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ICF Case Studies

Translating Interventions into Real-life Gains – a Rehab-Cycle Approach

Hope

Case Study 03



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Preface

Functioning is a central dimension in persons experiencing or likely to experience disability. Accordingly, concepts, classifications and measurements of functioning and health are key to clinical practice, research and teaching. Within this context, the approval of the **International Classification of Functioning, Disability and Health (ICF)** by the World Health Assembly in May 2001 is considered a landmark event.

To illustrate the use of the ICF in rehabilitation practice **Swiss Paraplegic Research (SPF)** together with **Swiss Paraplegic Centre (SPZ)**, one of Europe's leading (acute and rehabilitation) centres for paraplegia and spinal cord injury (SCI), performed a series of case studies. Conducting ICF-based case studies was one approach to address SPF's aim to contribute to optimal functioning, social integration, health and quality of life for persons with SCI through clinical and community-oriented research. The ICF-based case studies project began in October 2006.

In this project, persons of different age groups and gender and who are living with SCI of varying etiology and levels of severity, were accompanied during their rehabilitation at SPZ. The rehabilitation process is then described using the Rehab-Cycle® and the corresponding ICF-based documentation tools. Since persons with SCI are faced with a number of physical, psychological and social challenges, the case studies aimed to cover a broad spectrum of these challenges. With this in mind, each case study highlighted a specific theme of SCI rehabilitation.

A booklet is published for each case study conducted. To better understand the case studies described in these booklets, find below some basic information about SCI, the ICF, ICF Core Sets, the Rehab-Cycle® and the ICF-based documentation tools.

Spinal Cord Injury (SCI)

Spinal cord injury (SCI) is an injury of the spinal cord that results in a temporary or permanent change in motor, sensory, or autonomic functions of the injured person's body. The spinal cord is divided into four sections which can be further subdivided into individual segments:

- 8 cervical segments (C1 to C8)
- 12 thoracic segments (T1 to T12)
- 5 lumbar segments (L1 to L5)
- 5 sacral segments (S1 to S5)

The damage of the spinal cord is called lesion. Important functions such as mobility (motor functions) or sensation (sensory functions) fail below the lesion. To help determine future rehabilitation and recovery needs, the extent of a SCI in terms of sensory and motor functions is described using the American Spinal Injury Association (ASIA) impairment scale.

International Classification of Functioning, Disability and Health (ICF)

The ICF is a classification of the **World Health Organization (WHO)** based on the integrative bio-psycho-social model of functioning, disability and health. Functioning and disability reflect the human experience related to the body functions, body structures, and activities and participation. It is viewed in terms of its dynamic interaction with a health condition, personal and environmental factors.

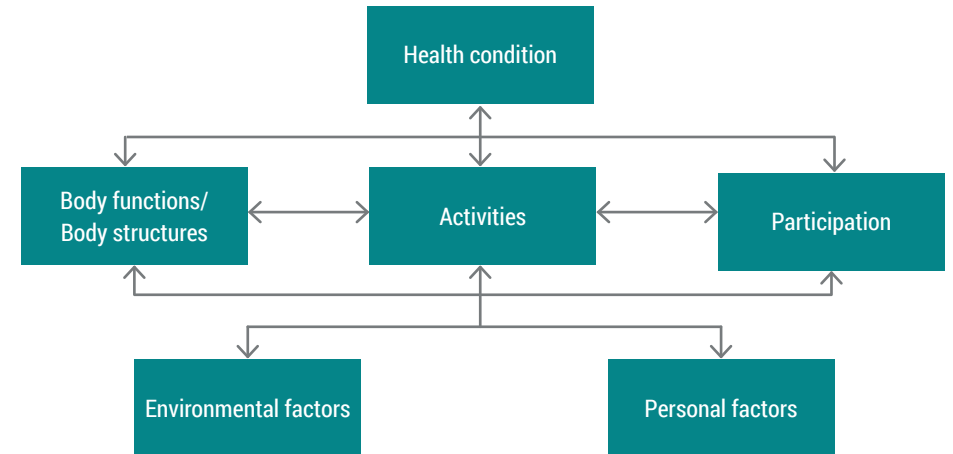


Figure 1: Bio-psycho-social model of functioning, disability and health

The ICF classification corresponds to the components of the model. Within each component, there is an exhaustive list of categories that serve as the units of the classification. ICF categories are denoted by unique alphanumeric codes and are hierarchically organized in chapter, second, third and fourth levels. When going from the chapter level to the fourth level, the category's definition becomes more detailed.

The classification also comprises so-called ICF qualifiers, which quantify the extent of a problem experienced by a person in a specific ICF category. Since environmental factors can also be facilitators, the ICF qualifier for facilitators are indicated with a plus sign.

