormack et al. (2017). They argue that Person-Centred Healthcare should support and explore the capability and capacity of both the providers and the receivers of healthcare (McCormack, Dulmen, Eide, Skovdahl, & Eide, 2017). Interestingly, using action research in exploring patient participation, which is closely linked to person-centred care (Castro et al., 2016; Kitson & Athlin, 2014), may potentially strengthen the capability and capacity of both groups.

The implications of our study are aligned with those of other studies in healthcare, reporting how action research contributed to changes in practice and to the empowerment of the staff involved, including nurses (Bergdahl, Benzein, Ternestedt, & Andershed, 2011; Friesen-Storms, Jolanda Moser & van der Loo, Sandra Beurskens, Anna JHM Bours, 2014; Tutton, 2005; Waterman et al., 2007). A common thread in these studies is the profound involvement of health professionals not just as informants but as co-creators and active participants.

The co-researchers emphasised that participating in this study changed them professionally. This is in line with the findings of Chen et al. (2012), who performed an action research study to adjust and embed nursing theory into the practice of SCI rehabilitation. They found action research to be a suitable method to assist the nurses in overcoming barriers by increasing their self-confidence and identifying their strengths which led to changes in SCI rehabilitation (Chen, Wu, Cheng, & Sung, 2012). The extra aspect of the findings in our study was the personal element of change and engagement that led to the quest to involve the patient's perspective in rehabilitation.

The connection between personal and professional change may be linked to the educative process within the study. According to Dewey, education is a social process involving areas of interest shared by all members. Furthermore, education is closely linked to democracy understood as '*a mode of associated living, of conjoint communicated experience*' (Dewey 2015, p. 82). Democracy facilitates free interaction between social groups and enables change of social habits. The mutual referring of one's own action to those of others and vice versa provides diversity and has a liberating effect on others and their own resources (Dewey, 2015; Greenwood & Levin, 2007). During the workshops, the interaction within the group became freer. The co-researchers exchanged views using relevant and robust professional arguments when they disagreed with each other. Moreover, if they felt the agenda of the workshop did not promote their discussion and they needed it to be changed, they changed it. By letting them modulate the content, they experienced how their well-argued assessments and judgements had the same weight as the PhD student's (who had planned the workshops).

One could argue that they were able to live out the democracy because they were provided with a space for communication and mandate to change.

Despite the promising aspects of action research as a means to securing a democratic process where staff is capable of identifying, acting on and changing habits (Dewey, 2015), the use of prototypes and the involvement of only eight out of 50 nurses limited the effect for the nursing in general. Despite the implementation of the four initiatives, the rest of the colleagues did not go through the same mental and professional processes and realisations.

Jangland and Gunningberg (2017) claimed that unexperienced staff and a high turnover were among the reasons for low effect of their implementation study. However, in our study, we had participants who had just completed their training as nurses and some who had just been employed at the centre. During the process, they all contributed to the reflections and discussions to develop the quality of practice. This suggests that involving staff in action research has an educative aspect which may be advantageous to introduce in a culture where the staff, newly qualified as well as experienced, are engaged in reflective rehabilitation that includes the patient's perspective.

Limitations

Despite having an advisory board with representatives from the centre's management, organisational obstacles were identified in this study as well as in other action research studies in healthcare (Montgomery et al., 2015). This meant that neither the contextual elements (organisation of clinical pathways in general), nor the conditions for nursing were changed. Hence, it depends on the individual nurse's ability to find time and space within the ordinary workload to apply the four initiatives – which is difficult. Therefore, we cannot illustrate the full potential of this approach. Accordingly, further studies are needed on how to underpin the findings of an action research study to fully explore the potentials of the methodology and of the outcome. With the notion of democracy as a life form where people should be able to change social habits (Dewey, 2015), it is a limitation that we did not negotiate the co-researchers' mandate outside the project or at least make the limitations clear.

Conclusions

Combining reflection, dialogue and creative activities with action facilitated resources and competences for the co-researchers to explore and address problems related to patient participation. Experiencing personal and

professional positive changes, the co-researchers developed a drive that enhanced their contribution to the overall involvement of the patient's perspective in rehabilitation. Accordingly, the co-researchers were a valuable force in the development of knowledge and solutions to patient participation.

The process of action research was a driver to develop and test new initiatives in nursing to support practice development in a comprehensive and carefully considered manner. However, more research is needed to learn how the organisation can underpin and further profit from the knowledge and skills developed by the participants.

References

- Angel, S., & Frederiksen, K. N. (2015). Challenges in achieving patient participation: A review of how patient participation is addressed in empirical studies. *International Journal of Nursing Studies*, 52(9), 1525–1538. <https://doi.org/10.1016/j.ijnurstu.2015.04.008>
- Bergdahl, E., Benzein, E., Ternstedt, B.-M., & Andershed, B. (2011). Development of nurses' abilities to reflect on how to create good caring relationships with patients in palliative care: an action research approach. *Nursing Inquiry*, 18(2), 111–122. <https://doi.org/10.1111/j.1440-1800.2011.00527.x>
- Borup Jensen, J. (2014). Musik, kunst og æstetisk læring. In G Duus, K. Kildedal, E. Laursen, & D. Tofteng (Eds.), *Aktionsforskning - en grundbog* (pp. 159–170). Frederiksberg: Samfundslitteratur. [Music, art and aesthetic learning]
- Borup Jensen, J. (2019). Design af aktionsforskningsprojekter - et æstetisk, samskabende blik på vidensudvikling. In M. S. K. Sunesen (Ed.), *Aktionsforskning indefra og udefra* (pp. 61–84). Frederikshavn: Dafolo. [Design of action research projects – an aesthetic, co-creative glance on knowledge development]
- Borup Jensen, J., & Rina Dahlerup. (2019). *Det vi ved om æstetiske læreprocesser*. Frederikshavn: Dafolo. [What we know about aesthetic processes of learning]
- Castro, E. M., Van Regenmortel, T., Vanhaecht, K., Sermeus, W., & Van Hecke, A. (2016). Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient Education and Counseling*, 99(12), 1923–1939. <https://doi.org/10.1016/j.pec.2016.07.026>
- Chen, H; Boore, J. (2005). Considering the physiological and psychological consequences of spinal cord injury. *British Journal of Neuroscience Nursing*, 1(5), 225–232.
- Chen, H.-Y., Wu, T.-J., Cheng, M.-L., & Sung, H.-H. (2012). Evaluation of super-link system theory for spinal cord injury patients using participatory action research in a rehabilitation hospital. *Rehabilitation Nursing: The Official Journal of the Association of Rehabilitation Nurses*, 37(3), 119–127. <https://doi.org/10.1002/RNJ.00040>
- Coghlan, D. (2019). *Doing action research in your own organization* (5th ed.). London: SAGE Publications Ltd.

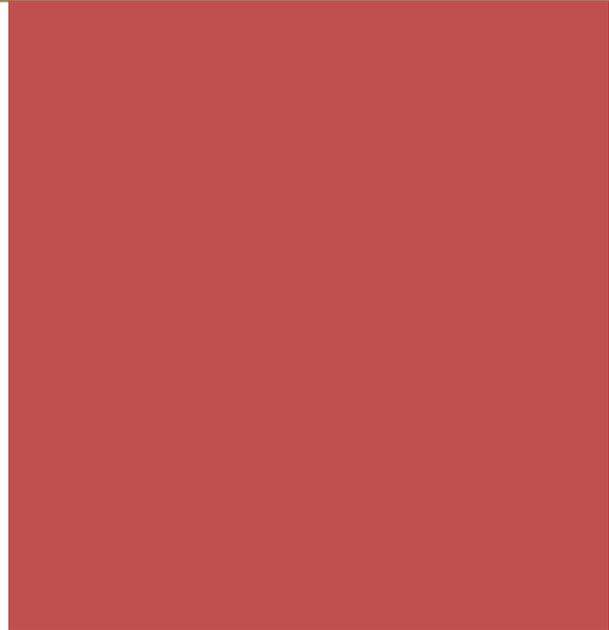
- Coghlan, D., & Shani, A. B. (Rami). (2015). Developing the Practice of Leading Change Through Insider Action Research: A Dynamic Capability Perspective. In H. Bradbury (Ed.), *The SAGE handbook of action research* (pp. 47–54). London: Sage Publication.
- Cordeiro, L., & Soares, C. B. (2018). Action research in the healthcare field. *JBIS Database of Systematic Reviews and Implementation Reports*, 16(4), 1003–1047. <https://doi.org/10.11124/JBISRIR-2016-003200>
- Coulter, A., & Ellins, J. (2006). *Patient-focused interventions A review of the evidence*. Retrieved from www.health.org.uk/QQUIP (report)
- Dansk Sygeplejeetisk Råd. *De Sygeplejeetiske Retningslinjer(2014)*. Dansk Sygeplejeetisk Råd (2nd ed.). Retrieved from: https://dsr.dk/sites/default/files/479/sygeplejeetiske_retningslinjer_2014.pdf [The nursing ethical guidelines]
- Dewey, J. (1980). The act of expression. In *Art as Experience* (pp. 58–81). New York: Berkley Publishing Group.
- Dewey, J. (1988). Construction and criticism. In J. A. Boydston (Ed.), *John Dewey - The later work 1925-1953* (pp. 125–145). Illinois: Southern Illinois University.
- Dewey, J. (2015). *Democracy and Education*. Sheba Blake Publishing. [United States of America]
- Dickson, R; Allan, A; O'Carroll, D. (2008). Biographical disruption and the experience of loss following a spinal cord injury: an interpretative phenomenological analysis. *Psychology & Health (PSYCHOL HEALTH)*, 23(4), 407–425.
- Duvald, I., Jensen, K. E., & Astrup, P. W. (2015). *Prøvehandling - en let innovationsmetode*. Gyldendal Buisness. [Prototypes – an Easy Method for Innovation]
- Eikeland, O. (2006). Condescending ethics and action research: Extended review article. *Journal of Action Research*, 4(1), 37–47. <https://doi.org/10.1177/1476750306060541>
- Eldh, A. C. (2019, December 1). Facilitating patient participation by embracing patients' preferences—A discussion. *Journal of Evaluation in Clinical Practice*. <https://doi.org/10.1111/jep.13126>
- Fire anbefalinger til styrket patientinddragelse*. (2014). Danske Patienter, Lægeforeningen, Dansk Sygeplejeråd. Retrieved from <https://www.danskepatienter.dk/politik/nyhedsarkiv/fire-anbefalinger-til-styrket-patientinddragelse>. [Four recommendations to strengthen patient participation]
- Fredens, K. (2018). *Læring med kroppen forrest*. Copenhagen: Hans Reitzels Forlag. [Learning, leaded by the body]
- Freil, M., Wandel, A., Pedersen, L., Jönsson, A. B. R., & Nyborg, M. (2014). *Læger og sygeplejerskers forståelse af patientinddragelse*. København. [Doctors and nurses understanding of patient participation]
- Friesen-Storms, Jolanda Moser, A., & van der Loo, Beurskens S, Bours, J. G. (2014). Systematic implementation of evidence-based practice in a clinical nursing setting: a participatory action research project. *Journal of Clinical Nursing*, 24, 57–68.
- Geisler, FH; Coleman, WP; Benzel, E; Ducker, T; Hurlbert, RJ; McDonald, JW; Sadowsky, C. (2002). Spinal cord injury. *Lancet (LANCET)*, 359, 417–425.

- Goodridge, D., McDonald, M., New, L., Scharf, M., Harrison, E., Rotter, T., ... Penz, E. D. (2019, July 1). Building patient capacity to participate in care during hospitalisation: A scoping review. *BMJ Open*, Vol. 9. <https://doi.org/10.1136/bmjopen-2018-026551>
- Greenwood, D., & Levin, M. (2007). *Introduction to Action Research Social Research for Social Change* (2. edition). California: SAGE Publication Inc.
- Jangland, E., & Gunningberg, L. (2017). Improving patient participation in a challenging context: a 2-year evaluation study of an implementation project. *Journal of Nursing Management*, 25(4), 266–275. <https://doi.org/10.1111/jonm.12459>
- Jensen, K. E., Jensen, J. P., Digman, A., & Bendix, H. W. (2008). *Principper for offentlig ledelse. Fra best practice til next practice*. København: Børsens Forlag. [Principles for public management. From best practice to next practice]
- Jørgensen, K. (2019). *Patientinddragelse - politik, profession og bruger*. Samfundslitteratur.[Patient participation - politics, profession, consumer]
- Joseph-Williams, N., Lloyd, A., Edwards, A., Stobbart, L., Tomson, D., Macphail, S., ... Thomson, R. (2017). Implementing shared decision making in the NHS: lessons from the MAGIC programme. *BMJ (Clinical Research Ed.)*, 357, j1744. <https://doi.org/10.1136/BMJ.J1744>
- Kitson, A. L., & Athlin, M. . (2014). Anything but Basic: Nursing's Challenge in Meeting Patients' Fundamental Care Needs. *Journal of Nursing Scholarship*, 46, 331–339. <http://dx.doi.org/10.1111/jnu.12081>
- Kwok, T., Pan, J. H., Lo, R., & Song, X. (2011). The influence of participation on health-related quality of life in stroke patients. *Disability and Rehabilitation*, 33(21–22), 1990–1996. <https://doi.org/10.3109/09638288.2011.553709>
- Laursen, E. (2012). Aktionsforskningens produktion af viden. In Gitte Duus, M. Husted, K. Kildedal, E. Laursen, & D. Tofteng (Eds.), *Aktionsforskning - en grundbog* (pp. 97–112). Frederiksberg: Samfundslitteratur. [The production of knowledge in action research]
- Lewin, K. (1946). Action Research and minority problems. *Journal of Social Issues*, 2(4), 34–46.
- Lindberg, J., Kreuter, M., Taft, C., & Person, L.-O. (2013). Patient participation in care and rehabilitation from the perspective of patients with spinal cord injury. *Spinal Cord*, 51(11), 834–837.
- Longtin, Y., Sax, H., Leape, L. L., Sheridan, S. E., Donaldson, L., & Pittet, D. (2010). Patient participation: Current knowledge and applicability to patient safety. *Mayo Clinic Proceedings*, 85(1), 53–62. <https://doi.org/10.4065/mcp.2009.0248>
- Martinsen, K. (2006). *Care and vulnerability*. Oslo: Akribe.
- McCormack, B., & Dewing, J. (2013). Action Research: Working with Transformational Intent. *Klinisk Sygepleje*, 32(03), 4–14.
- McCormack, B., Dulmen, A. M. van, Eide, H., Skovdahl, K., & Eide, T. (Eds.). (2017). *Person-centred healthcare research*. Hoboken: Wiley-Blackwell.

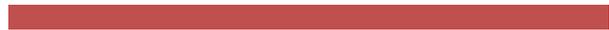
- Meyer, J. (2000). Qualitative research in health care: Using qualitative methods in health related action research. *BMJ*, *320*, 178–181.
- MidtLab. (n.d.). Prøvehandlinger. Retrieved from MidtLab website: <http://preview.www.midtlab.dk/om-midtlab/ordforklaring/provehandlinger/>. Accessed: December 2019. [Prototypes]
- Montgomery, A., Doulougeri, K., & Panagopoulou, E. (2015, September 21). Implementing action research in hospital settings: a systematic review. *Journal of Health, Organisation and Management*, Vol. 29, pp. 729–749. <https://doi.org/10.1108/JHOM-09-2013-0203>
- Nielsen, K. A., & Nielsen, S. B. (2006). Methodologies in Action Research. In K. A. Nielsen & L. Svensson (Eds.), *Action and Interpretive Research* (pp. 63–88). Maastricht: Shaker Publishing.
- Region Midtjylland. (2014). *Strategiplan for Kvalitet og Patientsikkerhed - Mål og indsatsområder på sundhedsområdet i Region Midtjylland 2014-2017*. [strategic plan for quality and patient safety - Goals and focus areas in Health, Central Region Denmark 2014-2017]
- Stacey, D., Légaré, F., Lewis, K., Barry, M. J., Bennett, C. L., Eden, K. B., ... Trevena, L. (2017). Decision aids for people facing health treatment or screening decisions. *The Cochrane Database of Systematic Reviews*, *2017*(4). <https://doi.org/10.1002/14651858.CD001431.PUB5>
- Svensson, L. & Nielsen, K. A. (2006). Action Research and Iterative Research. In K. A. Nielsen & L. Svensson (Eds.), *Action Research and Interactive Research: Beyond Practice and Theory* (pp.13–44). Maastricht: Shaker Publishing.
- Titchen, A., & McCormack, B. (2009). A Methodological Walk in the Forest: Critical Creativity and Human Flourishing. In K. Manley, B. McCormack, & V. Wilson (Eds.), *In International Practice Development in Nursing and Healthcare*. Blackwell Publishing Ltd.
- Titchen, Angie. (2018). *ORIGINAL PRACTICE DEVELOPMENT AND RESEARCH Flowing like a river: facilitation in practice development and the evolution of critical-creative companionship*. <https://doi.org/10.19043/ipdj81.004>
- Titchen, Angie, & McCormack, B. (2010). Dancing with stones: Critical creativity as methodology for human flourishing. *Educational Action Research*, *18*(4), 531–554. <https://doi.org/10.1080/09650792.2010.524826>
- Toppenberg, M., Grøn, U., Honoré, H., & Dam, B. (2013). Don't get it perfect – get it going. *Tidsskrift for Dansk Sundhedsvæsen*, *89*(4), 16–21.
- Tutton, E. M. M. (2005). Patient participation on a ward for frail older people. *Journal of Advanced Nursing*, *50*(2), 143–152. <https://doi.org/10.1111/j.1365-2648.2005.03373.x>
- Van De Velde, D., Bracke, P., Van Hove, G., Josephsson, S., & Vanderstraeten, G. (2010). Perceived participation, experiences from persons with spinal cord injury in their transition period from hospital to home. *International Journal of Rehabilitation Research*, *33*(4), 346–355. <https://doi.org/10.1097/MRR.0b013e32833cdf2a>
- Waterman, H., Marshall, M., Noble, J., Davies, H., Walshe, K., Sheaff, R., & Elwyn, G. (2007). The Role of Action Research in the Investigation and Diffusion of Innovations in Health Care: The PRIDE Project. *Qualitative*

Health Research, 17(3), 373–381.

- Weingart, S. N., Zhu, J., Chiappetta, L., Stuver, S. O., Schneider, E. C., Epstein, A. M., ... Weissman, J. S. (2011). Hospitalized patients' participation and its impact on quality of care and patient safety. *International Journal for Quality in Health Care : Journal of the International Society for Quality in Health Care / ISQua*, 23(3), 269–277. <https://doi.org/10.1093/intqhc/mzr002>
- Williams, R., & Murray, A. (2015). Prevalence of Depression After Spinal Cord Injury: A Meta-Analysis. *Archives of Physical Medicine and Rehabilitation*, 96(1), 133–140. <https://doi.org/10.1016/j.apmr.2014.08.016>
- World Health Organization (WHO). (2001). *International Classification of Functioning, Disability and Health*. Geneva: World Health Organization.
- World Medical Association. *Declaration of Helsinki – Ethical principles for medical research involving human subjects*. (n.d.). Retrieved from <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>. (Accessed: 15 October 2019)



**Appendix B:
Paper II**



Promoting patient participation

– Nurses as participants in the patient’s rehabilitation

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Abstract

Aims and objectives

To explore how nurses could support patients’ participation in rehabilitation in the process towards a meaningful life after spinal cord injury (SCI).

