

Misconceptions: Stroke Patient Recovery Expectations vs. What May Unfold — BLOG POST

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"They told me ... you told me ... but nobody really told me ..."

This is a typical comment that may be uttered by stroke patients later in the course of recovery, when reflecting back upon initial treatment visits. Some realizations which have been brought up in the course of my career involve:

- Expectations the patient may place on themselves; and,
- The difference in recovering from a skill-by-skill standpoint vs. a full return to prior level of function.

As therapists, we educate stroke patients on a regular basis at the start of treatment regarding the standard "first six months to a year" time frame for when the majority of improvements tend to occur through spontaneous recovery — that therapy can maximize this return, and that improvements can occur after as well with treatment. However, oftentimes, misconceptions occur along the way, as evidenced by the statement above, and this blog post will explore factors which play into this phenomenon.

Patient Expectations

First of all, patients may bring to the table a set of expectations when beginning to embark on recovering from a stroke. These expectations may be a barrier in the education regarding recovery that is provided by therapists, coloring the data that is presented. Examples of expectations may involve:

- the patient may feel like the prognosis communicated may not apply to the patient;
- that the typical challenges that stroke patients face will not relate to the situation at-hand;
- that the communicated time-frames for projected levels of recovery to come to fruition will not be as long as anticipated; and,
- the above expectations may be complicated by family/caregiver input as well.

Identifying What Can be Helpful

Having awareness of these expectations, and how they may possibly be barriers to understanding the education that can be provided on what to expect in stroke recovery are important first steps. The following statements/questions may be helpful:

"I would like to start by asking you what your goals are?"

Starting with this question opens the door to allowing the patient to focus on why they are caring about recovering. This allows the patient to describe tasks that they care about performing — that are meaningful to patient. Then, the conversation can be free-flowing.

"I would like to talk about what to expect in your recovery. I want to know what you already know. Can you tell me what you've been told to expect?"

This allows for information gathering into what data about stroke recovery to date the patient has been informed about, and what they have retained and understand.



"Can you tell me what you have been told your prognosis is?"

This opens the door to finding out the patient's understanding of how they have been informed about their recovery.

"Do you have questions about the range of time frames expected in seeing progress?"

This will allow a peek into acceptance of how the expected time frames will take for the anticipated improvements to occur.

Teachable Statements

After an assessment of the patient's expectations and understanding of the course of treatment occurs, the education process can occur in opening the door to providing information in what to expect in stroke recovery.

Below are some tidbits of data that might be useful:

— Treatment is often "two steps forward, one step back" in stroke recovery.

Differing from recovering, for example, from a surgery or an acute illness, a stroke course of improvements is like no other. Explaining to patients that it is a marathon, and not a sprint, may be helpful as well.

— Expect exhaustion and difficulties with activity tolerance.

Managing the various therapies and navigating the day-to-day schedule of living can be a challenge, and there is a physiological component to stroke recovery that has to be addressed with rest. Expecting the need for rest and planning for providing rest are important in stroke recovery, and anticipating these are important from the start. Forecasting exhaustion and working toward activity tolerance rather than being surprised when it is not present can be helpful.

Skills Improvement vs. Prior Level of Function Achievement Another realization that has been brought up in the course of my career involves the difference in recovering from a skill-by-skill standpoint vs. day-to-day, "real life" return to function.

It has been called "surface" vs. "deep" recovery. It has been called "skills" vs. "functional" — call it what you would like, patients know the difference between improving a specific skill, or task-based action or activity, vs. day-to-day, prior-level-of function living. Patients yearn for the later. The former helps them get to the later, but they desire the functional. As therapists, it is important for us to remember this. Patients desire to return to life as it was prior to the stroke. It is not about being able to perform this exercise or that exercise — this task or that task. It is about being about to get back to their lives as they were before, which involves a plethora of complex skills, all at once. And this also goes back to expectations. As skills start to return, some patients expect a prior-level of function return in all areas; however, this is not always the case. This can be disconcerting to patients, and deeply troubling as time passes during recovery.



The following is a list of suggestions to make when a patient describes and communicates disappointment regarding the mixed feelings of glee of return of certain skills, but a sadness that a full return to function hasn't occurred:

Listen.

Sometimes it is important for someone to have a chance to just voice what they are experiencing and know that they are being heard. Sometimes it is important to take time from the exercises or the planned activities of the day and address the emotions that a patient is experiencing at the moment. Oftentimes, a patient needs to address what has been holding them back in their therapy. This just might be the breakthrough that they are needing.

- After this is expressed, if appropriate, ask if they would like input. Sometimes, patients do not desire input, they just desire to be heard. Sometimes, patients do have questions or want to have a discussion.
- If indicated, provide input.

They may need to know about skills they do not realize they have improved upon that you have not yet mentioned yet. It may be that you will introduce new tasks during the session that will allow for the development of skills to pave the way to improve the missing links in their recovery.

- Provide encouragement in the progress that has been made. Everyone needs to know how they are improving. Everyone needs to know they are on the right track.
- Continue to support the patient to stay the course.

 Let the patient know they are fighting the good fight in trying to take back what the stroke affected.

 Maintain that they are doing everything within their power to fight this, and that you are proud of them.

There are a lot of factors that play into misconceptions about how the course of stroke treatment will unfold. Hopefully some of the above information will be helpful in navigating how to approach the topic of prognosis, expectations, outcome, challenges and the course of recovery with your next stroke patient.





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