Generic Scale of ICF Qualifiers	
0	NO problem (none, absent, negligible,...) 0-4%
1	MILD problem (slight, low,...) 5-24%
2	MODERATE problem (medium, fair,...) 25-49%
3	SEVERE problem (high, extreme,...) 50-95%
4	COMPLETE problem (total,...) 96-100%
8	not specified (used when there is insufficient information to quantify the extent of the problem)
9	not applicable (used to indicate when a category does not apply to a particular person)

ICF Core Sets

To facilitate the use of the ICF in clinical practice, it is essential to have ICF-based tools that could be integrated into the existing processes. The first step toward providing ICF-based tools for clinical practice was the development of ICF Core Sets. ICF Core Sets are shortlists of ICF categories that are considered to be most relevant for describing persons with a specific health condition or in a particular setting. In a rehabilitation setting an ICF Core Set can help guide the rehabilitation management process. ICF Core Sets have been developed for several health conditions e.g. for spinal cord injury, health condition groups e.g. for neurological conditions and for various settings. ICF Core Sets can serve as a basis when using the **ICF-based documentation tools** that follow the **Rehab-Cycle®**.

Rehab-Cycle® and corresponding ICF-based documentation tools

The Rehab-Cycle® is one approach that reflects the structured processes inherent in multidisciplinary rehabilitation management. The Rehab-Cycle® consists of an assessment phase, assignment phase, intervention phase and evaluation phase. An ICF-based documentation tool has been developed to guide each of the Rehab-Cycle® phases: the ICF Assessment Sheet, the ICF Categorical Profile, ICF Intervention Table and ICF Evaluation Display. These tools can help a multidisciplinary rehabilitation team to better understand the role of functioning within the rehabilitation process and to more comprehensively describe a person's functioning - hence support ICF-based rehabilitation management.

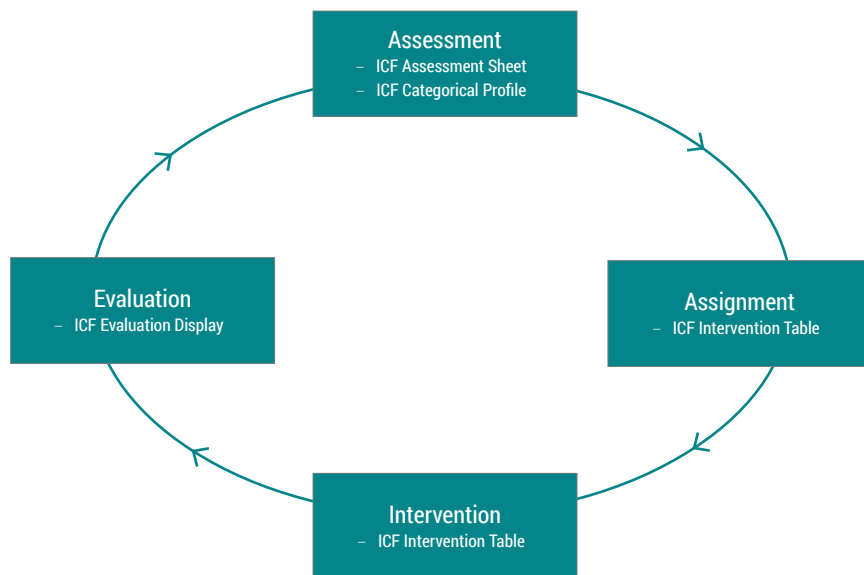


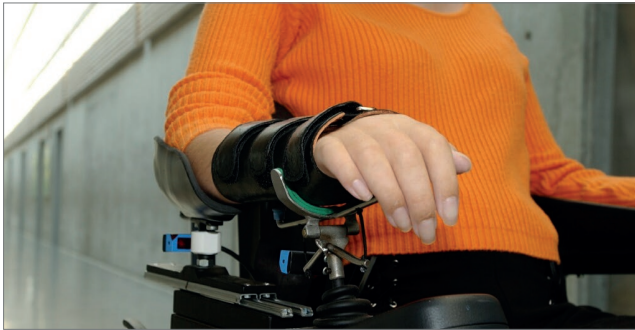
Figure 2: Rehab-Cycle®

You can find more detailed information about SCI, the ICF, ICF Core Sets, the Rehab-Cycle® and the ICF-based documentation tools on the website www.icf-casestudies.org.

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General Introduction



Intuitively, it can be said that hope plays a significant role in the process of rehabilitation. However, a central question is whether the feeling of hope can be supported by a rehabilitation team in an explicit way and integrated in the rehabilitation process to achieve better outcomes.

This case study aims to illustrate the role of hope in the rehabilitation of Helen, a person living with the debilitating Guillain-Barré Syndrome (GBS) – how her hopes, both realistic and less realistic, were funnelled, adapted and integrated for effective

rehabilitation management. See box 1 for more information on GBS. This case study offers a positive example of an intervention that built upon a person's realistic hopes as well as dealt with less realistic hopes in a constructive way.