Background

Persons with SCI have experienced a life-changing event. Therefore, they may need help during rehabilitation to re-interpret and adjust routines and wishes to their current situation and future possibilities. However, there is insufficient knowledge about how nurses – in practice – adjust their nursing to the patients’ perspectives and varying needs.

Design

Using an action research design, we investigated how patient participation could be supported at a Danish rehabilitation centre and, through action, learnt how to improve practice. A group of eight nurses participated actively in all processes of the two-year study.

Methods

Data – comprising of transcriptions of meetings, workshops and evaluations of four newly developed nursing initiatives – were analysed using Ricoeur’s phenomenological-hermeneutic approach.

Results

Understanding the patient’s situation was crucial to tailoring the patient’s rehabilitation to the patient’s life. Through nurses’ participation in the patient’s rehabilitation they were able to target the patient’s participation in rehabilitation to their situation, needs and life to come. Supported by four nursing initiatives, nurses altered their rehabilitation and cared for the patient’s perspective.

Conclusions

When nurses changed their approach and met the patient in a person-to-person relationship, they involved themselves in a collaborative process of rehabilitation. Together with changed views on rehabilitation and participation, the four nursing initiatives pave the way for attentive, engaged and caring nursing, tailored to the individual person with SCI.

Relevance to clinical practice

This study has practical implications to how nurses can take on the role of companion and participant in a collaborative process to support the patient’s path in rehabilitation by taking the patient’s routines, experiences and past as their point of departure for caring.

Keywords

Patient participation ; Rehabilitation ; Nurse-Patient relationship; Action Research; Caring; Nurse roles; Interpersonal Communication

Introduction

Despite being a key element in spinal cord injury (SCI) rehabilitation, it is challenging to bring the patient's perspective to the forefront of the care and rehabilitation process (Angel, Kirkevold, & Pedersen, 2011; Lindberg, Kreuter, Taft, & Person, 2013). Patients need help to adjust to living with spinal cord injury (Angel, 2010). In this respect, nurses' role in rehabilitation is untapped just as their ability to support their patients' participation is scarcely covered (Collis Pellatt, 2003; Mia I Loft et al., 2017; Mia Ingerslev Loft et al., 2019). Therefore, more knowledge is needed about how nurses can support their patients' participation.

Background

A spinal cord injury has far-reaching consequences on physical, psychological, social and existential levels (Angel, Kirkevold, & Pedersen, 2009; Chen, H; Boore, 2005; Dickson, R; Allan, A; O'Carroll, 2008; Geisler, FH; Coleman, WP; Benzel, E; Ducker, T; Hurlbert, RJ; McDonald, JW; Sadowsky, 2002; Post & van Leeuwen, 2012). This, often sudden, disruption of life and resulting changed circumstances impede the patients from living their lives as they used to. Hence, work life, family life and social life may change forever, decreasing the person's quality of life (Middleton, Tran, & Craig, 2007).

Therefore, persons with SCI are more likely to experience depression or anxiety or even commit suicide (Le & Dorstyn, 2016; Savic et al., 2018; Williams & Murray, 2015). What previously counted as core identifying elements of life may need to be redefined to achieve a sense of continuity and meaning in life (Angel et al., 2009; Gendreau & de la Sablonnière, 2014). Making the connections between prior, present and future life is central in relation to rehabilitation, where the focus is to ‘...enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life’ (*Chapter 4 Rehabilitation*, 2011).

The participation, however, is challenged by the fluctuating needs of the person throughout different stages after an injury (Angel, 2009). This calls for a flexible approach and dynamic care (Moreno, Zidarov, Raju, Boruff, & Ahmed, 2017). The Danish studies of Angel et al. (2009, 2011) also argue that patients’ ability to participate varies and therefore the form and extent must be negotiated from situation to situation throughout their stay. Nevertheless, the same studies also show how patients may encounter health professionals who have their own agendas and find it difficult to understand their patients. Consequently, some patients felt alone struggling to build a meaningful life, and therefore Angel et al. call for more patient participation (Angel, 2009; Angel et al., 2011).

The aim of this study was to explore how nurses can support the patient’s participation in rehabilitation. We were particularly interested in investigating how nurses could adapt their approach and ways of working to bring to light the patient’s values, wishes and preferences thereby enhancing the process of rehabilitation and the chances of the patient building a meaningful life post injury.

Methods

Setting

The study was conducted at the Spinal Cord Injury Centre of Western Denmark, which is one of two national rehabilitation centres in Denmark. Here, patients who have sustained spinal cord injuries are admitted for periods of 3–9 months and are offered care, treatment and rehabilitation by interdisciplinary health professionals. The 35-bed centre has approximately 100 admissions a year and provides life-long out-patient treatment.

Design

In four phases, we 1) identified the local problem with participation, 2) developed and planned actions, 3) conducted the actions via four prototypes of nursing initiatives and finally, 4) we evaluated the initiatives. The process was iterative and cyclic; the phases informed each other and the actions of the nurses (Bargal, 2006; Coghlan, 2019; Lewin, 1946).

Using the methodology of Action Research (AR) inspired by Dewey's pragmatic philosophy (Dewey, 2015;), the co-researchers experienced how patients participated in rehabilitation through methods where the co-researchers practiced their daily nursing; meanwhile they reflected upon it alone and afterwards in mutual critical reflection together with the PhD student and the PhD-supervisors. Co-researchers were engaged in workshops where art was combined with dialogue and reflection to gain access to emotions which according to Dewey can be a reaction to an objective situation enhancing, purifying and prolonging the perceptual experience (Dewey, 1958). The combination of co-researchers' actions in practice and their reflections in workshops and meetings led to new

experience about how to address the problems related to patient participation situated in the local context (Dewey, 2015).

Participants

A group of eight nurses (four registered nurses and four nursing assistants) had actively volunteered, after oral and written information, to participate in the study for two years. The members of the group were named and acted as co-researchers. This was due to their profound involvement in all phases of the study as described by Hummelvoll, Eriksson and Cutcliffe (2015). The patients participated in the problem-identification phase and the action phase. The female PhD student, who worked at the centre as a clinical nurse specialist, facilitated the study.

Data collection

Data were collected throughout the study consisting of log books (N=19), evaluations of the nursing initiatives (N=4), one day workshops (N=3), one hour meetings (N=19), the researchers' observations (N=19) and interviews with patients (N=11). Audio recorded data were transcribed verbatim and analysed material appeared in written form.

Analysis

The reflections, dialogue and actions combined resulted in knowledge development regarding own role and the development of the four nursing initiatives. To obtain a deeper understanding of the initiatives and how they respond to the challenges of patient participation, we conducted an in-depth analysis of the evaluation of our four nursing initiatives guided by Ricoeur's phenomenological-hermeneutic theory. By distancing ourselves from the original context and the concrete situation, we

were able to obtain a more universal understanding of the meaning (Ricoeur, 1976, 2002). Therefore, the nursing initiatives were analysed as a text open to interpretation. The analysis was conducted in three interrelated stages and we moved back and forth in the process to refine and challenge the analysis.

During the first stage, the naïve reading and interpretation, we were open to a sense of the text as a whole, a surface interpretation and assumption of what the text was about. The next stage, the structural analysis reading, was conducted as a line-by-line reading, where we moved from what the text said to what the text was about in a broader sense. As the text was unfolded, meanings were brought forth and condensed into themes. Finally, the third stage – critical analysis – consisted of an in-depth analysis of the two prior stages to reach the most probable understanding of what the text said about the research question. Finally, the findings were related to other studies (Ricoeur, 1976, 1991). Analysis was performed by the PhD student and under supervision of the PhD supervisors and discussed with the co-researchers.

Ethical considerations

The Danish Ethical Committee does not require approval for qualitative studies. Nevertheless, the Helsinki II Declaration and Ethical Guidelines for Nursing Research in the Nordic Countries were observed.

The study was approved by the management of the department, who also participated with representatives in a reference group together with a former patient, a co-researcher representative, the PhD supervisors and the PhD student.

Patients gave oral and written consent to participate; their participation was voluntary and it did not affect their nursing care if they declined to participate. A written agreement was made with the psychologist employed at the centre to attend participants if they felt discomfort or harm. For the wellbeing of the co-researchers, a written agreement was also made with the psychologist employed at the centre and a verbal agreement was made with a psychologist at the regional clinic for occupational medicine to provide support if necessary. The study was approved by the Danish Data Protection Agency (journal no. 1-16-02-503-15).

Findings

Acknowledging the need for the patient's participation, the co-researchers incorporated their new understanding into meaningful interventions adjusted to the rehabilitation pathway. Concretely, based on reflections on and discussions of the experiences and knowledge, they developed four nursing initiatives which were later tested and evaluated for their value as a resource to aid the nurses in supporting the patients' participation (Figure 1).

The four nursing initiatives

The initiatives worked independently but were linked and comprised the full clinical pathway with variations in content and focus (Figure 2). The aim was to take the perspective of the patient and therefore the headlines start with "My". The four initiatives were: "My wishes and needs", "My plan for the day", "My thoughts about my situation" and "My pathway meetings". All initiatives were described in the guidelines and included a guide for the nurse.

The four nursing initiatives	
My wishes and needs	<p>Aim</p> <ul style="list-style-type: none"> • The patient is prepared for his first interprofessional clinical pathway meeting • The patient provides information about his needs, preferences and wishes for the admission and the future
My plan for the day	<p>Aim</p> <ul style="list-style-type: none"> • The patient shares his needs, preferences and wishes for daily life at the rehabilitation centre • To align expectations for the clinical pathway and the different roles of patient and staff • Continuity, structure and overview of activities of the day and the clinical pathway • Assessment of the patient's resources and energy to participate in activities and the need for nursing assistance
My thoughts about my situation	<p>Aim</p> <ul style="list-style-type: none"> • The patient shares a narrative of his life including the current situation to support coherence between his past, present and his wishes and hopes for the future
My pathway meetings	<p>Aim</p> <ul style="list-style-type: none"> • The patient prepares for the clinical pathway meetings where he meets with all team members and closest relatives to plan and adjust the general pathway to his wishes, needs and preferences • The patient's current situation and reflections on the future together with his physical, psychological and social capabilities are combined with health and contextual parameters

Figure 1: The aim of the four nursing initiatives and how they correlate

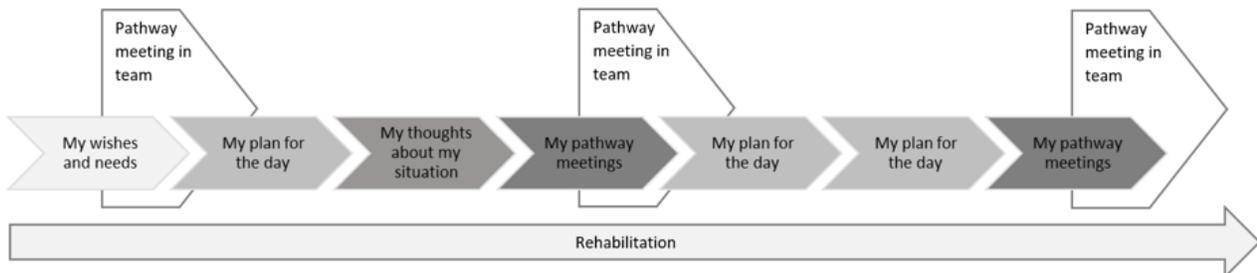


Figure 2: The four nursing initiatives as they appear during rehabilitation pathways

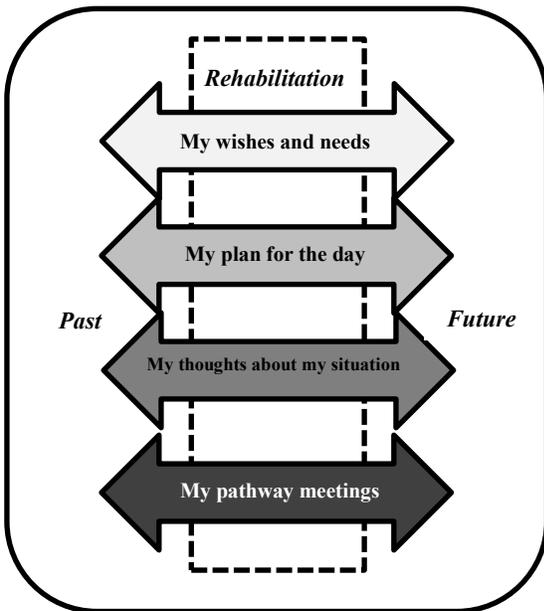


Figure 3: *The four nursing initiatives and their mediating function in rehabilitation between pre-injury life and future life of the SCI person*

When nurses provided space for the patient's participation, they realised how a lack of knowledge about the patient had influenced the nursing the patient had received. Therefore, the insight into the changed lives of persons with SCI made the nurses change their approach and attitude to patient rehabilitation. The nurses recognised that they themselves needed to participate in the rehabilitation process of the patient. This called for a relationship taking the form of companionship which was supported by four nursing initiatives implemented to elicit the patient's perspective. The framework for facilitating the patient's participation is elaborated on in four themes below:

Patient participation changes the approach of nurses and enhances rehabilitation

By exploring how the patients participated in the rehabilitation, the co-researchers became aware of the absence of the patient's perspective in the planning and conducting of rehabilitation. The nurses realised the necessity to make time and space for patients to put into words their previous routines and habits along with their wishes and difficulties in coming to terms with their situation.

Consequently, they encouraged patients to share personal perspectives related to their situation and possible consequences for their lives in relation to family, work and social activities. Asking patients to share their thoughts and understanding of their situation served to clarify matters not only for the nurses but also for the patients themselves. As a co-researcher puts it:

'We have had a deeper understanding since our conversation, as the background and his personality started to become clear. I can use that going forward when we are organising activities and more specifically how I guide/encourage/motivate the individual patient to get as far as possible in the rehabilitation process and to translate that into the bigger perspective, learning to live with a spinal cord injury.'

(Hanne, co-researcher, evaluation of nursing initiatives)

As the quote indicates, the co-researcher acknowledged the pivotal position of the patient's prior life, his views, values and wishes. Thus, it became apparent that getting access to patients' narratives and views of their situation was crucial. In fact, the patient's biography was decisive for adjusting, clarifying and negotiating the point of departure for rehabilitation. Coherent planning and efficient action in rehabilitation were linked to the recovery of the SCI person.

Consequently, rehabilitation should be considered a collaborative process where nurses and patients work together on the recovery of the patient to achieve the highest functionality and autonomy.

Nurse participation in the patient's rehabilitation enables collaboration and companionship

The explorative approach challenged the co-researchers' understanding of participation. Alongside the realisation that the nurses needed more thorough knowledge about the patient, the question about "*who participates in what*" arose. The co-researchers realised that they too had a central role to play. During one of the first meetings, one of the co-researchers asked:

'The basic premise must be: what is the reason for our meeting, what is it that the patient is to participate in and what am I participating in?'

(Rikke, co-researcher, meeting 2)

The nurses moved from solely focusing on how to support the patient's participation in rehabilitation to a new understanding of rehabilitation as a collaborative process in which they were participating as well. This shift in perspective and approach was illustrated by one of the co-researchers:

'We need to engage and be emotionally aware to find out what is going on with the patient.'

(Hanne, co-researcher, Workshop 1)

Actually participating in the patient's rehabilitation, the nurses gained more detailed knowledge about how to support the patient's participation. Hence, paradoxically, the shifts in perspective away from a unilateral focus on patient participation towards collaborative process ended up strengthening the patient's participation.

The feeling of a shared task promotes a caring engagement and a relationship built around enhancing the patient's ability to move forward. One of the nurses describes this as taking part in the patient's journey:

'Our collaboration is characterised by the knowledge that we have together but also the difficult journey that we have been through.'

(Annett, co-researcher, evaluation of nursing initiatives)

The shared journey was further elaborated on as if she was walking alongside the patient as a companion who did not lead but accompanied the patient in a supportive and caring manner. The nurses were attentive to the patients' needs including the needs that the patients had not realised themselves.

Nurse participation reinstates caring in nursing

Participation in the patient's rehabilitation increased awareness of the patient's situation. With this knowledge, the nurses felt obliged to form good relationships as a basis for providing care for their patients. By getting to know the patient as a person, the nurses became sensitive to the patient's situation and felt the need to reinstate caring in nursing to support the patient's participation. This led to an understanding of caring as the basis for rehabilitation nursing, and caring for physical needs entailed caring for the emotions related to those needs. This is in contrast to more task-oriented nursing where the task itself is an isolated goal. A co-researcher emphasised the core value of caring in nursing:

'We need to get back to our core job as nurses and nursing assistants. That is forming relationships and caring for our patients; once we have got that right, we can assist with bowel management (...)'.

(Lise, co-researcher, meeting 17)

The caring as an attitude and not only as a task enabled the nurses to help with specific physiological needs, such as bowel management. Bowel management, previously a very private and intimate routine, but a common task to a nurse, was now considered something that required a good relationship.

Listening attentively to the patient's reflections paved the way for thoughts and concerns, and the nurses experienced how this affected the patient. Through caring, they contributed to the psychological recovery process:

'She said that it felt good getting the chance to tell her story; it was such a relief that somebody had the time to listen to her. This was also why she embarked on a psychological journey, because she had to think about and verbalise how she was feeling.(...) She had been hospitalised at many different wards, but this was the first time that she felt anyone had time for her and showed that they cared. Isn't that wonderful?!'

(Ann, co-researcher, meeting 6)

The patient's ability to share experiences was described as a relief and a way for the patient to make sense of her situation. Moreover, nurses spending time and listening to their patients create space for rehabilitation based on caring nursing and planning of more precise and targeted rehabilitation.

Participation paves the way for a tailored rehabilitation process

The four nursing initiatives served as the structure and supportive guidelines when the nurses prioritised and allocated time and space to participate in their patients' rehabilitation and to remain present and attentive throughout the process.

A co-researcher expressed how the increased knowledge and understanding of the patient and his situation paved the way for a tailored rehabilitation process:

'It increased my understanding of the patient when I became aware of the resources, approaches and coping strategies that he had to get through a challenging period. It gave me an insight into the thoughts that the patient had about living with a spinal cord injury – his thoughts surprised me somewhat.'

(Maja, co-researcher, evaluation of the four initiatives)

In addition to the nurses' increased knowledge and understanding, the collaborative process also seemed to support the patient's reflection on his situation. The patients had the opportunity to explain who they were, how they were feeling and what they felt about their current situation. This fixed point in the current process was important to the patients, as it represented the point from

which their rehabilitation began in a, for them, meaningful way. The nurse, as an attentive listener, helped to identify valuable elements from the patients' pre-injury lives. They helped the patient understand what had happened and how this could be connected to their life before the injury and their life to come.

A co-researcher describes how the conversations broadened the perspective of the patient and opened up for a deeper self-understanding which aided rehabilitation:

'During conversations with patients, I often experienced how at first the patient focused on what had happened or what was difficult, but I also observed how patients "got through to the other side" and were able to verbalise what was worth looking forward to, their progress and not least the hopes they had.'

(Rikke, co-researcher, evaluation of the four initiatives)

One co-researcher explained how the new approach elicits what might be described as the code or – to use a common metaphor – pieces in a puzzle:

'This is where the code for the patient's drive, his motivation, energy, problems, doubts and frustrations may come to the surface. Here the pieces of the puzzle are inspected to see what will fit, and maybe a few of the pieces are positioned, but that is not the aim. The aim must be to find the pieces and start the puzzle.'

(Hanne, co-researcher, evaluation of initiatives)

The metaphor of a puzzle illustrates how the nurses perceived the new approach. A puzzle is complete when all the pieces are in place. However, in the case of rehabilitation, we discovered that it was not up to the nurse to finish the puzzle. It is not even to provide the pieces. Instead, it is to bring the patients' own pieces into play. The nurses' participation helped the patients discover their own pieces and by throwing light on the patients' pieces of the puzzle, the nurse supported their recovery as well as promoted the process of rehabilitation. Hence, moving towards a meaningful life after a spinal cord injury entailed a change in perspective on rehabilitation and participation.

Discussion

The present study revealed how nurses, when facilitating the patient's participation, recognised how their own participation implied a caring attitude and enabled an individually tailored rehabilitation process. The nurses' participation was characterised as a companionship where they cared for and supported their patients' path through rehabilitation. Hence patients' participation in rehabilitation altered when nurses took a different view of their role in their collaboration with patients.

The understanding of rehabilitation changed through reflection and action, from a dominant focus on physical and functional rehabilitation to a broader understanding of rehabilitation as a holistic process linked to the recovery of the SCI person and his disrupted life. This predominate focus on the physical part of rehabilitation is known from the literature. Despite positive outcomes, such as increased active rehabilitation engagement, enhanced personal control, improvements in quality of life and increased mental health and psychosocial adaption, psychological recovery is paid little attention in the clinical practice of rehabilitation (Y. Li, Bressington, & Chien, 2017). Even though Wade (2016) argues for rehabilitation to be viewed as a way of thinking rather than a way of doing (Wade, 2016), one of the obstacles to a changed approach may lie in the very definition of rehabilitation. The WHO definition of rehabilitation (*"the measures that help individuals (...)"*) (Chapter 4 *Rehabilitation*, 2011) entails an inherent logic of health professionals as providers of measures that help the individual. This may imply a strong focus on the patient's physical needs and an achievable goal setting within rehabilitation. Goal setting has also gained more focus during the last few years and been embraced as a key element in successful rehabilitation (Bovend'Eerd, Botell, & Wade, 2009; C. Li, DiPiro, Cao, Szlachcic, & Krause, 2016; Scobbie, Wyke, & Dixon, 2009). In a Cochrane

review, Levack et al. (2016) argue that goal setting does show improvements in rehabilitation (Levack et al. 2016). However, it has been reported to be difficult to set goals on which both patients and health professionals agree (Scobbie et al., 2009). Furthermore, goals are generally presented by the team members and not the patient (Bovend'Eerd et al., 2009).

Therefore, a unilateral view of rehabilitation as something achievable and measurable, outside the patient, may stand in the way of focusing on the existential psychological processes of the patient. To learn to live with a disability is a complex issue and various factors from the person's life affect the feeling of health (Mitra & Shakespeare, 2019). Even though the WHO's bio-psycho-social model for measuring health and disability (ICF) includes contextual, environmental and personal factors, it is criticised for not containing all aspects of a lived experience of health deprivations, and there is a call for a more holistic model (Mitra & Shakespeare, 2019). While the four nursing initiatives developed in this study focus on the process of rehabilitation linking it to a coherent life for the SCI person, they may also provide a framework for a broader model.

During the test of the initiatives, the nurses experienced how the new approach worked in clinical practice. Following the new guidelines, they felt it appropriate to supplement physical care and task-oriented nursing with a more person-centred caring element. Moreover, they recognised how the patient's unique situation made it impossible to predict preferences and needs. This is in line with the findings of Van de Velde et al., who argue that participation contains a cluster of subjective aspects manifesting themselves in various experiences regarding life situation and cannot be viewed solely objectively. It is multidimensional and includes interdependent relations between the person, the surrounding environment and the role the person gets to play or his level of autonomy (Van de

Veldea, Bracke, Van Hove, Josephsson, & Vanderstraeten, 2010). Hence, the patient's subjectivity or idiosyncrasies may be explored with a collaborative process, providing important insight into the patient's preferences and prior routines which in turn may qualify goal setting in rehabilitation.

The nursing initiatives established the framework for sharing time and sharing knowledge which are prerequisites for patient participation as stated by Angel and Frederiksen (2015). It also established a companionship between the nurse and the patient and interdependence between the SCI person's experiences and the elements of nursing provided in the process of rehabilitation.

Accordingly, the nurse-patient relationship was strengthened and the engagement of the nurse in the patient's situation created a personal bond. According to the Norwegian nurse and philosopher Martinsen, nurses must meet the patient with emotions on a person-to-person level. By doing so, their perception is broadened and grants access to a profound understanding of the patient as a person (Martinsen, 2006). Thereby, the nurses are allowed access 'to participate in the world of the other' (Martinsen, 2006 p. 74). Martinsen's view is supported by our empirical findings showing the pivotal need for nurses to participate in the SCI person's life to care for the person and support the process of rehabilitation. Hence, the nurses' perspective, approach and nursing care changed, not as a result of external demands or management prescriptions but as a consequence of their own experiences of a person-to-person relationship as to the most effective way of supporting SCI persons' paths to a meaningful life.

Limitations

The co-researchers were originators and evaluators of the four nursing initiatives. This is in line with other action research study designs where the actions (in this case test of initiatives) are developed and tested to answer a local problem where the renewed understanding and knowledge corresponds to the need of the users (Dewey, 2015; Hummelvoll et al., 2015). Nevertheless, with the analysis, interpretation and discussion in relation to the existing body of knowledge on the subject, we suggest that the findings may have travelling capacity as described by Hummelvoll et al. (2015) when modified and adjusted to other contexts.

Contextual and organisational issues relating to the process of changing nursing practice are highly relevant, though not elaborated on in this article. We will do so in a paper to follow.

As described by Angel and Frederiksen (Angel & Frederiksen, 2015), an obstacle to patient participation is nurses' attitudes and position as gatekeepers. The timeframe prevents the display of long-term possibilities and consequences of the nursing initiatives and the approach of the participating nurses, and we recommend that this is further elaborated on elsewhere.

Conclusion

Nurses can support patient participation in rehabilitation by actively engaging in the patient's journey and taking on the role of a companion. By doing so their commitment to improving patient's situation unfolds in a person-to-person meeting and accordingly an understanding of the patient's perspective. Taking on the roles of participants and companions and adopting a new approach aided by the four

nursing initiatives, nurses are able to enhance the effectiveness of rehabilitation by tailoring the process to the individual.

Relevance to clinical practice

The study provides answers to how nurses can initiate caring rehabilitation through a changed understanding of their own role and by using targeted nursing initiatives to support the patient's rehabilitation. When nurses participate in the patient's rehabilitation, they are able to tailor the process to the patient's perspective, using his narrative, values and routines as the focal point. Accordingly, they are able to support the patient in his efforts to build a coherent life post injury.

References

- Angel, S. (2009). The fight for a meaningful life. *Sygeplejersken / Danish Journal of Nursing*, 109(17), 48–53.
- Angel, S. (2010). Patient participation during rehabilitation after spinal cord injury. *Tidsskrift for Sygeplejeforskning*, 1, 20–25.
- Angel, S., & Frederiksen, K. N. (2015). Challenges in achieving patient participation: A review of how patient participation is addressed in empirical studies. *International Journal of Nursing Studies*, 52(9), 1525–1538. <https://doi.org/10.1016/j.ijnurstu.2015.04.008>
- Angel, S., Kirkevold, M., & Pedersen, B. D. (2009). Getting on with life following a spinal cord injury: Regaining meaning through six phases. *International Journal of Qualitative Studies on Health and Well-Being*, 4(1). <https://doi.org/10.3402/qhw.v4i1.4999>
- Angel, S., Kirkevold, M., & Pedersen, B. D. (2011). Rehabilitation after spinal cord injury and the influence of the professional's support (or lack thereof). *Journal of Clinical Nursing*, 20(11–12),

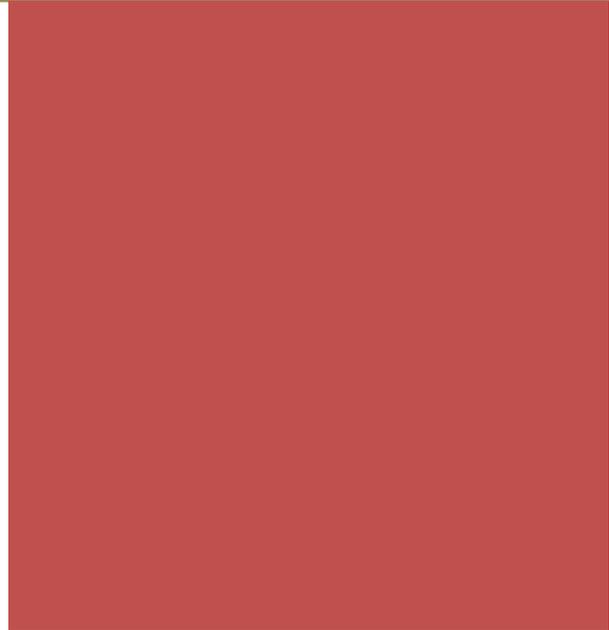
1713–1722. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/21323775>

- Bargal, D. (2006). Personal and intellectual influences leading to Lewin's paradigm of action research. *Action Research*, 4(4), 367–388. <https://doi.org/10.1177/1476750306070101>
- Bovend'Eerdt, T. J., Botell, R. E., & Wade, D. T. (2009). Writing SMART rehabilitation goals and achieving goal attainment scaling: a practical guide. *Clinical Rehabilitation*, 23(4), 352–361. <https://doi.org/10.1177/0269215508101741>
- Chapter 4 Rehabilitation*. (2011). Retrieved from https://www.who.int/disabilities/world_report/2011/chapter4.pdf?ua=1
- Chen, H; Boore, J. (2005). Considering the physiological and psychological consequences of spinal cord injury. *British Journal of Neuroscience Nursing*, 1(5), 225–232.
- Coghlan, D. (2019). *Doing action research in your own organization*.
- Collis Pellatt, G. (2003). Perceptions of the nursing role in spinal cord injury rehabilitation. *British Journal of Nursing*, 12(5), 292–299. <https://doi.org/10.12968/bjon.2003.12.5.11175>
- Dewey, J. (1958). *Experience and nature* (2.). New York: Dover Publications Inc.
- Dewey, J. (2015). *Democracy and Education*. Sheba Blake Publishing.
- Dickson, R; Allan, A; O'Carroll, D. (2008). Biographical disruption and the experience of loss following a spinal cord injury: an interpretative phenomenological analysis. *Psychology & Health (PSYCHOL HEALTH)*, 23(4), 407–425.
- Geisler, FH; Coleman, WP; Benzel, E; Ducker, T; Hurlbert, RJ; McDonald, JW; Sadowsky, C. (2002). Spinal cord injury. *Lancet (LANCET)*, 359, 417–425.
- Gendreau, A., & de la Sablonnière, R. (2014). The cognitive process of identity reconstruction after the onset of a neurological disability. *Disability and Rehabilitation*, 36(19), 1608–1617. <https://doi.org/10.3109/09638288.2013.859749>

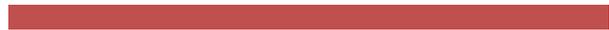
- Greenwood, D., & Levin, M. (2007). *Introduction to Action Research Social Research for Social Change* (2. edition). California: SAGE Publication Inc.
- Hummelvoll, J. K., Eriksson, B. G., & Cutcliffe, J. R. (2015). Local experience – central knowledge? - Methodological and practical implications for knowledge development in local mental health care settings. *Nordisk Sygeplejeforskning*, 5(03), 283–295. Retrieved from https://www.idunn.no/nsf/2015/03/local_experience__central_knowledge_-_methodological_and
- Le, J., & Dorstyn, D. (2016). Anxiety prevalence following spinal cord injury: a meta-analysis. *Spinal Cord*, 54(8), 570–578. <https://doi.org/10.1038/sc.2016.15>
- Levack, W. M., Weatherall, M., Hay-Smith, J. C., Dean, S. G., McPherson, K., & Siegert, R. J. (2016). Goal setting and strategies to enhance goal pursuit in adult rehabilitation: summary of a Cochrane systematic review and meta-analysis. *European Journal of Physical and Rehabilitation Medicine*, 52(3), 400–416. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/26771917>
- Lewin, K. (1946). Action Research and minority problems. *Journal of Social Issues*, 2(4), 34–46.
- Li, C., DiPiro, N. D., Cao, Y., Szlachcic, Y., & Krause, J. (2016). The association between metabolic syndrome and pressure ulcers among individuals living with spinal cord injury. *Spinal Cord*, 54(11), 967–972. <https://doi.org/10.1038/sc.2016.53>
- Li, Y., Bressington, D., & Chien, W. T. (2017). Systematic Review of Psychosocial Interventions for People With Spinal Cord Injury During Inpatient Rehabilitation: Implications for Evidence-Based Practice. *Worldviews on Evidence-Based Nursing*, 14(6), 499–506. <https://doi.org/10.1111/wvn.12238>
- Lindberg, J., Kreuter, M., Taft, C., & Person, L.-O. (2013). Patient participation in care and rehabilitation from the perspective of patients with spinal cord injury. *Spinal Cord*, 51(11), 834–837.

- Loft, Mia I, Poulsen, I., Esbensen, B. A., Iversen, H. K., Mathiesen, L. L., & Martinsen, B. (2017). Nurses' and nurse assistants' beliefs, attitudes and actions related to role and function in an inpatient stroke rehabilitation unit-A qualitative study. *Journal of Clinical Nursing*, *26*(23–24), 4905–4914. <https://doi.org/10.1111/jocn.13972>
- Loft, Mia Ingerslev, Poulsen, I., Martinsen, B., Mathiesen, L. L., Iversen, H. K., & Esbensen, B. A. (2019). Strengthening nursing role and functions in stroke rehabilitation 24/7: A mixed-methods study assessing the feasibility and acceptability of an educational intervention programme. *Nursing Open*, *6*(1), 162–174. <https://doi.org/10.1002/nop2.202>
- Martinsen, K. (2006). *Care and vulnerability*. Akribe.
- Middleton, J., Tran, Y., & Craig, A. (2007). Relationship Between Quality of Life and Self-Efficacy in Persons With Spinal Cord Injuries. *Archives of Physical Medicine and Rehabilitation*, *88*(12), 1643–1648. <https://doi.org/10.1016/j.apmr.2007.09.001>
- Mitra, S., & Shakespeare, T. (2019). Remodeling the ICF. *Disability and Health Journal*, *12*(3), 337–339. <https://doi.org/10.1016/j.dhjo.2019.01.008>
- Moreno, A., Zidarov, D., Raju, C., Boruff, J., & Ahmed, S. (2017). Integrating the perspectives of individuals with spinal cord injuries, their family caregivers and healthcare professionals from the time of rehabilitation admission to community reintegration: protocol for a scoping study on SCI needs. *BMJ Open*, *7*(8). <https://doi.org/10.1136/BMJOPEN-2016-014331>
- Post, M. W. M., & van Leeuwen, C. M. C. (2012). Psychosocial issues in spinal cord injury: a review. *Spinal Cord*, *50*(5), 382–389. <https://doi.org/10.1038/sc.2011.182>
- Ricoeur, P. (1976). *Interpretation theory: discourse and the surplus of meaning*. Texas Christian University Press.
- Ricoeur, P. (1991). *On Paul Ricoeur: narrative and interpretation* (D. Wood, ed.). London: Routledge.
- Ricoeur, P. (2002). The hermeneutical function of distanciation. *Philosophy Today*, 129–141.

- Savic, G., DeVivo, M. J., Frankel, H. L., Jamous, M. A., Soni, B. M., & Charlifue, S. (2018). Suicide and traumatic spinal cord injury—a cohort study. *Spinal Cord*, *56*(1), 2–6.
<https://doi.org/10.1038/sc.2017.98>
- Scobbie, L., Wyke, S., & Dixon, D. (2009). Identifying and applying psychological theory to setting and achieving rehabilitation goals. *Clinical Rehabilitation*, *23*(4), 321–333.
<https://doi.org/10.1177/0269215509102981>
- Van de Veldea, D., Bracke, P., Van Hove, G., Josephsson, S., & Vanderstraeten, G. (2010). Perceived participation, experiences from persons with spinal cord injury in their transition period from hospital to home. *International Journal of Rehabilitation Research. Internationale Zeitschrift Für Rehabilitationsforschung. Revue Internationale de Recherches de Réadaptation*, *33*(4), 346–355.
- Wade, D. (2016). Rehabilitation – a new approach. Part four: a new paradigm, and its implications. *Clinical Rehabilitation*, *30*(2), 109–118. <https://doi.org/10.1177/0269215515601177>
- Williams, R., & Murray, A. (2015). Prevalence of Depression After Spinal Cord Injury: A Meta-Analysis. *Archives of Physical Medicine and Rehabilitation*, *96*(1), 133–140.
<https://doi.org/10.1016/j.apmr.2014.08.016>



**Appendix C:
Paper III**



Nurses struggle for patient participation in rehabilitation

- A path littered with obstacles

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Abstract

Purpose

Patient participation is essential to target spinal cord injury (SCI) rehabilitation to the patient's needs, routines and way of life and nurses' perspective on current conditions and constraints is only sparsely identified in SCI rehabilitation. Therefore, the purpose was to explore how nurses strive to establish the patient's participation in rehabilitation.

Materials and methods

This action research study involved a group of eight nurses who participated for two years with identifying, testing and evaluating ways of supporting patient participation. Using the interpretive theory of Ricoeur, empirical data were analysed to identify central themes.

Results

Nurses recognised the impact of the patient's perspective. Still, they were *struggling* to find personal calmness and to create space for a conversation with the patient without being disturbed or having to perform other practical tasks. However, even after the test and evaluation of four newly developed nursing initiatives customised to the setting, the nurses still called for nursing to include the patient's perspective.