“Hope...provides comfort while enduring life threats and challenges”

Hope is a feeling that is characterized in simple terms by an anticipation of something good or something better will happen or of relief from something uncomfortable or bad. Hope is a multidimensional construct that provides comfort while enduring life threats and challenges. In general, it is positive and future-oriented and has an impact on a chronically ill person's attitude towards life and functioning. Hope can promote goal-directed activity particularly when focused on realistic expectations, carry persons through diverse struggles, and lead to personal growth

as a motivational factor promoting positive outcomes. A person's willpower can provide the person with the required energy and strength in the "hoping process".^{1,2,3}

Qualitatively, hope can be distinguished as “generalized hope” or as “particularized hope”. While “generalized hope” is intrinsic to a person and may serve as a positive coping strategy, “particularized hope” refers to hoping with a specific expectation or goal.³

Lastly, persons perceive hope in different ways, reflecting the different sources from which the person draws hope. People experience hope even

in negative situations or hope for things that are important to them but have a low likelihood of being realized.^{2,3,4}

Box 1 | Guillain-Barré Syndrome – A Complex Disease and Its long Road to Recovery

Guillain-Barré Syndrome (GBS) is an acute inflammatory disorder of the peripheral nervous system. It is a common cause of rapidly acquired paralysis. It is brought about by a person's own immune response to foreign antigens that is misdirected to a person's peripheral nerve cells, where the cells are stripped of their myelin sheaths that are critical to nerve functioning. This type of disease is sometimes referred to as an autoimmune disease and is often (though not always) triggered by a viral or bacterial infection.^{5,6,7} From a medical perspective, the process of GBS is divided into three phases:⁵

- **Initial phase (lasting up to 4 weeks):** from the start of symptoms until there is no further decline of symptoms
- **Plateau phase (lasting a few days to weeks):** there is a stabilization of physical status
- **Recovery phase (lasting a few weeks up to 2 years or longer):** a gradual decrease of symptoms

The initial symptoms include pain, numbness, varying degrees of weakness in the legs, which can then spread to the upper torso and arms and increase in intensity until the muscles can no longer be used, sometimes leaving a person almost completely paralyzed.^{5,7,8}

Although the prognosis for GBS is usually favourable, it is a serious condition that can result in permanent severe disability in 20% and in mortality in about 10% of the cases. Given this, all cases of GBS can be considered a serious threat to life. In cases where the lungs are paralyzed, GBS may result in death and artificial ventilation is required. Other associated symptoms may include loss of sensitivity, bladder and bowel disturbances, weakness of voice, respiratory function, ingestion and visual function (due to affected muscles), pain and fatigue. However, it should be noted that even in the most severe cases of GBS, recovery is possible, albeit to varying degrees.^{5,8,9}

Integrating Hope Into Rehabilitation Management for GBS

Given the uncertainty surrounding the progression of GBS¹⁰, rehabilitation management should be based on a dynamic process that can be adapted according to a person's situation. Both the person and rehabilitation team are constantly searching for new possibilities to deal with the consequences of the illness. Hope is an inspiring and a stimulating factor in the process of recovery, and works against the person's inclination to "give up". Hope also motivates the person to persevere with

rehabilitation. This may, in turn, lead to improvement in functioning.^{2,11}

Thus there is a reinforcing feedback cycle – hope and the process of hoping can drive rehabilitation. This, in turn, can lead to improvement in functioning, which then can result in even more hope. The rehabilitation team should therefore work to integrate a patient's hopes into the rehabilitation approach, promoting those that are realistic and minimizing those that are not.²

Helen's Story



"The tetraplegia just happened so suddenly. One morning it's a stomach ache ... then I'm unconscious for four weeks! Can you imagine? I awoke totally confused, and more or less paralyzed. It might be hard to grasp, but even in that state, I really believed that things will get better. Deep inside of me, I just knew it."

Helen, in 2007

Helen and Her Fight with GBS

Helen is extremely hopeful. Always the optimist, her personality embraces a promising outlook that is simply intrinsic. Such hopefulness played an important role in Helen's story.

"...even in that state, I really believed that things will get better. Deep inside of me, I just knew it."

Following her and her husband's retirement, Helen saw a bright future. Her two children were already grown and pursuing their careers. Helen and her husband were continuing to enjoy life together and were following their individual interests. She focused her energies on her canine companions and in enthusiastically directing a local obedience

school for dogs. At 67, Helen was not slowing down at all. For Helen, the future looked very good. It was in this frame of mind that she was suddenly and unexpectedly struck with Guillain-Barré Syndrome (GBS); see box 1. Given the abrupt onset of this disease and its associated tetraplegia, Helen's hopeful nature would become a central player in her recovery.

With plenty of daily exercise, no prior health problems and a good diet, Helen had always considered herself healthy. But for some weeks, she had been suffering from gastrointestinal problems. While not severe, the condition persisted, and about a month after experiencing the problems, she decided to visit her doctor at the local hospital. This visit to her physician could not have been more timely. Within a few hours she was admitted to the intensive care

unit with the diagnosis of GBS that was caused by a campylobacter infection.

The GBS progressed, leaving her with tetraplegia and unable to breathe properly. She then fell into one month of unconsciousness and disorientation. The medical team maintained her on artificial respiration and tube-fed her. Helen eventually awoke when her illness progressed to a status called 'sensomo-

toric incomplete high tetraplegia'. This meant that she had no motor functions while having sensations, experienced autonomic dysregulation that affected her gastrointestinal system and respiratory insufficiency that required artificial ventilation. Despite these complications, two months after the onset of GBS her medical team felt that her recovery was sufficient enough to discharge her from the intensive care unit.