Conclusion

The setting and intrinsic conditions must change if rehabilitation nursing is to include the patient's perspective in rehabilitation. This is relevant to rehabilitation because getting to grips with the patient's perspective is of utmost importance to support patient participation.

Keywords: Rehabilitation; Caring; patient centred care; patient participation; spinal cord injury; culture, organisational; action research

Introduction

Including the patient's wishes, preferences and demands in healthcare has become an agenda shared by politicians, health professionals and consumer organisations in Denmark and other Western European countries [1–4]. Many benefits substantiate this view, such as increased quality of life, the knowledge gained to make decisions on treatment, cost-effectiveness and a reduction in adverse events [1,5–7]. However, changing clinical practice to a more attentive patient involving approach is it is linked to challenges [8,9].

Among others, Lindberg et al. [10] find the patient's participation essential to spinal cord injury (SCI) rehabilitation. The authors reported that rehabilitation should be structured around the individual patient's capabilities and needs, and health professionals should take the time to listen to the patient's preferences, problems and symptoms. Others have emphasised the need for patient participation in SCI rehabilitation to gain control over life, autonomy, independence and quality of life [11–13]. However, as stated by Van de Velde et al. [14], participation is often related to the observable physical performance and less to the person's inner perspective and subjective dimensions. The fact is that being independent and self-sufficient is not synonymous with being autonomous, and the aim should be to empower patients to master their own lives and to reintegrate into society. Van de Velde et al.

emphasise that you can only achieve that by learning about the patient's perspective [14]. Therefore, health professionals are urged to engage the patient in dialogue to reveal his perspective, wishes and demands and tailor the rehabilitation process accordingly [12].

Bear in mind that listening to the patient's perspective is a core element of nursing [15,16], and it is no surprise that patient participation is found to improve the quality of care [7,13]. Nevertheless, nurses struggle to involve patients in rehabilitation that takes the patient's perspective into account and reflects the person's needs and wishes [17,18]. In a review, Angel and Frederiksen [8] list several obstacles to patient participation: insufficient time, insufficient knowledge and nurses' attitude and understanding of the patient's situation. Nurses also tend to dominate the relationship. Consequently, researchers stress the necessity of strengthening the nurse-patient relationship to facilitate person-centred nursing [19–21].

The challenges of involving patients in their care and treatment may be alleviated by using shared decision aids on which Stacey et al. [5] reported several positive outcomes. However, in a Cochrane review, Légaré et al. [22] emphasised the need for more research into the effects of interventions to enhance shared decision-making and thereby the involvement of patients [22]. Nevertheless, Elwyn et al. [23] criticised the unilateral focus on decision aids and their short-term outcomes for patients. Instead, to see long-term results as they appear in the culture of the organisation, they argue for more research into the processes, interaction and impact on the professionals when implementation strategies are evaluated [23]. However, some studies do add to the body of knowledge related to the culture of the organisation. In a two-year evaluation study of an implementation project involving a range of actions, Jangland & Gunningberg [9] found minor improvement on patient-centred care and patient participation. In conclusion, they found that improving patient participation in a busy healthcare setting is very challenging and dedicated leadership is required for changes to occur. Another study covering seven wards at two English hospitals emphasised the need for

organisational support and local ownership for successful implementation (of shared decision-making) and a break with “we do it already” [24].

Little is known about the challenges of implementing initiatives to improve the involvement of the patient’s perspective within SCI rehabilitation settings. The study of Melin et al. [25] is one of the few studies viewing patient participation in SCI rehabilitation from a staff perspective. They found requisites and constraints by interviewing 13 interprofessional staff members; nurses were not classed as rehabilitation staff, but were categorised as “other professions”. Another study compared structured patient interviews with recordings of nursing activities and chart reviews for correlation. In this study, Bailey et al. [13] found multiple better outcomes as a consequence of patient participation in nursing activities and urged nurses to engage patients more. Nevertheless, Bailey et al. [13] did not involve the nurses or ask for their views in the study [13]. Only one study was found addressing nurses’ conditions and roles in SCI rehabilitation, as perceived by nurses [26].

Hence, despite the importance of the patient’s perspective to patient participation, little is known about nurses’ perspective on the matter and under which conditions they are able to support the patients with SCI to participate in their rehabilitation. The aim of the present study was to remedy this gap in the literature.

Materials and methods

Setting

The centre which has 35 beds and an out-patient clinic for life-long follow-up, was one of two highly specialised spinal cord injury rehabilitation centres in Denmark. Patients were hospitalised for 3–8 months during their initial rehabilitation sessions. Doctors, social workers, psychologists, occupational therapists and physiotherapists, nurses and nursing

assistants were all members of the interprofessional team providing rehabilitation. The Spinal Cord Injury Centre of Western Denmark (SCIWDK) serves a population of 3.5 million.

Participants

Eight staff members, four registered nurses (3.5 years of education) and four nursing assistants (3 years of education), volunteered to participate in the study for two years. They were partners who contributed actively within all aspects of the four phases with clinical expertise, knowledge, curiosity, reflection and drive [27,28] and they are named as co-researchers. The call for co-researchers was open and the co-researcher participants applied out of interest and motivation. The group turned out to be diverse in terms of education, experience and personal characteristics. Their ages ranged from 26 to 56 and their employment seniority within SCI rehabilitation nursing ranged from 3 months to 20 years (Table 1). The PhD supervisors participated in meetings and workshops on equal terms with the co-researchers and the PhD student who facilitated the processes.

An advisory Board was led by the PhD student with members of the interprofessional leadership team, a co-researcher representative, PhD supervisors and a former patient (living with the consequences of SCI) were linked to the study; they provided a mandate for the findings and supported the processes during the study.

Co-researcher	Education	Age (28–56)	Years of experience (1–20)	Years of experience in SCI rehabilitation (0.3–19)
Lise	Nursing assistant	54	9	9
Annett	Nursing assistant	56	19	19
Rikke	Nursing assistant	39	14	14
Tine	Nursing assistant	32	11	8
Hanne	Nurse	46	20	0.3
Line	Nurse	39	9	9
Maja	Nurse	26	1	1
Ann	Nurse	28	5	1.5

Table 1: Co-researcher characteristics

Research design

Based on Dewey's philosophy and pragmatic action research, we wanted to provide a structure that promoted an openness to learn through a combination of critical dialogue, reflection and action [29,30]. The method provided opportunities for learning from mistakes as well as successes and the possibility to correct the developed initiative or even dismiss it if it proved ineffective [30–32]. The design supported the development, testing and incorporating of new initiatives while nurses developed their competences, a praxis for reflection and new knowledge [29,33]. The process was iterative but structured in four overall phases (problem identification, planning, actions and evaluation) [34–36].

Data collection and preparation

The data collected consisted of co-researchers' written evaluations of four nursing initiatives and verbatim transcriptions of meetings and workshops. The analysis was of empirical data from the evaluation phase, including a workshop and meetings held after the testing of the four nursing initiatives (Table 2). During this phase, the co-researchers experienced the conditions while working with the four initiatives within their clinical practice.

<p style="text-align: center;">The four nursing initiatives</p> <p style="text-align: center;">All initiatives are conversations between the primary nurse and the patient in private surroundings, e.g. the patient's room</p>			
My wishes and needs	My plan for the day	My thoughts about my situation	My pathway meetings
<ul style="list-style-type: none"> • Prepare for the first interprofessional clinical pathway meeting • Achieve knowledge about the patient's preferences, values and wishes for the admission and for the future. 	<ul style="list-style-type: none"> • Plan daily activities for the patient based on the patient's needs, wishes, preferences and prior routines. • Create continuity and structure and plan the patient's participation and the need for nursing assistance. 	<ul style="list-style-type: none"> • Support the patient's understanding of the situation through a coherent narrative of his life. • Support coherence between past, present and the wishes and hopes for the future. 	<ul style="list-style-type: none"> • Help the patient reflect on his situation to lay the foundation for sharing his perspective at the clinical pathway meetings, where all team members and closest relative plan the overall pathway together with the patient. • Adjust the pathway to the patient's wishes, needs, preferences, and the current physical, psychological and social functional capability together with considerations about the future.

Table 2: The aims of conversations and how they are displayed in the four nursing initiatives.

Analysis

The co-researchers' reflections and analysis during the action research process were further elaborated on in an in-depth phenomenological-hermeneutic analysis (Paul Ricoeur, 1913–2005). Using Ricoeur's philosophy of interpretation, we achieved a detailed understanding of the conditions under which nurses elicit the patient's perspective. In three interrelated stages, we analysed what was once a situational statement from one person to another objectified as text to disclose possible interpretations and a more universal understanding [37,38]. In the first stage, the naïve interpretation, we read the text several times with an open mind to achieve an immediate understanding of the text as a whole. In the next stage, the structural analysis, we moved from what the text specifically said (sentence by sentence) to what the

text was talking about, the reference [38,39], and various themes emerged. Finally, in the third stage, we conducted a critical interpretation aiming at the most probable understanding of what the text said more universally about the conditions for working with the patient's perspective. In a non-linear process, we went back and forth to develop a trustworthy interpretation of the text [38]. This was further validated in the large material of all four phases for recognisability and finally critically reviewed and related to current evidence on the subject.

Ethical considerations

The study was conducted in accordance with the Helsinki II Declaration [40] and the Ethical Guidelines for Nursing Research [41], and it received the approval of the SCIWDK interprofessional board.

The well-being of the co-researchers was a particular priority, as they openly shared thoughts, worries and insecurities to an extent requiring careful conduct. Hence, we made a written agreement with the regional clinic for occupational medicine and the psychologist at the centre to intervene if necessary.

The Danish Data Protection Agency approved the study (journal no. 1-16-02-503-15).

Results

The naïve interpretation provided an understanding of the nurses who, despite having developed initiatives that supported patient participation, struggled to create space for the patient's perspective in rehabilitation. During the structure analysis, four main themes emerged.

Recognising the impact of the patient's perspective for patient participation

Daily nursing practice was highly task-oriented and scheduled to fit in with the patient's training. Nurses assisting patients with their morning routines were on a tight schedule to

finish in time for training. Nurses often took control of tasks, and patients would only get to practise their skills and improve self-sufficiency if there was time. Prior to the study, the nurses did learn about their patients' needs during morning routines, but they were surprised by the insight they got into their patients' lives, values and prior routines when testing the nursing initiatives. Furthermore, they realised how a relationship built on trust prompted conversations of depth, vulnerability and confidentiality, which laid the foundations for the patients taking control, engaging and sharing in the planning of their rehabilitation. Moreover, the co-researchers felt they were able to support patient participation and target rehabilitation for the life to come:

"It is preparing the patient to get to grips with his own life again and to engage with the new everyday life around the corner. This enhances the rehabilitation process because the patient is better equipped for his new life."

(Lise, co-researcher, evaluation of nursing initiatives)

The conversation affected both the patients and the co-researchers. Given the space for reflection, the patients did reflect on their situation and shared thoughts and experiences from their lives. They also shared their thoughts on how living with SCI would affect their future possibilities and position in society.

Focusing on the patients' needs, wishes and concerns about living with SCI, the co-researcher's role was to encourage the patient undertaking the process by being open, interested and showing that she cared. The impact was surprising to both the co-researcher and patient:

"The patient was surprised how many topics we had covered, as she was not really aware of anything in particular that she wanted to talk about. (...) our conversation about everyday life following discharge and about managing expectations, both one's own expectations and those of relatives, friends, the ex-husband and children, really touched me. It was also in this connection that I particularly experienced a

'revelation'. IT REALLY DOES WORK – those conversations make all the difference!!!"

(Lise, co-researcher, evaluation of nursing initiative)

With experience, the nurses detached themselves more from the guidelines; they deviated and conducted conversations in less planned and structured settings and improvised, seizing the moment for a conversation when it emerged. However, it was neither the structure nor the guidelines promoting the conversations. During the two-year study, the nurses' experience clearly established the importance of focusing on the patient's perspective to support patient participation in rehabilitation. Nevertheless, the nurses struggled to set aside other tasks to make time for conversations and to be attentive listeners.

Struggling to be attentive to the patient's perspective

The co-researchers struggled to find the time and space to work with the individual patient and get to grips with the patient's perspective. The nurses were unaccustomed to a situation, where they were only expected to be present, attentive and listening; they were used to conversations when the primary aim was collecting data about the patient's current (physical) condition. Therefore, they found it difficult to be enough at ease to just listen:

"We may well find this the most difficult thing of all. Because we are so used to collecting data. (...) and the fact that you just need to be there and must be able to deal with nobody saying anything for a while."

(Trine, co-researcher, workshop 3)

It was not only the pauses that were uncomfortable and something to endure; the co-researchers also struggled with their urge to act while sitting with the patient. As the nurses were unaccustomed to engaging their patients in deep and important conversations, they were left feeling insecure and hesitant. One co-researcher mentions that she would bring coffee to the conversation to calm her nerves:

"As nursing staff, we are trained, practised and accustomed to acting, fixing, reacting, organising, fussing – it is very rare that we just sit and talk."

(Rikke, co-researcher, workshop 3)

Even though the nurses valued and acknowledged the benefit of the conversations, they struggled overcoming their reluctance, lack of training and pressure to prioritise other practical tasks around the patient. Furthermore, they felt they were needed elsewhere and the thoughts of other tasks intruded on their concentration. Despite their difficulties, the nurses persevered and forced themselves to “sit on their hands”, even though it was unnatural to them. The pressure from other tasks made the nurses attempt to elicit the patient’s perspective while they were performing other tasks or on an ad-hoc basis during tiny breaks in the patient’s day.

Searching for time to elicit the patient’s perspective

Even though the patient’s perspective was necessary to facilitate the patient’s participation, the other tasks on the ward were prioritised. Spending time with one patient without doing practical tasks ultimately made the nurses feel that they were bailing out on their colleagues:

"... but it is difficult to get started on a conversation – when do we have the time? How many interruptions will we have? I feel bad leaving the ward. All those thoughts you have in your head when you go in and say that you will now be sitting with this patient for half an hour."

(Ann, co-researcher, workshop 3)

This indicates that spending time with one patient alone ranked alongside leaving the ward and the working community. Furthermore, it shows how conversations were viewed in everyday nursing: something that could only take place when all other tasks on the ward were completed. Moreover, conversations were viewed as an add-on to rehabilitation and they were expected to be set aside when other (physical or practical) tasks appeared. Furthermore, the

nurses were expected to remain available and interruptions were commonplace. The dilemma of wanting to live up to the expectations of colleagues and to conduct the conversations as arranged became a source of frustration. They became reluctant to plan and promise time dedicated to the individual patient alone, because they were unsure if they could keep their word:

"... well, so I did not get to do that today. And that is probably what I find most stressful – all the good intentions. I became reluctant to make any appointments ..."

(Lise, co-researcher, meeting 16)

The nurses wanted to forge relationships with their patients built on trust and cancelling appointments meant letting patients down. Therefore, the nurses searched for alternative solutions. They seized the moment whenever it occurred and had the conversations with their patients within any setting, for example by the bedside, during other activities or in between practical activities, even though they knew from experience how important it was to have these conversations in calm settings with no other activities. An example was when the patient was seated on the toilet:

"Annett: (...) Many of my conversations take place in the bathroom. The patients relax and I perform the bowel management.

Ann: Well, that was what we were talking about (...). Because it has actually been like that for many years, but it really ought not to be.

Annett: You are absolutely right (...) I also think that we will probably have to; with all the fuss we have here regularly, we will have to grab the chance when we get it and not think about whether it is perfect ..."

(Annett, Ann, co-researchers, meeting 16)

The co-researcher ended up compromising on the setting and consequently also the patient's ability to be in control of the setting around bowel management which is usually a private matter. Even though the other co-researchers opposed having conversations during intimate situations in the bathroom, they too described how they created space to elicit the patient's perspective in alternative ways. In that sense, they accepted the terms. Nevertheless, they also

called for nursing to include scheduled time to explore and establish the patient's perspective on more equal terms with other nursing activities.

The call for nursing to include the patient's perspective

As nurses are expected to be constantly available, endure interruptions and help patients finish on time, their efforts to explore and establish the patient's perspective depend on the goodwill of nursing and the interprofessional colleagues. As undisturbed conversations were not a regularly occurring part of rehabilitation, the nurses felt they needed to argue for them as an integrated part of rehabilitation nursing. An example of the struggle and fight for legitimacy is voiced by one of the co-researchers:

"... why is it not (...) equally valid to go in and say: we have a conversation today; it is an integrated part of the treatment. You might just as well look at it like that ..."

(Maja, co-researcher, meeting 16)

This co-researcher resented having to ask her colleagues for permission to schedule a conversation with a patient. Validity was highlighted as a term to establish a mandate in a biomedical context just as the argument of conversation forming a natural part of the clinical pathway in line with other activities. This indicates that the general attitude towards the content of rehabilitation relate to the physical training of function and skills. It was further elaborated on in the next quote where the nurse describes the efforts needed to implement this approach in rehabilitation:

"You are also thinking, well (...) it is part of the rehabilitation process here at VCR, it is part of the package, (...), why is it then that we have to put in so much effort to try to (...) get it changed instead of just being able to say to the patient: today (...) you and I are having a conversation ..."

(Hanne, co-researcher, meeting 16)

The co-researcher experienced how the schedules of interprofessional colleagues put pressure on the time nurses had with their patients. The fact that some elements of rehabilitation were ranked above others was clear. To change this situation and to widen the group of people who had the mandate to plan the patient's time demanded an overall structural change. However, even though interprofessional colleagues and managers expressed their support, the structures, planning and conduction of rehabilitation remained unchanged. To conclude, the co-researchers wanted to change nursing practice. However, they did not have the mandate to accomplish that on their own.

Discussion

Acknowledging how pivotal the patient's perspective was to successful rehabilitation, the nurses were eager to change nursing practice. However, the findings of this study show that even after the test and evaluation of customised nursing initiatives, it was still difficult to involve the patient's perspective and the nurses sought alternative solutions to have the time to elicit the patient's perspective. Furthermore, the group of co-researchers stressed the necessity to change the structures around rehabilitation and particularly the culture of the ward. However, none of these strategies were easy to implement. It was obvious that rehabilitation was structured around training with physiotherapists (PT) and occupational therapists (OT). This was illustrated in the organisation of morning care where the primary focus was on getting ready for training. Consequently, the nurse provided care separated from the patient's rehabilitation. Just as indicated by Christiansen and Feiring [42], activities which potentially contained important aspects of rehabilitation towards autonomy and increased self-care were rushed through when time was short and patients were in danger of missing out on the "real" training. Hence, the nurse took over on morning routines instead of actively involving the patient. This conflicted with the important integrative function of rehabilitation nursing as described by Kirkevold [43] where new skills learnt during PT and OT sessions

were transferred into everyday skills [43]. As a result, the nurses experienced how their contribution to patients' rehabilitation appeared less important and how training had a disproportionate dominant position in the process of rehabilitation. This was also described in a recent Danish study on stroke rehabilitation, where Loft et al. [44] found a discrepancy between how the patient and the health professionals regarded rehabilitation. Here, the patient's view on rehabilitation was equal to training [44]. Furthermore, Loft et al. [44] state that the quality of nursing was compromised due to lack of time. This was related to the organisation of the ward where nurses and patients had to finish morning routines to be on time for training with the PT [44]. Similarly, the study conducted by Christiansen and Feiring [42] at three different stroke and brain injury rehabilitation centres in Norway found that patients had difficulties understanding how morning care was more than merely something to get over and done with.

In the present study, a co-researcher expressed her frustration at a workshop, where she emphasised how nursing care was just as valid as other elements of rehabilitation. Nevertheless, the nurses experienced a lack of impact to change the understanding and structures of rehabilitation. Consequently, the nurses resigned themselves to fit in with the current organisation. The lack of impact may derive from an unclear understanding of the nurses' contribution to rehabilitation from nurses, colleagues and patients. This is supported by numerous other studies where nurses struggle for a clear role, function and position in the interprofessional team [26,42–46]. Even though many of the studies explore different elements of the nurses' role, such as coaching, collaborating, consulting and educating, providing emotional support and managing bodily functions, they do not provide answers as to how to prioritise in a busy rehabilitation ward.

Therefore, the difficulties providing space for the patient's perspective were not just a result of an inexpedient organisation. With an unclear role, the restraints also came from

within the nursing profession. The culture and underlying understanding that nobody was “done” with the day’s tasks (making the patient ready for training, preparing rounds, coordinating with the local authority, dispensing medicine, etc.) before all nurses had finished their tasks was a hindrance. Often this left no time with the patients without practical tasks as a justification. Hence, the nurses did not stand united behind the idea of prioritising time to learn the patient’s perspective and the impact was impaired.

This is similar to the findings of Kitson and Athlin [20], who describe how task-oriented nursing is dominating nursing today, whereas building a relationship and encouraging patient participation are often omitted [20].

Hence, we found that pressure from task-oriented nursing restrained time for establishing a relationship and listening to the patient’s perspective and thereby the true function of rehabilitation nursing.

The nurses in this study call for a change in structures and culture to make a shared platform for the patient’s perspective. According to Jangland and Gunningberg [9], a possible solution to make changes and adapt to a new practice is the involvement of dedicated nurse managers. Furthermore, Joseph-Williams et al. [24] suggest development of ownership for the staff involved. However, the nursing staff was involved in our study, the involved nurses *did* believe they should pay more attention to the patient’s perspective and the nurse management explicitly expressed an interest in providing space for nursing rehabilitation to involve the patient’s perspective and participation. Even so, there was no shift in the overall rehabilitation organisation to provide space for nurses to provide care which takes account of the individual patient’s perspective.

Even though Chen et al. [47] argue that nurses can change SCI rehabilitation nursing using action research, we encountered difficulties changing nursing rehabilitation. However, the co-

researchers did change their own views on the patient's perspective and participation in nursing and to some extent their nursing care.

By testing new initiatives, developed and adjusted to the setting and context, we discovered a wide gap between the wish to take the patient's perspective into account and actually being able to do so. We also found that the overall organisation and structures must change for nursing to take the necessary position to support the patient towards a meaningful life.

Limitations

Further research is needed on how to provide space and mandate for nurses to provide care within a rehabilitation setting on the same terms as the rest of the interprofessional team. Moreover, it would be valuable to learn more about the nursing profession's self-image and tendency to keep in line with the expectations of other professions. Though the patient's perspective is at the centre of this study, it would be valuable to engage the patients with SCI to an even greater extent.

Conclusion

Even though embedding the patient's perspective in rehabilitation is essential and a cornerstone in nursing, nurses felt incapable of finding time or strength to do so in the current structures and conditions. Nurses felt untrained and found it difficult to achieve the calmness and presence that was necessary to elicit the patient's perspective and participation.

Moreover, constant interruptions had to be endured and it was difficult to set aside or hand over other tasks to colleagues and pay full attention to the patient. Therefore, nurses sought alternative solutions to have the time to elicit the patient's perspective and support their participation. Taking the patient's perspective into account requires a change in practice, which in turn demands the right conditions and an organisation structure where nursing and

conversations with patients are viewed as equally important to other elements of the patient's rehabilitation.

References

1. Castro EM, Van Regenmortel T, Vanhaecht K, Sermeus W, Van Hecke A. Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient Education and Counseling*. 2016; 99(12):1923–39.
2. Faelles ansvar for sundhed. Sundhedsplan for Region Midtjylland 2013. [Shared responsibility for health. Health Plan for Central Region Denmark 2013] [Internet]. Region Midtjylland [Central Region Denmark]; 2013. [Citet 2019 Aug 28]. Available from: www.regionmidtjylland.dk. Danish.
3. Videnscenter for brugerinddragelse i sundhedsvæsenet [Knowledge Center for User Involvement]. [Internet] [Citet 2019 Aug 28]. Available from: <http://www.vibis.dk/>. Danish.
4. Exploring patient participation in reducing health-care-related safety risks. WHO Regional Office for Europe. Copenhagen; 2013.
5. Stacey D, Légaré F, Lewis K, Barry MJ, Bennett CL, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2017 Apr;12 (4)
6. Weingart SN, Zhu J, Chiappetta L, Stuver SO, Schneider EC, Epstein AM, et al. Hospitalized patients' participation and its impact on quality of care and patient safety. *Int J Qual Heal Care*. 2011 Jun 1;23(3):269–77.
7. Coulter A, Ellins J. Patient-focused interventions A review of the evidence. Picker Institute Europe. The Health Foundation. 2006 August
8. Angel S, Frederiksen KN. Challenges in achieving patient participation: A review of how patient participation is addressed in empirical studies. *Int J Nurs Stud*. 2015 Sep;52(9):1525–38.

9. Jangland E, Gunningberg L. Improving patient participation in a challenging context: a 2-year evaluation study of an implementation project. *J Nurs Manag.* 2017 May;25(4):266–75.
10. Lindberg J, Kreuter M, Taft C, Person L-O. Patient participation in care and rehabilitation from the perspective of patients with spinal cord injury. *Spinal Cord.* 2013 Nov 3;51(11):834–7.
11. Angel S, Kirkevold M, Pedersen BD. Rehabilitation after spinal cord injury and the influence of the professional's support (or lack thereof). *J Clin Nurs.* 2011 Jul;20(11–12):1713–22.
12. Scheel-Sailer A, Post MW, Michel F, Weidmann-Hügler T, Baumann Hölzle R. Patients' views on their decision making during inpatient rehabilitation after newly acquired spinal cord injury-A qualitative interview-based study. *Health Expect.* 2017 Oct;20(5):1133–42.
13. Bailey J, Dijkers MP, Gassaway J, Thomas J, Lingefelt P, Kreider SED, et al. Relationship of nursing education and care management inpatient rehabilitation interventions and patient characteristics to outcomes following spinal cord injury: the SCIR rehab project. *J Spinal Cord Med.* 2012 Nov 19;35(6):593–610.
14. Van de Velde D, Bracke P, Van Hove G, Josephsson S, Devisch I, Vanderstraeten G. The illusion and the paradox of being autonomous, experiences from persons with spinal cord injury in their transition period from hospital to home. *Disabil Rehabil.* 2012 Mar 6;34(6):491–502.
15. Henderson V. *The Nature of Nursing: A Definition and Its Implications for Practice, Research, and Education.* New York: National League for Nursing Press; 1966
16. Martinsen K. *Care and vulnerability.* Oslo: Akribes; 2006. 185 p.
17. Loft MI, Martinsen B, Esbensen BA, Mathiesen LL, Iversen HK, Poulsen I. Call for human contact and support: an interview study exploring patients' experiences with inpatient stroke rehabilitation and their perception of nurses' and nurse assistants' roles and functions. *Disabil Rehabil.* 2019 Feb 13 ;41(4):396–404.
18. Angel S. Patient participation during rehabilitation after spinal cord injury. *Tidsskr*

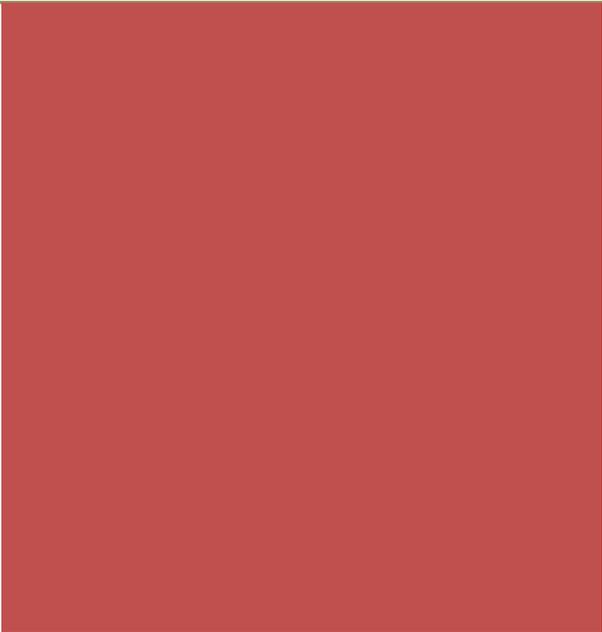
sygeplejeforskning. 2010;1:20–25.

19. Kitson A, Marshall A, Bassett K, Zeitz K. What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *J Adv Nurs*. 2013 Jan 1;69(1):4–15.
20. Kitson AL, Athlin M. Anything but Basic: Nursing's Challenge in Meeting Patients' Fundamental Care Needs. *J Nurs Scholarsh*. 2014;46:331–339.
21. McCormack B, Dulmen AM van, Eide H, Skovdahl K, Eide T. *Person-centred healthcare research*. Hoboken: Wiley-Blackwell; 2017. 226 p.
22. Légaré F, Adekpedjou R, Stacey D, Turcotte S, Kryworuchko J, Graham ID, et al. Interventions for increasing the use of shared decision making by healthcare professionals. *Cochrane Database Syst Rev*. 2018 Jul 19;7.
23. Elwyn G, Frosch DL, Kobrin S. Implementing shared decision-making: consider all the consequences. *Implement Sci*. 2015 Dec 8;11(1):114.
24. Joseph-Williams N, Lloyd A, Edwards A, Stobbart L, Tomson D, Macphail S, et al. Implementing shared decision making in the NHS: lessons from the MAGIC programme. *BMJ*. 2017 Apr 18 ;357:1744.
25. Melin J, Persson L-O, Taft C, Kreuter M. Patient participation from the perspective of staff members working in spinal cord injury rehabilitation. *Spinal Cord*. 2018 Jun 24;56(6):614–20.
26. Pellatt CG. Perceptions of the nursing role in spinal cord injury rehabilitation. *Br J Nurs*. 2003 Mar;12(5):292–9.
27. Reason P, Bradbury H. Introduction. In: Reason P, Bradbury H, editors. *The SAGE handbook of action research*. 2th ed. London: Sage Publication; 2008.
28. Hummelvoll JK, Eriksson BG, Cutcliffe JR. Local experience – central knowledge? - Methodological and practical implications for knowledge development in local mental health care settings. *Nord sygeplejeforskning*. 2015 Oct 15;5(03):283–95.
29. Greenwood D, Levin M. *Introduction to Action Research Social Research for Social Change*. 2th ed. California: SAGE Publication Inc; 2007.

30. Dewey J. *Democracy and Education*. New York: Sheba Blake Publishing; 2015.
31. Otto Scharmer C. *Theory U: Leading from the Future as It Emerges*. Cambridge, Massachusetts: echnology of Presencing. Society for Organizational Learning; 2007. 533 p.
32. Dewey J. *How We Think*. New York: Dover Publications Inc.; 1998
33. Nielsen KA, Svensson LG, editors. *Action Research and Interactive Research: Beyond Practice and Theory*. Maastricht: Shaker Publishing; 2006.
34. Coghlan D, Brannick T. *Doing Action Research in Your Own Organization*. 3rd ed. London: SAGE Publication; 2010.
35. Lewin K. Action Research and minority problems. *J Soc Issues*. 1946;2(4):34–46.
36. Bargal D. Personal and intellectual influences leading to Lewin’s paradigm of action research. *Action Res*. 2006 Dec 24;4(4):367–88.
37. Ricoeur P. The Hermeneutical Function of Distanciation. *Philos Today*. 1973 ;17(2):129–41.
38. Ricoeur P. *Interpretation theory: discourse and the surplus of meaning*. Texas: Christian University Press; 1976. 107 p.
39. Ricoeur P. The hermeneutical function of distanciation. *Philos Today*. 2002;129–41.
40. Declaration of Helsinki – Ethical principles for medical research involving human subjects [Internet]. World Medical Association. [cited 2019 Sep 1]. Available from: <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>
41. Ethiske retningslinier for sygeplejeforskning i Norden [Ethical guidelines for nursing research in the Nordic countries] Sygeplejerskers Samarbejde i Norden [Nurses Collaboration in the Nordic Countries]; 2003. Danish.
42. Christiansen B, Feiring M. Challenges in the nurse’s role in rehabilitation contexts. *J Clin Nurs*. 2017 Oct;26(19–20):3239–47.
43. Kirkevold M. *The Role of Nursing in Rehabilitation of Stroke Survivors an Extended*

Theoretical Account. *Adv Nurs Sci*. 2010;33(1):27–40.

44. Loft MI, Poulsen I, Esbensen BA, Iversen HK, Mathiesen LL, Martinsen B. Nurses' and nurse assistants' beliefs, attitudes and actions related to role and function in an inpatient stroke rehabilitation unit-A qualitative study. *J Clin Nurs*. 2017 Dec ;26(23–24):4905–14.
45. Pryor B, O'Connell J. Incongruence between nurses' and patients' understandings and expectations of rehabilitation. *J Clin Nurs*. 2009;18(12):1766–74.
46. Portillo MC, Cowley S. Working the way up in neurological rehabilitation: the holistic approach of nursing care. *J Clin Nurs*. 2011 Jun ;20(11–12):1731–43.
47. Chen H-Y, Wu T-J, Cheng M-L, Sung H-H. Evaluation of super-link system theory for spinal cord injury patients using participatory action research in a rehabilitation hospital. *Rehabil Nurs*. 2012 May;37(3):119–27.



**Appendix D:
Declarations of
authorship
paper I,II and III**

Declaration of co-authorship concerning article for PhD dissertations

Full name of the PhD student: Randi Steensgaard

This declaration concerns the following article/manuscript:

Title:	Promoting the patient's participation in rehabilitation by engaging nurses in research
Authors:	Steensgaard Randi, Kolbæk Raymond, Borup Jensen Julie, Angel Sanne

The article/manuscript is: Published Accepted Submitted Ready for submission

If published, state full reference:

If accepted or submitted, state journal: Nursing Inquiry

Has the article/manuscript previously been used in other PhD or doctoral dissertations?

No Yes If yes, give details:

Your contribution

Please rate (A-F) your contribution to the elements of this article/manuscript, **and** elaborate on your rating in the free text section below.

- A. Has essentially done all the work (>90%)
- B. Has done most of the work (67-90 %)
- C. Has contributed considerably (34-66 %)
- D. Has contributed (10-33 %)
- E. No or little contribution (<10%)
- F. N/A

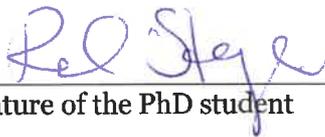
Category of contribution	Extent (A-F)
The conception or design of the work:	B
<i>Free text description of PhD students contribution (mandatory)</i> The first draft of the design of the manuscript, revising on commentary and guidance from the co-authors.	
The acquisition, analysis, or interpretation of data:	B
<i>Free text description of PhD students contribution (mandatory)</i> Conducting the analysis of the data under supervision.	
Drafting the manuscript:	B
<i>Free text description of PhD students contribution (mandatory)</i> First draft of the manuscript and revising on commentary and guidance from the co-authors.	
Submission process including revisions:	B

Free text description of PhD students contribution (mandatory)
Finalization and submission of the manuscript

Signatures of first- and last author, and main supervisor

Date	Name	Signature
05/02 2020	Randi Steensgaard	Randi Steensgaard
05/02 2020	Sanne Angel	Sanne Angel
5/2/20	Sanne Angel	Sanne Angel

Date: 5/2-20



Signature of the PhD student

Declaration of co-authorship concerning article for PhD dissertations

Full name of the PhD student: Randi Steensgaard

This declaration concerns the following article/manuscript:

Title:	Promoting patient participation – Nurses as participants in the patient's rehabilitation
Authors:	Randi Steensgaard, Raymond Kolbæk, Sanne Angel

The article/manuscript is: Published Accepted Submitted Ready for submission

If published, state full reference:

If accepted or submitted, state journal: Journal of Clinical Nursing

Has the article/manuscript previously been used in other PhD or doctoral dissertations?

No Yes If yes, give details:

Your contribution

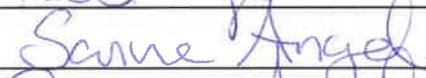
Please rate (A-F) your contribution to the elements of this article/manuscript, **and** elaborate on your rating in the free text section below.

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- C. Has contributed considerably (34-66 %)
- D. Has contributed (10-33 %)
- E. No or little contribution (<10%)
- F. N/A

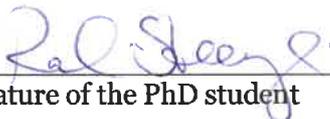
Category of contribution	Extent (A-F)
The conception or design of the work:	B
<i>Free text description of PhD students contribution (mandatory)</i> The first draft of the design of the manuscript, revising on commentary and guidance from the co-authors.	
The acquisition, analysis, or interpretation of data:	B
<i>Free text description of PhD students contribution (mandatory)</i> Conducting the analysis of the data under supervision.	
Drafting the manuscript:	B
<i>Free text description of PhD students contribution (mandatory)</i> First draft of the manuscript and revising on commentary and guidance from the co-authors.	
Submission process including revisions:	B

*Free text description of PhD students contribution (mandatory)
Finalization and submission of the manuscript*

Signatures of first- and last author, and main supervisor

Date	Name	Signature
20/1/20	Randi Steensgaard	
5.2.20	Sanne Angel	
5.2.20	Sanne Angel	

Date: 5/2-20



Signature of the PhD student

Declaration of co-authorship concerning article for PhD dissertations

Full name of the PhD student: Randi Steensgaard

This declaration concerns the following article/manuscript:

Title:	Nurses struggle for patient participation in rehabilitation -A path littered with obstacles
Authors:	Randi Steensgaard, Raymond Kolbæk, Helge Kasch, Sanne Angel

The article/manuscript is: Published Accepted Submitted Ready for submission

If published, state full reference:

If accepted or submitted, state journal: Disability and Rehabilitation

Has the article/manuscript previously been used in other PhD or doctoral dissertations?

No Yes If yes, give details:

Your contribution

Please rate (A-F) your contribution to the elements of this article/manuscript, **and** elaborate on your rating in the free text section below.