"After realizing that she was totally dependent on others, the wish for greater autonomy was at the forefront of Helen's mind."

After realizing that she was totally dependent on others, the wish for greater autonomy was at the forefront of Helen's mind. When her rehabilitation program began, she thought that the most important functions she needed to improve involved her hands. She believed that gaining more functioning in her hands would allow her to do more on her own without the support of others. However, Helen's rehabilitation team considered this unrealistic at that point in time. Regardless, her rehabilitation team acknowledged Helen's hopefulness, and took

on the challenge (and opportunity) of finding a way to integrate Helen's hopefulness into the rehabilitation process while maintaining focus on efforts that were realistic and achievable.

Fortunately, the Rehab-Cycle® approach to rehabilitation management can facilitate the integration of hope in rehabilitation in that it encourages the rehabilitation team to consider the person's perspective when planning rehabilitation interventions.

Helen's Slow Start to Recovery and a New Rehab-Cycle®

Overall Helen's progress toward recovery was very slow. Seven months after starting rehabilitation, she completed the first cycle of rehabilitation or Rehab-Cycle®.

improving only very slowly, leaving no muscle power in her hands and limited muscle power in her arms and legs. Needless to say, her abilities in the activities of daily living (ADL) were extremely limited.

In this first Rehab-Cycle® Helen and her rehabilitation team sought to optimize her body functions, such as respiratory, urinary and bowel functions, that was one step forward towards achieving the ultimate goal of optimal independence. At the end of this first Rehab-Cycle® mechanical ventilation at night was still required; while she could breathe, she could not fully expand her lungs on her own. In addition, Helen's hand and arm functions were

After seven months a new Rehab-Cycle® began that aimed towards Helen's discharge from the rehabilitation centre. Initially, it had been planned that Helen would be discharged home 9 months after admission. However, due to the unusually slow progress in her recovery, the rehabilitation team was not very optimistic about a timely release.

“Due to the unusually slow progress in her recovery, the rehabilitation team was not very optimistic about a timely release.”

Box 2 | A Challenge to Rehabilitation: The Uncertain Prognosis of Persons with GBS

Although much is known about GBS^{5,6,7,8,9,10,11} the progression of the disease is unpredictable.^{9,10} While the plateau phase is defined by an unchanged functioning status in the person and the recovery phase with improvement in functioning, the number and degree of symptoms, the duration of the disease phases and the extent of the recovery itself varies greatly from patient to patient. In fact, the course of the disease cannot be reliably predicted in the acute phase, since it differs from one person to the other. What is known is that the prognosis is worse in elderly persons, those who experi-

enced rapid disease onset, and who were bedbound and required ventilation during the peak of disease severity.^{5,8,10}

Although the prognosis for persons with GBS is generally favourable^{5,10,12} rehabilitation professionals are not able to make any reliable statements about the course of the disease. Consequently, persons with GBS are confronted with uncertainty about their recovery. In light of this uncertain prognosis, hope can play a major role in facilitating the rehabilitation process.^{1,2,3,4,11}

Assessment



Helen's Perspective

Helen's tetraplegia left her with very little motor function. However, she could still feel sensations. As mentioned, her hopes focused on increasing her ability to wash and dress herself, and re-gain use of her hands.

Additionally, Helen had a number of other needs. Due to weakened musculature around her mouth, she found chewing to be strenuous and could only speak very quietly, leading to difficulties with communication and conversation. This latter issue compelled her to limit her visitors to family only; talking with friends was just too exhausting.

While she was able to breathe sufficiently, she required a ventilator at night to ensure her lungs were adequately ventilated. Lastly, Helen was having trouble in transferring herself into and out of bed, and she also felt very insecure moving around in her wheelchair.

Health Professional Perspective

The impairments Helen experienced due to GBS affected not only her range of motion but also her ability to fully breath, exercise, ingest food and water, and talk. Helen could control her respiration, but she was not able to inflate her lungs fully. Furthermore, while she could sense her need to urinate and defecate, she was unable to control her bladder nor her bowel movements. Based on the experience during the first Rehab-Cycle® and

Helen's recovery up to the time of the assessment, the rehabilitation team felt that substantial improvement in Helen's hand functions was unlikely and that the prognosis was simply uncertain. As a result of the loss of functioning in her hands, Helen's ability to perform self-care was impaired. Self-care along with many of Helen's other activities of daily living were severely limited.

Contextual factors i.e. personal and environmental factors were also of importance in Helen's rehabilitation. For example, personal factors such as her hopeful and optimistic personality as well as her extensive knowledge about GBS (due to efforts by her daughter, a nurse, who informed her about GBS) served as facilitators of the rehabilitation process. In fact, Helen was able to build her beliefs and hopes for improvement upon the knowledge she acquired about GBS.