- A. Has essentially done all the work (>90%)
- B. Has done most of the work (67-90 %)
- C. Has contributed considerably (34-66 %)
- D. Has contributed (10-33 %)
- E. No or little contribution (<10%)
- F. N/A

Category of contribution	Extent (A-F)
The conception or design of the work:	B
<i>Free text description of PhD students contribution (mandatory)</i> The first draft of the design of the manuscript, revising on commentary and guidance from the co-authors.	
The acquisition, analysis, or interpretation of data:	B
<i>Free text description of PhD students contribution (mandatory)</i> Conducting the analysis of the data under supervision.	
Drafting the manuscript:	B
<i>Free text description of PhD students contribution (mandatory)</i> First draft of the manuscript and revising on commentary and guidance from the co-authors.	
Submission process including revisions:	B



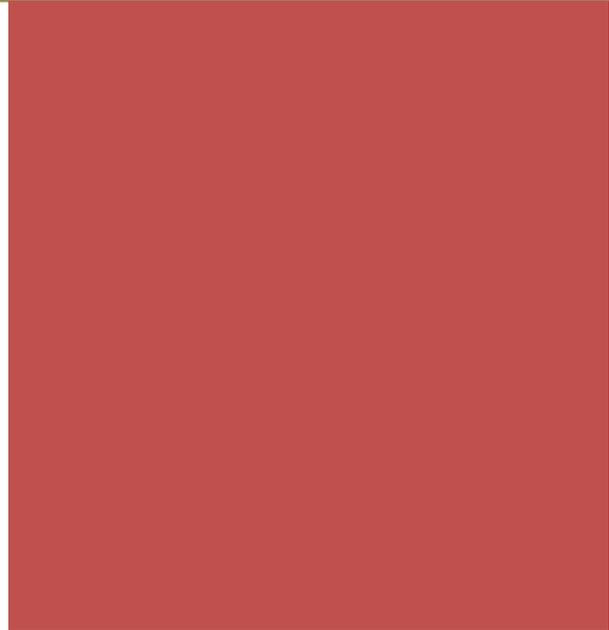
Free text description of PhD students contribution (mandatory)
Finalization and submission of the manuscript

Signatures of first- and last author, and main supervisor

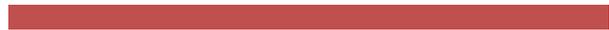
Date	Name	Signature
05/02 2020	Randi Steensgaard	Randi Steensgaard
05/02 2020	Sanne Angel	Sanne Angel
5/2 20	Sanne Angel	Sanne Angel

Date: 5/2-20

Randi Steensgaard
Signature of the PhD student



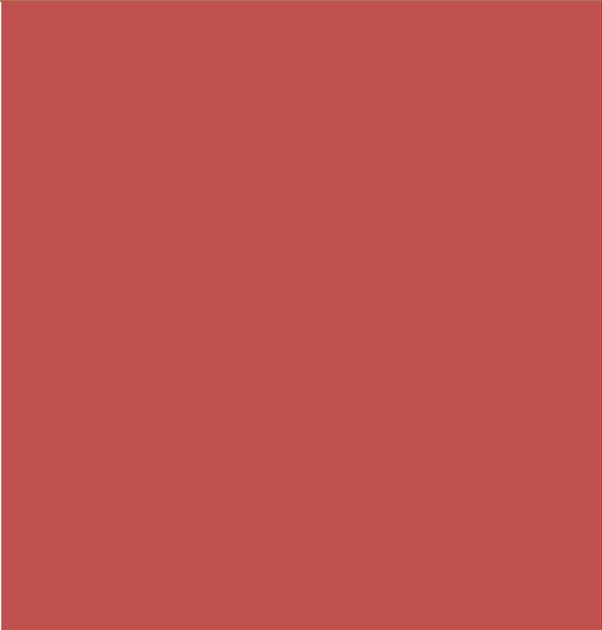
Appendix E: Prototype 1



Prototype – My wishes and needs	
Purpose	<p>Aim:</p> <p>To obtain knowledge about</p> <ul style="list-style-type: none"> ▪ the patient’s wishes and needs for the admission and for the future ▪ the patient’s preferences and experiences in life <p>To prepare patient for the first interdisciplinary clinical pathway meeting</p> <p>To plan rehabilitation so the patient can participate according to their wishes and needs</p>
Participants	Co-researchers and the patients they are primary contact persons for when they receive new, newly injured patients at the centre.
When	<ul style="list-style-type: none"> ▪ Time for prototype testing: 16 June – 22 September 2016 ▪ Within the first two weeks of admission
Where	<ul style="list-style-type: none"> ▪ Location of the prototype testing: Spinal Cord Injury Centre of Western Denmark
Task	<p>Co-researchers’ tasks:</p> <ul style="list-style-type: none"> ▪ Conduct a conversation with newly admitted patients within the first two weeks ▪ Use the guide “Powerful questions” ▪ Plan the conversation with the patient and document the time in the electronic patient journal ‘MidtEPJ’ in ‘nurse-patient conversation’. Create a new SFI and rename it ‘my wishes and needs conversation’ and in ‘Clinical Logistic’ under the tab ‘something else the nurses need’(Andet sygeplejen skal bruge’) and rename it ‘Prototype one’ ▪ After the conversation, document the new knowledge where it is relevant in the electronic patient journal (e.g. bowel, bladder, ADL) <p>PhD student’s task:</p> <ul style="list-style-type: none"> ▪ Inform and discuss the prototype and its implications to clinical practice with nursing managers.
Evaluation	<p>The PhD student will develop and email an evaluation form for the prototype when the prototype testing has been initiated.</p> <p>The evaluation contains</p> <ul style="list-style-type: none"> ▪ <i>Form:</i> duration and opportunity for conduction ▪ <i>Content:</i> what did you talk about? ▪ <i>What happened at the conversation:</i> What happened? How did it go? How does the patient feel now? How did the “Powerful questions” work? ▪ <i>Effect:</i> Did the conversation support coherence in the patient’s life? Did it support the planning of nursing? Did it increase the patient’s own participation in rehabilitation (directly or indirectly?)
Adjustment and implementation (if not rejected)	The evaluation of the prototype is discussed with the co-researchers. The PhD student presents the results to the management, who will decide how the results should affect clinical practice at the centre.

Guide to prototype – my wishes and needs	
Framework	<p>Inform about:</p> <ul style="list-style-type: none"> ▪ How much time you have ▪ The aim of the conversation
Helping questions	<p>(Knowledge we would like to obtain: Type of life; Philosophy of life; Roles; Preferences; Interests; Functions; Routines; Relations – persons with surplus to help; Ways of learning; Course of illness up till now; How the patient feels; Wishes for the future; Current concerns and worries)</p> <p>Use and choose the most appropriate questions – adjust to the patient and his situation:</p> <ul style="list-style-type: none"> ▪ Tell me a little about your everyday life before the injury ▪ Your family, job, spare time interests ▪ How did you and your family plan the day? What were your activities and tasks? ▪ How have you experienced the course of your illness up till now? ▪ Is there anything from the course of your illness that has affected you more than anything else? By this I mean: have there been any good experiences you wish for us to pass on to your stay here? Or have you had any bad experiences that you wish to avoid from happening again? ▪ Do you have any support to handle your situation currently? ▪ Who do you think you can get support from if you need more support to handle your situation? Friend, spouse, siblings? ▪ Do you experience that your relatives have the resources or surplus energy to support you to the extent that you need? ▪ Are you good at asking for help when something is difficult? ▪ How does the spinal cord injury affect you and your life currently? ▪ What limits do you experience as a consequence of the spinal cord injury? ▪ How do you think the spinal cord injury will affect your life in the time to come? ▪ What do you feel is the biggest challenge or problem currently? ▪ How does the spinal cord injury affect you as a person? ▪ Does the spinal cord injury affect the way you regard yourself? How does it affect the way you see yourself (in relation to what you appreciate, your interests, physically, body image)? ▪ Rehabilitation aims at getting you as self-sufficient as possible. To begin with we will help you a lot. Later you will learn to do things for yourself. ▪ What can we do for you to have a good day? (e.g. “lark” or “night owl”, special needs?) ▪ How and in what way do you think you learn new skills best (speed, practical, theoretical, visual)?

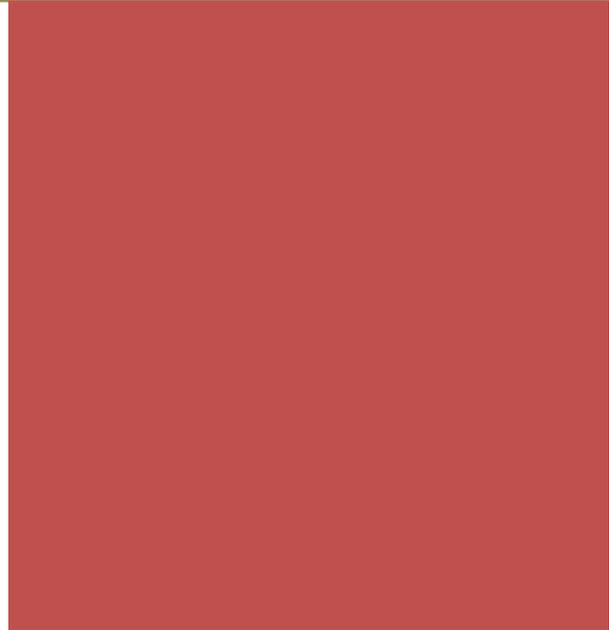
Ending the conversation	<ul style="list-style-type: none">▪ I have to round off this conversation▪ Are there any of the issues we have touched on that you would like me to follow up on?
Evaluation	<p>To remember the conversation, it is recommended that you write down half a page about what you talked about, what happened and what you noticed and what made an impression.</p> <ul style="list-style-type: none">▪ Reflect on how you experienced the conversation:<ul style="list-style-type: none">○ Was something difficult?○ What worked well?○ What do you need to follow up on?



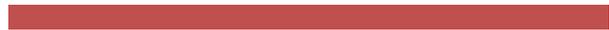
**Appendix F:
Prototype 2**

Prototype – My thoughts about my situation	
Purpose	<p>Aim</p> <ul style="list-style-type: none"> ▪ To support the patient’s understanding of the situation and of himself through a narrative about what has happened and how this affects his current situation ▪ To support the patient in creating coherence between past, present and wishes for the future
Participants	Co-researchers together with the patient for whom they are the primary care provider.
When	<ul style="list-style-type: none"> ▪ Time for prototype testing: 26 October – 11 November 2016 ▪ Approximately one month after prototype one
Where	<ul style="list-style-type: none"> ▪ Location of the prototype testing: Spinal Cord Injury Centre of Western Denmark
Task	<p>Co-researchers’ tasks:</p> <ul style="list-style-type: none"> ▪ Conduct the conversation, using a narrative approach: <ul style="list-style-type: none"> ○ follow the patient’s story ○ the aim is not to gain knowledge but to support self-understanding ○ no leading or value-laden questions ○ open questions ○ be curious – leave the patient to unfold and elaborate on his utterance even though you might have an idea about what it is/what he means ○ avoid making own conclusions (e.g. if the patient says: ‘you know how it is/you know what I mean’ – ask probing questions ▪ Prepare for the prototype-testing: <ul style="list-style-type: none"> ○ Document the conversation in the electronic patient journal MidtEPJ in ‘nurse-patient conversation’. Create a new SFI and clearly, state that it is the test of prototype two ○ If it is not possible to conduct the test of the prototype, describe why ○ Document and plan the time in ‘Clinical Logistic’ under ‘Something else the nurses need’ (”Andet sygeplejen skal bruge”) and change the name to ‘Prototype 2’ <p>PhD student’s task: Inform and discuss the prototype and its implications for clinical practice with nursing managers.</p>
Evaluation	<p>The PhD student will develop and email an evaluation form for the prototype when the prototype testing has been initiated.</p> <p>The evaluation contains:</p>

	<ul style="list-style-type: none"> ▪ <i>Form</i>: Duration and opportunity for conduction ▪ <i>Content</i>: What did you talk about? ▪ <i>What happened at the conversation</i>: What happened? How did it go? How does the patient feel now? ▪ <i>Effect</i>: Did the conversation support coherence in the patient's life? Did it support the planning of nursing? Did it increase the patient's own participation in rehabilitation (directly or indirectly?)
Adjustment and implementation (if not rejected)	The evaluation of the prototype is discussed with the co-researchers. The PhD student presents the results to the management, who will decide how the results should affect clinical practice at the centre.
Guide to prototype	
Framework	<p>Inform about:</p> <ul style="list-style-type: none"> ▪ How much time you have ▪ The aim of the conversation <p>Suggestions (choose the most appropriate):</p> <ul style="list-style-type: none"> ○ I would like to know what you think about your current situation ○ I would like to know what happened to you since your injury. ○ I would like to know something about how you are doing. ○ I would like to follow up on (a subject from the conversation in prototype one).
Helping questions	<ul style="list-style-type: none"> ▪ What concerns do you have? ▪ What are you thinking about? ▪ How are you? ▪ Is everything going as you hoped?
Supportive comments	<ul style="list-style-type: none"> ▪ When you say that, what is it you think about and try to express? ▪ Please tell me more about that.
Ending the conversation	<ul style="list-style-type: none"> ▪ It is about time to wrap up. Do you have anything further?
Evaluation	<p>To remember the conversation, it is recommended that you write down half a page about what you talked about, what happened and what you noticed and what made an impression.</p> <p>Reflect on how you experienced the conversation. Was something difficult, what worked well and what do you need to follow up on?</p>

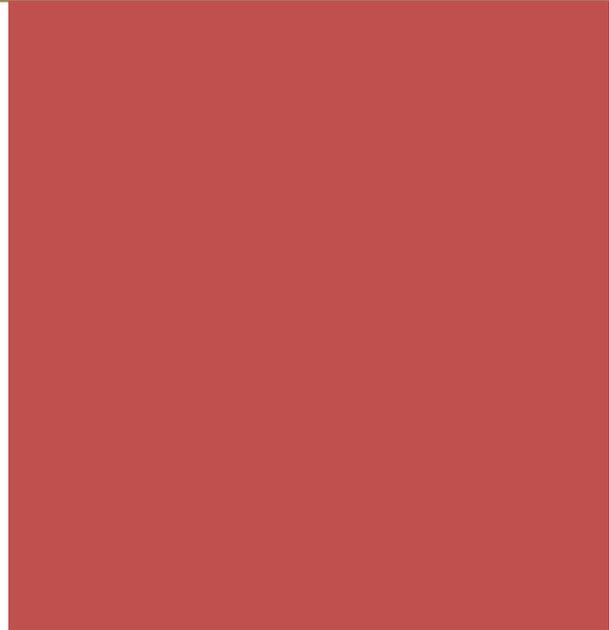


**Appendix G:
Prototype 3**

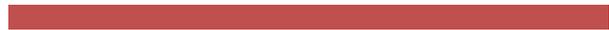


Prototype – My plan for the day	
Purpose	<ul style="list-style-type: none"> ▪ To plan a clinical pathway of which the starting point is the patient’s needs, preferences and wishes for daily life at the rehabilitation centre. ▪ To align expectations to the clinical pathway and the different roles of patient and various staff. ▪ To strive towards continuity, structure and create an overview of activities of the day and the clinical pathway. ▪ To make sure the patient can be as active as possible and participate in line with his resources and energy.
Participants	Co-researchers together with the patient for whom they are the primary care provider.
When	<ul style="list-style-type: none"> ▪ Test: 8 March – 3 April 2016 ▪ Held no later than one week after admission (preferably within 24 hours after admission) and continually throughout the admission every time there are changes in the patient’s wishes, needs and self-sufficiency
Where	<ul style="list-style-type: none"> ▪ Location of the prototype testing: Spinal Cord Injury Centre of Western Denmark
Task	<p>Co-researchers’ tasks:</p> <ul style="list-style-type: none"> ▪ Up to 30 minutes conversation with primary nurse or nursing assistant in a private room with no interruptions. ▪ Develop a plan for the dag together with the patient – agree on content of a 24-hour plan ▪ Follow up on the plan for the day and adjust the plan to the patient’s needs, wishes and preferences ▪ Inform inter-professional colleagues on the agreements and plans. Everybody can adjust the plan together with the patient once it has been developed ▪ Plan the conversation with the patient and document the time in the electronic patient journal ‘MidtEPJ’ in ‘nurse-patient conversation’. Create a new SFI and rename it ‘my plan for the day’ and in ‘Clinical Logistic’ under the tab ‘something else the nurses need’ (Andet sygeplejen skal bruge’) and rename it ‘Prototype three’ ▪ Document in a shared day and night care plan using the letters H,P,U to indicate how the nurse or team-member should assist the patient H: Help P: practice U: unassisted <ul style="list-style-type: none"> ○ In the comments field of the electronic patient journal, list important factors such as philosophy, way of life, normal pattern of everyday, physical and psychological factors, job and hobbies related to the planning of the rehabilitation on a daily and long

	<p>term plan, elements from the conversation which are relevant for rehabilitation and the inter-disciplinary status and effort.</p> <ul style="list-style-type: none"> ▪ Print the plan and hand it to the patient. ▪ Bring the plan for the day to the goal-setting meetings (team and patient): Adjust the plan according to the goals and hand out the agreed plan to the patient. <p>Clinical pathway coordinators: Make sure the plan for the day is started, preferable within the first 24 hours after admission when the co-researchers are not present.</p> <p>PhD student’s task:</p> <ul style="list-style-type: none"> ▪ Inform the clinical pathway coordinators about their tasks ▪ Inform and discuss the prototype and its implications for clinical practice with nursing managers ▪ Develop a flexible template for the plan for the day in the electronic patient journal
Evaluation	<p>The PhD student will develop and email an evaluation form for the prototype when the prototype testing has been initiated.</p> <p>The evaluation contains</p> <ul style="list-style-type: none"> ▪ <i>Form:</i> duration and opportunity for conduction ▪ <i>Content:</i> what did you talk about? ▪ <i>What happened at the conversation:</i> What happened? How did it go? How does the patient feel now? ▪ <i>Effect:</i> Did the conversation support coherence in the patient’s life? Did it support the planning of nursing? Did it increase the patient’s own participation in rehabilitation (directly or indirectly?)
Adjustment and implementation (if not rejected)	<p>The evaluation of the prototype is discussed with the co-researchers. The PhD student presents the results to the management, who will decide how the results should affect clinical practice at the centre.</p>
Guide to prototype – My plan for the day	
Guide to prototype	<p>Suggestions for items on the plan for the day:</p> <ul style="list-style-type: none"> ▪ Time for: eating, resting, mobilisation, bladder-emptying, personal hygiene, positioning, activities of daily living (ADL), training, etc. ▪ Comments box in the “activity” in the electronic patient journal: Write briefly relevant factors of the patient’s past and present that influence the approach and plan. This could be: type of life, motivation, life philosophy, psychological, contextual factors, etc. Take your starting point in the knowledge you achieved at the “the patient wishes and demands” conversation.



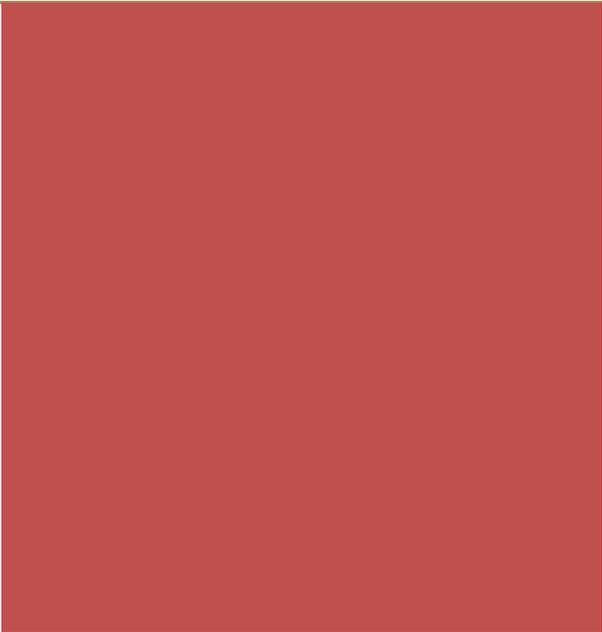
Appendix H: Prototype 4



Prototype – My clinical pathway meetings	
Purpose	<p>The primary nurse conducts a conversation with the patient to</p> <ul style="list-style-type: none"> ▪ Prepare him for active participation in the interdisciplinary conference (mid-term and discharge conference). ▪ Help the patient reflect on and express his actual situation, including physical, psychological, social health status and functional capacity combined with personal and contextual factors. ▪ Support the patient in expressing his thoughts and considerations about the future and relate this to rehabilitation and the co-operation with the team.
Participants	<p>Co-researchers and the patient are primary contact persons. The nursing coordinators will participate by appointment with the primary contact persons, if they cannot attend themselves.</p>
When	<ul style="list-style-type: none"> ▪ Time for prototype testing: 6 November 2017 – 2 February 2018 ▪ One week prior to the second clinical pathway meeting and again one week prior to the clinical pathway meeting – discharge.
Where	<ul style="list-style-type: none"> ▪ Location of the prototype testing: Spinal Cord Injury Centre of Western Denmark
Task	<p>Co-researchers' tasks:</p> <ul style="list-style-type: none"> ▪ Conduct a conversation prior to the conference using the guide leading up to the conference. ▪ Plan the conversation with the patient and document the time in the electronic patient journal 'MidtEPJ' in 'nurse-patient conversation'. Create a new SFI and rename it 'my pathway meeting conversation' and in 'Clinical Logistic' under the tab 'something else the nurses need' (Andet sygeplejen skal bruge') and rename it 'Prototype four' ▪ Document elements from the conversation which are relevant for rehabilitation and the inter-disciplinary status and effort. <p>PhD student's task:</p> <ul style="list-style-type: none"> ▪ Inform and discuss the prototype and its implications for clinical practice with nursing managers.
Evaluation	<p>The PhD student will develop and email an evaluation form for the prototype when the prototype testing has been initiated. The evaluation contains</p> <ul style="list-style-type: none"> ▪ <i>Form</i>: Duration and opportunity for conduction ▪ <i>Content</i>: What did you talk about? ▪ <i>What happened at the conversation</i>: What happened? How did it go? How does the patient feel now? ▪ <i>Effect</i>: Did the conversation support coherence in the patient's life? Did it support the planning of nursing? Did it increase the patient's own participation in rehabilitation (directly or indirectly?)

<p>Adjustment and implementation (if not rejected)</p>	<p>The evaluation of the prototype is discussed with the co-researchers. The PhD student presents the results to the management, who will decide how the results should affect clinical practice at the centre.</p>
<p>Guide to prototype – My clinical pathway meetings</p>	
<p>Framework</p>	<p>Inform about:</p> <ul style="list-style-type: none"> ▪ How much time you have ▪ The aim of the conversation <ul style="list-style-type: none"> ○ Mid-term: The purpose of this conversation is to consider how we can plan the rest of your rehabilitation and how the collaboration with your team can support your pathway ○ Discharge: The purpose of this conversation is to consider together how the rehabilitation may be conducted to support a good discharge
<p>Helping questions</p>	<ul style="list-style-type: none"> ▪ Tell about the conference: ▪ What will happen? ▪ What topics will be addressed? ▪ Ask about the situation: ▪ Are there any topics of particular importance we should address at the conference? ▪ How have you experienced your clinical pathway since we last spoke/up till now? <ul style="list-style-type: none"> ○ Additional question: is there anything which has made a special impression on you? Anything you would like us to be especially aware of? ▪ Do you get support from anyone with handling your situation? <ul style="list-style-type: none"> ○ Do you experience that your relatives have the resources and surplus energy to support you to the extent that you need? ○ Do you have sufficient support from the staff at the rehabilitation centre? ▪ In your assessment, what is your biggest challenge or problem at the moment? Regarding: <ul style="list-style-type: none"> ○ changes in the body (pain, spasticity, wounds, etc.) ○ Thoughts, emotions, worries, feeling of loss ○ Social: Family, work, education, home, week leave ▪ Thoughts about the future: <ul style="list-style-type: none"> ○ How do you think the spinal cord injury will affect your life going forward? ○ What thoughts, hopes and goals do you have about the future? ▪ Before the mid-term conference: <ul style="list-style-type: none"> ○ What wishes and expectations do you have for the rest of your admission? ▪ Before discharge:

	<ul style="list-style-type: none"> ○ What thoughts do you have about the discharge? ○ What thoughts do you have about the future and the everyday life for you and your relatives? ○ What goals, wishes and expectations do you have for the remaining part of your admission? ○ Is there anything about the discharge that makes you uncomfortable? Is there anything we can do to remedy this?
Supportive comments	<ul style="list-style-type: none"> ▪ When you say that, what is it you think about? ▪ Please try and tell me more about that... ▪ That sounds difficult... (avoid saying "I understand that, I know how that feels, etc.")
Ending the conversation	<ul style="list-style-type: none"> ▪ I have to round off this conversation ▪ Are there any of the issues we have touched on that you would like me to follow up on?
Evaluation	<p>To remember the conversation, it is recommended that you write down half a page about what you talked about, what happened and what you noticed and what made an impression.</p> <ul style="list-style-type: none"> ▪ Reflect on how you experienced the conversation: <ul style="list-style-type: none"> ○ Was something difficult? ○ What worked well? ○ What do you need to follow up on?



**Appendix I:
Literature search
strategy**

Literature search strategy

I performed a literature search prior to the study on patient participation, spinal cord injury and rehabilitation in CINAHL (14 results) (Appendix table 3) and PubMed (50 results) (appendix table 2) (within the last 20 years/Nordic languages or English). A total of seven articles were relevant to this study.

I found no studies on spinal cord injury rehabilitation using action research to enhance patient participation. However, I let the methodology of action research guide the way into the area of patient participation in spinal cord injury rehabilitation. Here, questions from practice guided the study rather than theoretical questions (Reason 2006).

This means that it was the findings of the first phase (the problem identification phase) that guided the direction for further exploration and action. Therefore, the following search strategy will illustrate the procedure.

Systematic searches

I was assisted by the medical library to perform the literature search and the search was inspired by PICO (Pico template appendix table 1) (<https://wiki.joannabriggs.org/display/MANUAL/2.6.2+Review+question>).

Appendix table 1. PICO template for the search

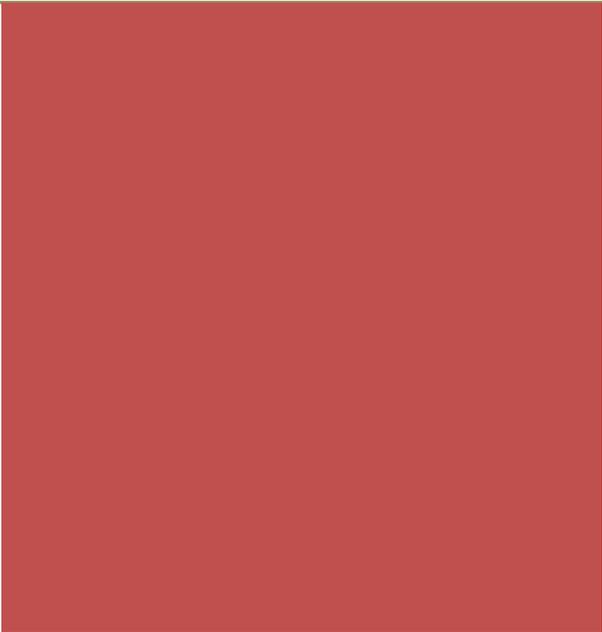
	P opulation	P henomenon of I nterest	C ontext
	AND → AND		
↓ OR ↓	Spinal cord injury	Patient participation	Rehabilitation
	Synonyms and associated words (see Appendix table 2 and 3)	Synonyms and associated words (see Appendix table 2 and 3)	Synonyms and associated words (see Appendix table 2 and 3)

Appendix table 2. Template for the PubMed search

PubMed		Spinal cord injury	Patient participation	Rehabilitation	Complementary words
		AND → AND → AND			
MeSH	↓	Spinal cord injuries paraplegia quadriplegia	Patient participation	Rehabilitation	Quality of life Nursing Care Health literacy Critical pathways Cooperative behaviour Patient care planning
Text Word	OR ↓ OR ↓	spinal cord injur* quadriplegi* spinal cord trauma* locked-in syndrome* tetraplegi* lower extremity paralys* lower limbs paralys* SCI spinal cord transection*	patient participation patient involvement patient engagement patient empowerment consumer participation consumer involvement	Rehabilitation Rehabilitation"[Subheading]	Care planning Nursing care management Recovery Life quality QOL Quality of life Meaningful life Clinical pathways
Limitations		Language limited to: Danish, Swedish, Norwegian, English	Language limited to: Danish, Swedish, Norwegian, English	Language limited to: Danish, Swedish, Norwegian, English	Language limited to: Danish, Swedish, Norwegian, English

Appendix table 3. Template for the CHINAL search

CINAHL		Spinal cord injury	Patient participation	Rehabilitation	Complementary words
		AND → AND → AND			
Subject heading (MH)	↓ OR ↓	Spinal Cord Injuries+" Quadriplegia Paraplegia+	Consumer Participation	Rehabilitation+	Action Research Nursing Care+ Nursing Interventions Nursing Care Plans+ Patient Care Plans+ Caring+ Cooperative Behaviour Quality of Life+
Boolean/Phrase	↓ OR ↓	(spinal cord) N3 (trauma* or laceration* or transection*) lower limb paralys* lower extremity paralys* spinal paraplegia* paraplegia tetraplegi* locked in syndrome quadripleg*	(patient or consumer) N3 (participat* or involvement or empowerment)	Rehabilitation	Action research Meaningful life Quality of life Patient-centered care Person-centered care
Limitations		Language limited to: Danish, Swedish, Norwegian, English	Language limited to: Danish, Swedish, Norwegian, English	Language limited to: Danish, Swedish, Norwegian, English	Language limited to: Danish, Swedish, Norwegian, English



**Appendix J:
Patient
information**

Vestdansk Center for Rygmarvsskade

**Mod et meningsfuldt hverdagsliv
efter en rygmarvsskade -
rehabilitering med afsæt i
patientdeltagelse**



Ph.d. studerende Randi Steensgaard
Vestdansk Center for Rygmarvsskade
Søndersøparken 11
8800 Viborg
Telefon: 23815302
E-mail: randi.steensgaard@midt.rm.dk

Projektet er støttet af
Novo Nordisk Fonden

Information om deltagelse i et forskningsprojekt

Du får denne information, fordi vi gerne vil bede dig om at overveje at deltage i forskningsprojektet, der beskrives herunder.

På Vestdansk Center for Rygmarvsskade er vi meget interesseret i at skabe de bedste vilkår for patientens deltagelse under indlæggelse på centeret. Vi anser det som en vigtig del af rehabiliteringsprocessen og helt afgørende for, at man opnår størst mulig uafhængighed, selvstændighed og kontrol over eget liv både under og efter udskrivelsen.

Vi ved, at energien til og ønske om at deltage aktivt i egen rehabilitering varierer over tid og fra patient til patient.

Derfor må den professionelle indsats løbende tilpasses den enkelte patients ressourcer og behov. At sikre dette er udfordrende og kompleks. Vi mangler viden om deltagelse og værktøjer der kan støtte de sundhedsprofessionelle og patienten i at målrette rehabiliteringen mod det liv, patienten skal leve efter udskrivelsen.

Med dette forskningsprojekt er vi interesserede i at finde ud af hvad der skal til for at støtte patientens deltagelse og hvordan vi gør det rent praktisk. Samtidigt vil projektet skabe ny viden om patientdeltagelse, der kan tilpasses og justeres så den enkeltes værdier, præferencer og ønsker for fremtiden bliver styrende for rehabiliteringen.

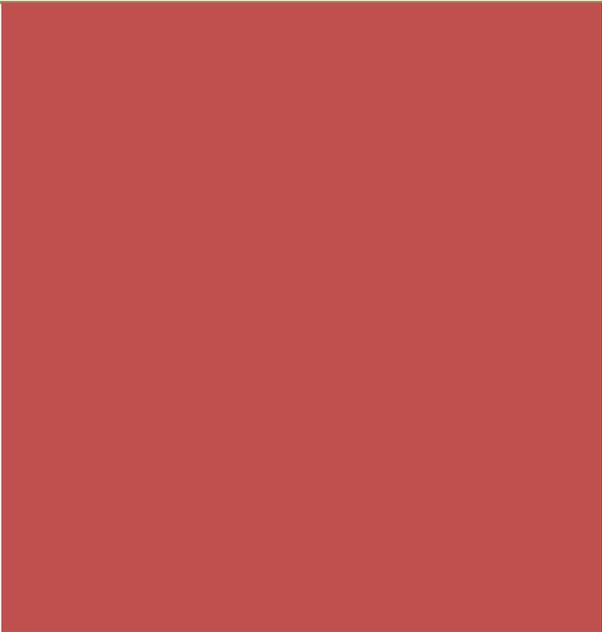
Projektet foregår på VCR i Viborg og gennemføres under vejledning fra Sektion for Sygepleje, Aarhus Universitet og Center for Sygeplejeforskning, Regionshospital Midt. Projektet lægger

op til et tæt samarbejde mellem forsker og afdelingens personale. Derfor inddrages en medforskergruppe bestående af 9 sygeplejersker og social- og sundhedsassistenter. Projektet har fire faser. I den første afdækkes udfordringerne og kompleksiteten ved patientdeltagelse. I fase to beskrives og planlægges nye tiltag. I den tredje fase afprøves de nye tiltag og disse evalueres i fase 4. Medforskergruppen deltager i alle 4 faser der ledes af ph.d. studerende, Randi Steensgaard.

Det er frivilligt at deltage og du kan til enhver tid melde dig ud af projektet. Det får ingen betydning for kvaliteten af den sygepleje du modtager under resten af din indlæggelse.

Har du spørgsmål til projektet og hvad det betyder for dig, hvis du melder dig kan du henvende dig til:

**Randi Steensgaard, ph.d. studerende,
Klinisk Sygeplejespecialist, MHSc(Nurs),
Vestdansk Center for Rygmarvsskade,
Neurologisk afdeling, Hospitalsenhed Midt,
Mobil: 23815302,
Email: Randi.Steensgaard@Midt.RM.dk**



**Appendix K:
Approval Danish
Data Protection
Agency**

Helge Kasch, MD, ph.d., Associate professor,
forskningsansvarlig overlæge
Hospitalsenhed Midt
Vestdansk Center for Rygmarvsskade
Søndersøparken 11,
8800 Viborg

**Vedrørende projektet: Mod et meningsfuldt hverdagsliv -
rehabilitering med afsæt i patientdeltagelse**

Sagsnr.: 1-16-02-503-15

Ovennævnte projekt er anmeldt til Region Midtjyllands
interne fortegnelse over forskningsprojekter med anmodning
om følgende ændringer:

Forventet tidspunkt for projektets afslutning og
oplysningernes sletning, anonymisering eller overførsel til
Rigsarkivet er ændret fra 01-10-2019 til 01-10-2021.

Ændringerne til projektet er hermed registeret på Region
Midtjyllands interne fortegnelse over forskningsprojekter.
Registreringen slettes ved projektets afslutning.

Behandlingen af personoplysningerne blev påbegyndt den
02-11-2015.

Personoplysningerne slettes, anonymiseres eller indsendes
til Rigsarkivet senest ved projektets afslutning den
01-10-2021, eller tidligere hvis det ikke længere er
nødvendigt og relevant at behandle personoplysningerne.

Personoplysningerne vil blive opbevaret eller behandlet på
følgende adresser:

1. HE Midt
Vestdansk Center for Rygmarvsskade
Søndersøparken 11
8800 Viborg

Projektet omfatter ikke en biobank.

Der må alene behandles lovligt indsamlede
personoplysninger. Det forudsættes, at alle øvrige
nødvendige tilladelser er indhentet, herunder eventuelle
skriftlige patientsamtykker.

For behandlingen af journaloplysninger gælder særlige regler.
Vi henviser til Region Midtjyllands retningslinje om "Opslag i
patientjournaler og andre elektroniske patientsystemer,
regional retningslinje", der ligger i eDok.

Eventuelle ændringer af de forhold, der indgår i anmeldelsen,
skal anmeldes til Juridisk kontor, Region Midtjylland via
databasen snarest muligt og inden den anmeldte
afslutningsdato.

Opmærksomheden skal henledes på følgende:

Det følger af databeskyttelseslovens § 10, stk. 1, at personoplysninger som nævnt i databeskyttelsesforordningens artikel 9, stk. 1, og artikel 10 må behandles, hvis dette alene sker med henblik på at udføre statistiske eller videnskabelige undersøgelser af væsentlig samfundsmæssig betydning, og hvis behandlingen er nødvendig af hensyn til udførelsen af undersøgelserne.

Det fremgår desuden af § 10, stk. 2, at de oplysninger, der er omfattet af stk. 1, må ikke senere behandles i andet end videnskabeligt eller statistisk øjemed. Det samme gælder behandling af andre oplysninger, som alene foretages i statistisk eller videnskabeligt øjemed efter databeskyttelsesforordningens artikel 6.

De omhandlede oplysninger nævnt i artikel 9, stk. 1, og artikel 10 omfatter følsomme oplysninger om race eller etnisk oprindelse, politisk, religiøs eller filosofisk overbevisning eller fagforeningsmæssigt tilhørsforhold samt behandling af genetiske data, biometriske data med det formål entydigt at identificere en fysisk person, helbredsoplysninger eller oplysninger om en fysisk persons seksuelle forhold eller seksuelle orientering. Det omfatter endvidere oplysninger om straffedomme og lovovertrædelser.