“...personal factors such as her hopeful and optimistic personality as well as her extensive knowledge about GBS... served as facilitators of the rehabilitation process.”

Environmental factors impacted Helen's case as both facilitators as well as barriers. Facilitators included a supportive family and rehabilitation team and her two dogs. Among the barriers included her pre-rehabilitation home; since this could not be adapted for Helen's needs, it meant that she had to relocate to another flat that was more conducive to her health condition. Another

barrier was the lack of insurance that would pay for her special wheelchair.

These contextual factors and other factors that were determined during the assessment phase in Helen's new Rehab-Cycle® were documented in the ICF Assessment Sheet, and translated into the corresponding ICF categories that served as the basis for the ICF Categorical Profile.

Goal-setting/Determination of Intervention Targets

“I really believe that things will change. And I continue to be hopeful that change is possible despite minimal recovery in such a long period of time. If I didn't believe this, nothing would happen.”

Helen

Goal-Setting – Striking a Balance

Helen's sense of hope and consequently her personal goals centred on improving her hand functions. Due to the slow course of her initial Rehab-Cycle® following her release from the intensive care unit, Helen found her dependency on others at the best of times difficult and at the worst of times degrading. She particularly disliked being washed and dressed by others. For this reason the use of her hands was essential to re-attaining the dignity and independence she desired. Accordingly, all of her psychological focus and efforts went into reaching a level of fine hand function that would again allow her the freedom to dress and clean herself independently and attend to her normal activities of daily living.

However, given the uncertainty surrounding the prognosis for GBS, Helen's rehabilitation team was conservative in setting goals. Moreover, the rehabilitation team felt that substantial improvement in hand functions was an unrealistic goal at that point in time. At the same time Helen's rehabilitation team recognized that Helen's desire for enhanced hand use and ultimately increased autonomy was driven by her intrinsic inner strength, hope and optimism.

In the end, Helen's rehabilitation team decided to define 'optimal independence' as a global goal. This goal was intentionally kept broad to allow for adaptation according to Helen's progress. This and other more detailed goals were outlined in the ICF Categorical Profile, a visualization of Helen's functioning status at the time of the assessment as reflected in the rating of relevant ICF categories using ICF qualifiers. Along with her long-term goals i.e. global goal and service-program goal, Helen's ICF Categorical Profile also shows her short-term cycle goals. See *“Table 1: ICF Categorical Profile” on page 24 at the end of this booklet.*

For this Rehab-Cycle®, a service-program goal was set – discharge to home. To achieve the service-program goal, more specific cycle goals were elaborated:

- Improved speaking and ingestion functions
- Improved respiratory functions
- Improved mobility through increased independence in transferring, changing body positions and wheelchair mobility

Identification of Intervention Targets

For the service-program goal and each cycle goal appropriate intervention targets were identified. Intervention targets are those ICF categories that are to be addressed with interventions in the rehabilitation program. Helen's ICF Categorical Profile includes ICF categories that reflected the results of the assessment and subsequently documented on the ICF Assessment Sheet. However, not all of

the categories listed were defined as intervention targets, since only categories for which a goal was identified and were addressed in the intervention phase of the Rehab-Cycle® were considered intervention targets.

The intervention targets were documented in the ICF Intervention Sheet.

Assignment and Intervention



“We celebrate her improvements together... These little celebrations keep and strengthen her sense of hope... and motivates both of us for the next little steps.”

Throughout the intervention phase Helen's rehabilitation team constantly sought balance between Helen's hopes and the realistic steps toward achieving the goals set. The team members who worked closely and at length with her remained conscious of the need to support Helen's hopefulness while also remaining focused on things over which they had control.

Helen's occupational therapist (OT), for instance, focused on improving the mobility of several upper extremity joints through the use of passive mobilization and hand braces. The OT was also responsible for helping Helen to find and arrange adaptations for a wheelchair-accessible flat. Proprioception i.e. the ability to sense the relative position of body parts was among other intervention targets that were addressed by the physical therapist through standing balance training and body positioning. These interventions, the inter-

vention targets that were addressed with the interventions, and the rehabilitation team member(s) responsible for performing the interventions were outlined in the ICF Intervention Table created for Helen. See *“Table 2: ICF Intervention Table” on page 26 at the end of this booklet.*

In addition to the interventions that tackled the targets related to body functions e.g. passive mobilization, activities and participation e.g. transfer training and environmental factors e.g. organization and testing of wheelchairs, Helen and her rehabilitation team also integrated personal factors – hope, inner strength and optimism – as one intervention target. Since tackling this target required a concerted effort, all the members of Helen's rehabilitation team were assigned to address this through individual counseling and guidance.