Videregivelse af personoplysninger må kun ske efter forudgående tilladelse fra Region Midtjylland, Juridisk Kontor.

Det følger endvidere af Databeskyttelseslovens § 10, stk. 3, at videregivelse af oplysninger til tredjemand uden for databeskyttelsesordningens territoriale område, af biologisk materiale eller med henblik på offentliggørelse i et anerkendt videnskabeligt tidsskrift el.lign., kræver tillige forudgående tilladelse fra Datatilsynet.

Opmærksomheden skal endvidere henledes på nedenstående generelle vilkår:

1. Helge Kasch, MD, ph.d., Associate professor, forskningsansvarlig overlæge, Hospitalsenhed Midt, Vestdansk Center for Rygmarvsskade er ansvarlig for overholdelsen af de fastsatte vilkår.
2. Oplysningerne må kun anvendes til brug for projektets gennemførelse.
3. Alle, der deltager i behandling af personoplysninger, skal efterleve vilkårene i dette brev.
4. Databehandlerens behandling af oplysninger skal tilsvarende efterleve vilkårene i dette brev.
5. Lokaler, der benyttes til opbevaring og anden behandling af oplysninger, skal være indrettet således, at uvedkommende ikke kan få adgang.
6. Den projektansvarlige skal i overensstemmelse med Region Midtjyllands retningslinjer og politikker for

informationssikkerhed sikre, at personoplysninger behandles på en måde, der sikrer tilstrækkelig sikkerhed for de pågældende oplysninger, herunder beskyttelse mod uautoriseret eller ulovlig behandling og mod hædeligt tab, tilintetgørelse eller beskadigelse, under anvendelse af passende tekniske eller organisatoriske foranstaltninger.

Den projektansvarlige skal desuden sikre, at der ikke behandles urigtige eller vildledende oplysninger. Oplysninger skal være korrekte og om nødvendigt ajourførte; der skal tages ethvert rimeligt skridt for at sikre, at personoplysninger, der er urigtige i forhold til de formål, hvortil de behandles, straks slettes eller berigtiges.

7. Oplysninger skal opbevares på en sådan måde, at det ikke er muligt at identificere de personer, der behandles oplysninger om, i et længere tidsrum end det, der er nødvendigt til de formål, hvortil de pågældende personoplysninger behandles.
8. Anden lovgivning med krav til behandling af oplysninger i forbindelse med projektet forudsættes overholdt.

Side 3

Behandlingsregler

9. Personoplysninger, der er omfattet af databeskyttelseslovens § 10, må ikke indgå i administrativ eller konkret sagsbehandling. Oplysningerne må heller ikke anvendes som grundlag for konkrete retlige eller faktiske foranstaltninger over for de omhandlede personer eller andre personer. Det er kun resultatet af den videnskabelige eller statistiske bearbejdning af personoplysninger, der kan bruges i administrativ sammenhæng, og kun under forudsætning af, at anvendelsen af resultaterne sker på en sådan måde, at det ikke er muligt at identificere enkeltpersoner. (Databeskyttelseslovens § 10, stk. 2)
10. Oplysningerne skal i videst muligt omfang behandles i en form, hvor de ikke er umiddelbart personhenførbare, f.eks. i krypteret form eller under et løbenummer i stedet for under personnummer. (Databeskyttelsesforordningen artikel 5, stk. 1, litra e.)
11. Formidling af undersøgelsesresultater skal ske på en sådan måde, at det ikke er muligt for udenforstående at identificere enkeltpersoner.
12. Personoplysningerne skal ved en undersøgelses afslutning slettes, anonymiseres eller tilintetgøres, således at det efterfølgende ikke er muligt at identificere enkeltpersoner, der indgår i undersøgelsen. Alternativt kan oplysninger overføres til opbevaring i arkiv efter reglerne i arkivlovgivningen. (Databeskyttelsesforordningens artikel 5, stk. 1, litra e, og databeskyttelseslovens § 14)

Datasikkerhed

13. Den dataansvarlige myndighed skal selv fastsætte uddybende sikkerhedsregler, der beskriver hvordan myndigheden i praksis har implementeret de krævede sikkerhedsforanstaltninger. De uddybende bestemmelser skal som minimum omfatte organisatoriske forhold og fysisk sikring, herunder sikkerhedsorganisation, administration af adgangskontrolordninger og autorisationsordninger samt kontrol med autorisationer. Der skal endvidere fastsættes instrukser, som fastlægger ansvaret for og beskriver behandling og destruktion af ind- og uddatamateriale samt anvendelse af it-udstyr. Desuden skal der fastsættes retningslinjer for myndighedens eget tilsyn med overholdelsen af sikkerhedsforanstaltningerne. De interne bestemmelser skal gennemgås mindst én gang hvert år med henblik på at sikre, at de er fyldestgørende og afspejler de faktiske forhold i myndigheden.
14. Medarbejdere, der håndterer personoplysninger i forbindelse med statistiske og videnskabelige undersøgelser, skal have instruktion og oplæring i, hvad de må gøre med oplysninger, og hvordan de skal beskytte oplysningerne. Myndigheden skal bl.a. gøre medarbejderne bekendt med de regler, der er fastsat i medfør af punkt 1.
15. Adgang til personoplysningerne skal begrænses til personer, der har et sagligt behov for adgang. Det skal være så få personer som muligt. Der bør være tale om medarbejdere, som ikke samtidig beskæftiger sig med almindelig administrativ sagsbehandling vedrørende personer, om hvem der behandles oplysninger i statistisk eller videnskabeligt øjemed. Autorisationer skal angive, i hvilket omfang brugeren må forespørge, inddatere eller slette personoplysninger.
16. Der skal mindst hvert halve år foretages kontrol af, at de autoriserede personer fortsat opfylder betingelserne for at have adgang til oplysningerne.
17. Der skal etableres en teknisk adgangskontrol i it-systemerne, således at autoriserede personer skal identificere sig over for systemet for at få adgang til at foretage behandlinger i overensstemmelse med autorisationen.
18. Det skal registreres, hvis der er forgæves forsøg på at få adgang til it-systemerne. Hvis der registreres et nærmere fastsat antal på hinanden følgende afviste adgangsforsøg, skal der blokeres for yderligere forsøg.
19. Der skal foretages maskinel registrering (logging) af alle anvendelser af personoplysninger. Registreringen skal mindst indeholde oplysning om tidspunkt, bruger, type af anvendelse og angivelse af den person, de

anvendte oplysninger vedrørte, eller det anvendte søgekriterium. Loggen skal opbevares i 6 måneder, hvorefter den skal slettes.

20. Ved brug af eksterne databehandlere til håndtering af personoplysninger skal der foreligge skriftlige databehandleraftaler. Det gælder eksempelvis, når der anvendes en ekstern part til statistisk bearbejdning af oplysningerne.

Databehandleraftalerne skal leve op til Databeskyttelsesforordningens artikel 28. Det skal bl.a. fremgå af en aftale, at databehandlerne udelukkende handler efter instruks fra den dataansvarlige. Hvis den eksterne part også benytter databehandlere ved opgavens løsning, er disse også databehandlere for den dataansvarlige (såkaldte underdatabehandlere), og pålægges samme databeskyttelsesretlige forpligtelser som selve databehandleren. Der skal tillige udfærdiges en databehandleraftale med en underdatabehandler.

Note:

Der vil være tale om en databehandler i de tilfælde, hvor oplysninger overlades til en ekstern part, der skal udføre opgaver på vegne af den dataansvarlige, og hvor databehandleren udelukkende handler på instruks fra den dataansvarlige. Databehandleren får ikke selv ejerskab over oplysningerne og kan ikke selv anvende oplysningerne til egne formål.

Der vil til gengæld være tale om videregivelse til en ny dataansvarlig i de tilfælde, hvor en tredjepart modtager oplysninger fra Region Midtjylland, uden at regionen har mulighed for instruere modtageren i behandlingen af oplysningerne. Ved en videregivelse får modtageren et selvstændigt ejerskab over oplysningerne.

21. Den projektansvarlige varetager indgåelse af eventuel databehandleraftale i overensstemmelse med Region Midtjyllands retningslinjer herfor:

intranet.rm.dk/organisation/informationssikkerhed/databehandleraftaler

Hvis databehandleren er etableret i en anden medlemsstat, skal det desuden af aftalen fremgå, at de yderligere bestemmelser om sikkerhedsforanstaltninger for databehandlere, som eventuelt er fastsat i den pågældende medlemsstat, også er gældende for databehandleren.

22. Den dataansvarlige skal aktivt sikre, at de krævede sikkerhedsforanstaltninger overholdes hos alle databehandlere og eventuelle underdatabehandlere.
23. Hvis behandling af personoplysninger finder sted på it-udstyr uden for den dataansvarlige myndigheds lokaliteter (eller på udstyr, som ikke er en del af myndighedens almindelige system), skal myndigheden

sikre de fornødne sikkerhedsforanstaltninger og fastsætte særlige retningslinjer herom.

24. Der må kun etableres eksterne kommunikationsforbindelser, hvis der træffes særlige foranstaltninger for at sikre, at uvedkommende ikke gennem disse forbindelser kan få adgang til personoplysninger.
25. På steder, hvor der foretages behandling af personoplysninger, skal der træffes forholdsregler med henblik på at forhindre uvedkommendes adgang til oplysningerne. Hvis personoplysningerne lagres på udtagelige og mobile datamedier, f.eks. på USB-nøgler, skal der sikres mod, at uvedkommende kan tilgå oplysningerne på det bærbare datamedie i tilfælde af, at det mistes/stjæles. Alternativt skal bærbare datamedier opbevares forsvarligt aflåst, så uvedkommende er fysisk afskåret fra at tilgå mediet eller fjerne det fra den fysiske lokalitet. Samme forholdsregler skal træffes i forhold til sikkerhedskopier af data.
26. I forbindelse med reparation og service af dataudstyr, der indeholder personoplysninger, og når datamedier skal sælges eller kasseres, skal der træffes de fornødne foranstaltninger for at sikre, at personoplysninger ikke kan komme til uvedkommendes kendskab.
27. Ind- og uddatamateriale skal opbevares og håndteres på en sådan måde, at uvedkommende ikke kan få adgang til at gøre sig bekendt med de personoplysninger, som er indeholdt heri. Medarbejdere, som samtidig beskæftiger sig med almindelig administrativ sagsbehandling vedrørende personer, om hvem der behandles oplysninger i statistisk eller videnskabeligt øjemed, bør herunder ikke have adgang til materialet.

Ind- og uddatamateriale skal slettes eller tilintetgøres, når det ikke længere skal anvendes til de formål, hvortil det er indsamlet og behandlet, dog senest efter en af den dataansvarlige myndighed nærmere fastsat frist. Ved tilintetgørelse skal det sikres, at materialet ikke misbruges eller kommer til uvedkommendes kendskab.

Manuelle ("papir") oplysninger

28. Manuelt materiale, herunder udskrifter, fejl- og kontrollister mv. med oplysninger, der direkte eller indirekte kan henføres til bestemte personer, skal opbevares forsvarligt aflåst og på en sådan måde, at uvedkommende ikke kan gøre sig bekendt med indholdet.

Biobank og biologisk materiale

29. Prøver med biologisk materiale og biologisk materiale i biobanker skal opbevares forsvarligt aflåst, således at uvedkommende ikke har adgang til det, og på en sådan måde, at det sikres, at materialet ikke fortabes, forringes eller hændeligt eller ulovligt tilintetgøres.
30. Biologisk materiale, der er mærket med personnummer eller navn, skal opbevares under iagttagelse af særlige sikkerhedshensyn.
31. Projektansvarlige skal fastsætte interne retningslinjer i projektet for opbevaring af biologisk materiale. Retningslinjerne skal ajourføres mindst én gang om året.
32. Senest ved projektets afslutning skal biologisk materiale enten destrueres eller anonymiseres fuldstændigt og oplysningerne slettes, tilintetgøres eller anonymiseres, således at det efterfølgende ikke er muligt at identificere enkeltpersoner, der indgår i undersøgelsen.

Videregivelse/ udlevering

33. Videregivelse/udlevering af personhenførbare oplysninger til andre (dataansvarlige) må kun ske, hvis oplysningerne hos modtageren udelukkende skal bruges i statistisk eller videnskabeligt øjemed. Det fremgår af databeskyttelseslovens § 10, stk. 2.
34. Videregivelse/udlevering må **kun** ske efter forudgående tilladelse fra Region Midtjylland, Juridisk Kontor.

Det fremgår af Databeskyttelseslovens § 10, stk. 3, at videregivelse af oplysninger omfattet af stk. 1 og 2 til tredjemand tillige kræver forudgående tilladelse fra Datatilsynet, når videregivelsen:

- o sker til behandling uden for databeskyttelsesforordningens territoriale anvendelsesområde,
 - o vedrører biologisk materiale eller
 - o sker med henblik på offentliggørelse i et anerkendt videnskabeligt tidsskrift el.lign.
35. Oplysninger kan herudover videregives, hvis det fremgår af anden lovgivning, at oplysningerne skal videregives.

Ændringer i projektet

36. Ændringer, herunder forlængelse, skal anmeldes i databasen.

Der henvises til Region Midtjyllands hjemmesider for yderligere oplysninger vedr. korrekt anmeldelse af ændringer: www.rm.dk/sundhed/faginfor/forskning/Forskningsprojekter

Der gøres opmærksom på, at det kun er den projektansvarlige, der kan anmelde ændringer til projektet.

Ved projektets afslutning

37. Oplysninger (herunder også biologisk materiale) skal slettes, anonymiseres eller tilintetgøres senest ved projektets afslutning, medmindre en fortsat opbevaring kræves efter anden gældende lovgivning. Det må efterfølgende ikke være muligt at identificere enkeltpersoner i projektet.
38. Alternativt kan oplysningerne overføres til arkiv efter arkivlovens regler.
39. Sletning/anonymisering af oplysninger fra elektroniske medier mv. skal ske på en sådan måde, at oplysningerne ikke kan genetableres og at der på ingen mulig måde via koder eller andet, kan findes tilbage til en identificerbar person.

Overførsel af oplysninger til tredjelande

40. Overførsel af oplysninger til tredjelande, herunder overførsel til behandling hos databehandler, kræver forudgående tilladelse fra Datatilsynet.
41. Overførsel kan dog ske uden tilladelse fra Datatilsynet ved anvendelse af Kommissionens standardkontrakter. Overførsel kan desuden ske uden tilladelse fra Datatilsynet, hvis den registrerede konkret har givet udtrykkeligt samtykke hertil.
42. Overførsel af oplysninger skal ske med bud eller anbefalet post. Ved elektronisk overførsel skal der træffes de fornødne sikkerhedsforanstaltninger mod, at oplysningerne kommer til uvedkommendes kendskab. Herunder skal der anvendes kryptering, hvis følsomme personoplysninger overføres via internettet (eller andre åbne net), og sikring af sikkerhed for autenticitet (afsenders og modtagers identitet) og integritet (de transmitterede oplysningers ægthed) skal ske i fornødent omfang ved anvendelse af passende sikkerhedsforanstaltninger.

Ovenstående vilkår er gældende indtil videre. Region Midtjylland forbeholder sig ret til senere at tage vilkårene op til revision, hvis der skulle vise sig behov for det.

Anmeldelsen offentliggøres på Region Midtjyllands hjemmeside i fortegnelsen over forskningsprojekter: www.rm.dk/sundhed/faginfo/forskning/Forskningsprojekter

Oplysningspligt over for den registrerede

I de tilfælde hvor der ikke sker indsamling hos de registrerede selv, er der som udgangspunkt ikke en oplysningspligt.

I de tilfælde, hvor der sker indsamling af oplysninger hos den registrerede/deltageren (ved interview, spørgeskema, klinisk eller paraklinisk undersøgelse, behandling, observation m.v.) skal der imidlertid uddeles/fræmsendes nærmere information om projektet til den registrerede/deltageren i overensstemmelse med Databeskyttelsesforordningens artikel 13. Der skal dermed gives følgende oplysninger:

- Navn og kontaktoplysninger (telefonnummer, e-mailadresse eller lignende) på den dataansvarlige.
- Kontaktoplysninger (navn, telefonnummer, e-mailadresse eller lignende) på databeskyttelsesrådgiveren.
- Formålene med og lovgrundlaget for behandlingen.
- Eventuelle modtagere eller kategorier af modtagere. Der er her tale om overordnede angivelser af modtagere såsom andre offentlige myndigheder, samarbejdspartnere mv.
- Om oplysningerne vil blive overført til et land eller en international organisation udenfor EU/EØS.
- Det tidsrum, hvor personoplysningerne vil blive opbevaret, eller de kriterier, der anvendes til at fastlægge dette tidsrum.
- Retten til at anmode om berigtigelse.
- Retten til at anmode om sletning.

For projekter godkendt efter Komitéloven kan personoplysninger, der allerede er indgået i projektet, ikke kræves slettet, jf. Komitélovens §3, stk. 4.

- Retten til at anmode om begrænsning af behandling af personoplysninger.
- Retten til at gøre indsigelse mod behandling af personoplysninger.
- Retten til at trække et samtykke tilbage.
- Retten til at klage til Datatilsynet.
- Borgeren skal oplyses om automatiske afgørelser (herunder profilering).
- Hvis borgeren har pligt til at oplyse regionen om sine personoplysninger, skal regionen gøre borgeren opmærksom på denne pligt. Borgeren skal oplyses om retsgrundlaget og konsekvenserne af ikke at give de nødvendige oplysninger.

Den registrerede bør endvidere oplyses om, at projektet er anmeldt internt i Region Midtjylland, samt at Region Midtjylland har fastsat nærmere vilkår for projektet til

beskyttelse af den registreredes privatliv.

Indsigtsret

Den registrerede har ikke krav på indsigt i de oplysninger, der behandles om den pågældende.

Offentliggørelse af forskningsresultater

Offentliggørelse af forskningsprojektets resultater må ikke indeholde oplysninger, der kan henføres til de registrerede.

Ved offentliggørelse af *Word-filer* eller *PowerPoint* præsentationer skal det sikres, at alle personlige oplysninger slettes.

Vejledning til sikring heraf findes på Regions Midtjyllands hjemmeside samt pjece fra IT- og Telestyrelsen "*Gemmer I på skjulte data i Office-filer?*"

Videregivelse af forskningsoplysninger kræver Datatilsynets tilladelse, når videregivelsen sker med henblik på offentliggørelse i et anerkendt videnskabeligt tidsskrift el.lign.

Læs mere

Du kan læse mere om databeskyttelse på Region Midtjyllands intranet via følgende link:
intranet.rm.dk/organisation/Informationssikkerhed/databeskyttelsesforordning

Derudover kan der findes mere information om databeskyttelse på Datatilsynets hjemmeside:
www.datatilsynet.dk

Venlig hilsen

Juridisk Kontor – Fortegnelse over forskningsprojekter i Region Midtjylland

Annette Engsig

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