Box 3 | Additional Factors to Consider for Integrating Hope into Rehabilitation

Health professionals have an opportunity to choose supportive interventions that recognize and integrate the power of hope as an important personal resource in the recovery phase of GBS. Despite a person's limitations, hope can offer needed energy and motivation to allow the person to move forward in rehabilitation. A number of factors may play an important role for integrating hope in rehabilitative interventions:^{3,13,14}

- setting realistic goals
- belief in oneself and ability to handle one's future
- persons who participate in their own care have a greater sense of hope

- promoting a sense of control by informing the person about developments in treatment/rehabilitation
- making available resources such as information about the disease as well as information related to spirituality
- awareness of own feelings
- relationship with family, friends, caregivers
- flexibility of person and rehabilitation team to adapt to changes and evolving circumstances
- acknowledgement that there is a future; being future/goal-oriented

Members of the rehabilitation team describe their experiences of working with Helen and of promoting hope as part of Helen's rehabilitation:

"Helen shifts between phases of intense hope for improvement and suffering from her impairments ... a lot of both optimism and pessimism..."

"To inspire hope in Helen, I tell her that I share her hopefulness that her functioning will improve. Nevertheless, it's important to clarify over and over again that we are not working on her hand function right now but on the improvement of realistic activities like maneuvering the wheelchair on her own. That means focusing on the present rather than the more uncertain future...To emphasize this, I highlight every little improvement when it happens. For example, she is now able to move an electrical wheelchair with a standard control. This is a major improvement because she will no longer need expensive technology

and it increases her independence. These small triumphs really motivate her and further strengthens her hope."

Helen's Occupational Therapist

"To maintain and strengthen Helen's hope, I tried to explain to her that her hand function alone isn't enough for her to manage her day. Improving hand function is still a future global goal, but at the moment we have to define smaller, achievable goals...We celebrate her improvements together (for example, by going for coffee). These little celebrations keep and strengthen her sense of hope...and motivates both of us for the next little steps."

Helen's Physical Therapist

"I try to steer the middle course between fostering too much and too little hope. She has to be patient. I try to strengthen her patience, to maintain hope for improvement."

Helen's Nurse

Evaluation

Helen's evaluation just one month into the second Rehab-Cycle[®] was quite remarkable.

I can move the wheelchair on my own now and this gives me a little more independence and freedom – but this little bit is so much to me! I don't need to be accompanied any longer. Actually, my hope and goal [of improving hand function] wasn't met, but a lot of other things improved.

Helen

At eight months following the onset of Guillain-Barré Syndrome (GBS) and one month after the start of this Rehab-Cycle[®], Helen exceeded all expectations. Her respiratory functions improved to the extent that her tracheostomy tube was able to be removed. She was also able to transfer herself to and from her bed to her newly-chosen wheelchair and was able to move around using the wheelchair independently.

"At eight months following the onset of GBS... Helen exceeded all expectations".

These improvements in her functioning, among other things, were documented in the ICF Evaluation Display. See "Table 3: ICF Evaluation Display" on page 28 at the end of this booklet. Helen's ICF Evaluation Display illustrates the results of the evaluation after eight months of rehabilitation interventions; it shows the goals attained. Noteworthy is the fact that many of Helen's goals were achieved beyond expectations. Especially noteworthy was her achievement in the intervention target 'Transferring oneself while sitting'. Helen's

rehabilitation team aimed to maintain a goal value of '3' or severe impairment (the value at the initial assessment was also '3'). At re-evaluation, Helen's ability to transfer herself while sitting was rated with '1' or only mild impairment. This was a major improvement.

While certainly a positive development in Helen's recovery and strive for independence, these exceptional results exemplifies the difficulty Helen's rehabilitation team had in making an accurate prognosis about her rehabilitation outcome.

To Helen's elation and despite falling short of her initial hopes for substantial improvement in hand functions, all three cycle goals were met.

"My lungs are better and I can breathe at night now just wearing a face mask. I can raise my legs a little better and move my arms while I am lying. Even transferring works well now, and this was pretty difficult for me."

"I am getting more and more hopeful, because I am continuously able to do more things. I'd say that this further strengthens my optimism. The therapists also keep me optimistic; they understand how to motivate me, and I have a good relationship with them. I also deeply feel that I'm more stable now. Maybe this has resulted from my inner strength. In fact, I have to say that this disease has made me stronger."

"Regarding optimism, I need optimism to have hope; it is an essential part of hope. And having hope also depends a lot on my environment. If I had been somewhere where I did not feel comfortable, I would not have recovered very well, and my optimism and

hope would have been diminished. Here I really feel optimally supported. How I am looked after and treated has actually helped me experience hope and optimism. I can definitely sense if someone is treating me only as a job or because he or she enjoys it and wants to achieve success. This has a lot of influence on me. Now I feel that my strength is coming back."

Helen

Despite this progress, Helen still had many challenges to confront on her path to recovery. For example, her mobility was still very limited due to the impaired use of her arms and hands, and

her respiratory functions were still somewhat hindered despite the strides made. Furthermore, her health insurance did not cover all of her rehabilitation costs, leaving financial worries on the horizon.

"I am getting more and more hopeful, because I am continuously able to do more things. I'd say that this further strengthens my optimism."

Discussion

Guillain-Barré Syndrome (GBS) is a debilitating disease that can strike unexpectedly at any age and result in serious neuromuscular paralysis, including different degrees of tetraplegia.^{5,6,7} GBS presents specific challenges and opportunities that are well-illustrated in Helen's case.

"The interaction between a person's sense of hope and rehabilitation management can be a significant factor in driving recovery."

For Helen, like with many GBS patients, a significant challenge to rehabilitation involves the uncertain prognosis – individuals progress at a different rate through the phases of the disease, and reach different levels of recovery.^{8,9,10} As evident in Helen's final evaluation, this uncertainty makes accurate prediction of rehabilitation outcomes difficult. However, having specific short-term goals that can be adjusted according to improvement can provide a good and accurate picture of progress along the continuum of rehabilitation.

Helen's hopeful personality demonstrated some of the opportunities and potential pitfalls of hope as it relates to GBS. Helen's case has shown that hope can play a critical role in the recovery phase of GBS when it is focused on attainable goals.^{2,3} Hope and the influence of hope in rehabilitation is influenced by a variety of factors.^{3,13,14} In Helen's case, she struggled against dependency and sought autonomy. Her knowledge about the disease, her personality and the degree to which the rehabilitation team was able to support and strengthen her sense of hope all played a role in her achievements.

The rehabilitation team helped to set realistic goals and refocused those that were less realistic, such as Helen's strong desire to spotlight improvement in her hand use as the focus of rehabilitation. Importantly, without demotivating Helen the rehabilitation team was able to refocus and encourage her in those areas where she could most improve. Helen's sense of hope toward recovery and independence was further reinforced as many of her intervention targets gradually improved and milestones were met. In fact, the goals established for Helen were reached beyond all expectations.

The interaction between a person's sense of hope and rehabilitation management can be a significant factor in driving recovery. While it is certainly true that a shift from a pessimistic to an optimistic personality is probably difficult if not impossible, it is the rehabilitation team's obligation to help support, guide and focus the person's hopes as best as possible, and assist him or her to avoid the pitfalls of setting unrealistic goals. Reliable information and attainable short-term milestones foster the sense of hope in a person with GBS.

Annex

- Table 1: ICF Categorical Profile
- Table 2: ICF Intervention Table
- Table 3: ICF Evaluation Display
- Literature
- Questions

Table 1: ICF Categorical Profile

ICF Categorical Profile																							
Assessment																							
ICF categories																							
	ICF Qualifier	ICF Qualifier				Goal Relation	Goal value																
		0	1	2	3			4	problem														
Global Goal: Optimal independence											2												
Service-Program-Goal: Discharge to home																					0		
Cycle goal 1: Improved speaking and ingestion functions																					1		
Cycle goal 2: Improved respiratory functions																					2		
Cycle goal 3: Improved mobility																					3		
ICF categories																							
		problem																					
b260	Proprioceptive functions																					3	
b265	Touch function																					-	
b28014	Pain in upper limb																					3	1
b310	Voice functions																					1	1
b445	Respiratory muscle functions																					2	2
b510	Ingestion functions																					1	1
b525	Defecation functions																					SP	3
b620	Urination functions																					SP	3
b7101	Mobility of several joints																					3	3
b7304	Power of all muscles of the limb																					3	3
b7305	Power of muscles of the trunk																					3	2
b760	Control of voluntary movement functions																					3	3
b7603	Supportive functions of the arms																					3	2
s810	Structure of areas of the skin																					SP	0
d410	Changing basic body positions																					3	4
d4153	Maintaining a sitting position																					-	-
d4200	Transferring oneself while sitting																					3	3
d440	Fine hand use																					-	-
d445	Hand and arm use																					3	4
d450	Walking																					-	-
d465	Moving around using equipment																					3	2
d510	Washing oneself																					-	-
d520	Caring for body parts																					-	-
d530	Toileting																					-	-
d540	Dressing																					-	-
d550	Eating																					-	-
d560	Drinking																					-	-
d855	Non-remunerative employment																					-	-
d9201	Sports																					-	-
d9205	Socializing																					-	-
																						-	-
e1151	Assistive products...for personal use in daily living																					-	-
e1201	Assistive products...for personal mobility																					3	4+
e1251	Assistive products...for communication																					-	-
e155	Design, construction...of buildings for private use																					SP	1+
e310	Immediate family																					-	-
e350	Domesticated animals																					-	-
e355	Health professionals																					-	-
e750	General social support services																					-	-
e800	Health services																					SP	2+
pf	Knowledge of disease																					-	-
pf	Hope, inner strength, optimism																					SP	4+

Table 1: ICF Categorical Profile; ICF Qualifier: rate the extent of problems (0 = no problem to 4 = complete problem) in the components of body functions (b), body structures (s), activities and participation (d) and the extent of positive (+) or negative impact of environmental (e) and personal factors (pf); Goal Relation: 1, 2, 3 refers to Cycle goal 1, 2, 3; SP refers to Service-Program Goal; Goal value refers to the ICF qualifier to achieve after an intervention.

Table 2: ICF Intervention Table

ICF Intervention Table											
	Intervention target	Intervention	Doc	Nurse	PT	OT	Speech	SW	First value	Goal value	Final Value
Body function/-structure	b260	Proprioceptive functions							3	3	2
	b28014	Pain in upper limb			x				x	2	1
	b310	Voice functions							2	1	
	b445	Respiratory muscle functions	Training of respiratory muscles			x					
			Mechanical ventilation at night		x					3	2
	b510	Ingestion functions	Training of muscles of the mouth							2	1
	b525	Defecation functions	Medication	x					x	4	3
	b620	Urination functions	Medication	x						4	3
			Catheterization		x					4	3
	b7101	Mobility of several joints	Passive movement							3	3
			Adaptation of braces				x				
	b7304	Power of muscles of all limbs	Active movement							4	3
	b7305	Power of muscles of the trunk	Static and dynamic muscle training			x				2	2
	b760	Control of voluntary movement functions	Active movement			x				4	3
b7603	Supportive functions of the arms	Prop-up training			x				3	2	
s810	Structure of areas of the skin	Daily inspection		x					0	0	
d410	Changing basic body positions	Training of changing body positions							4	4	
d4200	Transferring oneself while sitting	Transfer training			x				3	3	
d445	Hand and arm use	Assistance/Instruction			x				4	4	
d465	Moving around using equipment	Assistance/Instruction			x				3	2	
Environmental Factors	e1201	Assistive products and technology for personal indoor and outdoor mobility and transportation							x	2 (+)	4 (+)
	e155	Design...of private building							x	4	1 (+)
	e5800	Health services								x	1 (+)
Personal Factors	pf	Hope, inner strength, optimism								2 (+)	4 (+)
											4 (+)

Table 2: ICF Intervention Table. Doc = Physician; PT = Physical Therapist; OT = Occupational Therapist; Speech = Speech therapist; SW = Social Worker. The first value refers to the rating at the initial assessment, the goal value refers to the rating that should be achieved after the intervention, and the final value refers to the actual rating at the second assessment or evaluation. ICF qualifiers were used to determine these ratings (0 = no problem to 4 = complete problem) in the intervention targets. For the interventions targets representing environmental (e) and personal factors (pf), the plus sign next to value indicates a facilitator.

Table 3: ICF Evaluation Display

ICF Evaluation Display															
Assessment								Evaluation							
ICF categories								ICF Qualifier							
	ICF Qualifier	Goal Relation	Goal value	problem				facilitator				ICF Qualifier	Goal achievement		
				0	1	2	3	4	0	1	2			3	4
Global Goal: Optimal independence			2												not evaluated yet
Service-Program-Goal: Discharge to home			0												not evaluated yet
Cycle goal 1: Improved speaking and ingestion functions			1												+
Cycle goal 2: Improved respiratory functions			2												+
Cycle goal 3: Improved mobility			3												+
b260	Proprioceptive functions	3	3												+
b28014	Pain in upper limb	3	1												+
b310	Voice functions	1	1												+
b445	Respiratory muscle functions	2	2												+
b510	Ingestion functions	1	1												+
b525	Defecation functions	SP	3												+
b620	Urination functions	SP	3												+
b7101	Mobility of several joints	3	3												+
b7304	Power of all muscles of the limb	3	3												+
b7305	Power of muscles of the trunk	3	2												+
b760	Control of voluntary movement functions	3	3												+
b7603	Supportive functions of the arms	3	2												+
s810	Structure of areas of the skin	SP	0												+
d410	Changing basic body positions	3	4												+
d4200	Transferring oneself while sitting	3	3												+
d445	Hand and arm use	3	4												+
d465	Moving around using equipment	3	2												+
e1201	Assistive products...for personal mobility	4+	4+												+
e155	Design, construction...of buildings for private use	3	4+												-
e5800	Health services	SP	1+												-
pf	Hope, inner strength, optimism	SP	4+												+

Table 3: ICF Evaluation Display; ICF Qualifier: rate the extent of problems (0 = no problem to 4 = complete problem) in the components of body functions (b), body structures (s), activities and participation (d) and the extent of positive (+) or negative impact of environmental (e) and personal factors (pf); Goal Relation: 1, 2, 3 refers to Cycle goal 1, 2, 3; SP refers to Service-Program goal; Goal value refers to the ICF qualifier to achieve after an intervention; Goal achievement: + means achieved, - means not achieved.

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Questions

- Q1. **Explain the connection between illness and the sense of hope.** *(Refer to page 8 for the answer.)*
- Q2. **Describe the symptoms and the three developmental stages of Guillain-Barré Syndrome (GBS).** *(Refer to page 9 for the answer.)*
- Q3. **What are the benefits of integrating hope into rehabilitation management of a person with GBS?** *(Refer to page 9 for the answer.)*
- Q4. **In Helen's case, how was her sense of hope fostered in rehabilitation management?** *(Refer to page 18 for the answer.)*
- Q5. **Based on the ICF Evaluation Display how would you evaluate the role Helen's sense of hope has played in her rehabilitation. Compare your evaluation with the comments made by Helen herself.** *(Refer to page 19 for the answer.)*

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