Becoming normal: A grounded theory study on the emotional process of stroke recovery

By Patti Gallagher, RN, MN, CNS

Abstract

The purpose of this grounded theory study was to examine the emotional process of stroke recovery, personally experienced by stroke survivors. Nine stroke survivors living in Atlantic Canada participated in this study. Data collection came from formal unstructured interviews and one group interview.

The central problem experienced by these stroke survivors was being less than 100%. The basic social process used to address this problem was becoming normal, which is composed of three stages: recognizing stroke will not go away, choosing to work on recovery, and working on being normal. Each stage has several phases.

Being less than 100% is the emotional result of being unable to do certain things that serve to form individuals' identities. A critical finding was that physical and emotional recovery is inseparable, and recovery is directed towards regaining the ability to perform these certain things. Becoming normal was influenced both positively and negatively by the following conditions: personal strengths and attributes, past history, family support, professional support, faith and comparing self to peers.

The results of this study have implications for nursing practice, nursing education and nursing research. It adds to nursing knowledge by illuminating the close relationship between physical and emotional recovery, the duration of the stroke recovery process, and the necessity for survivors to make a deliberate choice to recover.

Introduction

Stroke, a sudden and catastrophic event, can instantly change the life of the affected individuals and those close to them. Considerable investigation has focused on the physical effects of stroke and functional recovery patterns. Unfortunately, the same is not true about the emotional effects of stroke. Indeed, very little is written about emotional recovery from acute stroke. At the same time, what is written is often not supported by the use of scientific tools or sound research methods, which could enhance the significance of the findings (Kelly-Hayes, et al., 1998; Kirkevold, 1997; Roberts & Counsell, 1998). Understanding emotional effects and, more specifically, the process of emotional recovery after a stroke can be important to enhancing stroke recovery work. This includes work performed by health care professionals who interact with people who experience stroke, as well as with their families.

Often, health care professionals who care for stroke survivors note that many people work hard to recover from stroke and regain their life. However, there are others who do not seem to be able to motivate themselves to undergo similar work (Doolittle, 1991; 1992; MacLean, Pound, Wolfe, & Rudd, 2002). As a clinician who works with stroke survivors, I wanted to examine stroke survival work from the perspective of persons who considered themselves stroke survivors. I hoped to gain an understanding of what drives a stroke survivor to work on recovery.

The purpose of this grounded theory study was to examine the process of emotional recovery after stroke from the perspective of stroke survivors. The resulting substantive theory of "becoming normal" adds to nursing knowledge with a new framework of stroke recovery that is grounded in the stroke

Devenir normal : une étude théorique à base empirique sur le processus émotionnel de rétablissement après un accident vasculaire cérébral

Résumé

Le but de cette étude théorique à base empirique était d'examiner le processus émotionnel de rétablissement après un accident vasculaire cérébral, tel qu'il est vécu par les survivants d'un accident vasculaire cérébral. Neuf survivants d'un accident vasculaire cérébral résidant au Canada atlantique ont participé à cette étude. Les données proviennent d'entrevues formelles non-structurées.

Le problème principal vécu par ces survivants d'accident vasculaire cérébral était de fonctionner à moins de 100%. Le processus social de base utilisé pour résoudre ce problème était de devenir normal, ce qui comprend trois étapes : reconnaître que l'accident vasculaire cérébral ne disparaitra jamais, choisir de travailler à son rétablissement et s'efforcer à devenir normal. Chaque étape comprend plusieurs phases.

Fonctionner à moins de 100 % est le résultat émotionnel de l'incapacité à accomplir certaines choses qui servent à construire l'identité individuelle. Une découverte essentielle a été que les rétablissements physique et émotionnel sont indissociables, et que le rétablissement vise à retrouver cette capacité d'accomplir certaines choses. Devenir normal était influencé de manière positive et négative par les conditions suivantes : atouts et attributs personnels, antécédents, soutien familial, soutien professionnel, confiance et comparaison avec les autres.

Les résultats de cette étude ont des conséquences dans les soins infirmiers, la formation du personnel infirmier et la recherche en sciences infirmières. Elle complète les connaissances en sciences infirmières car elle a établi une relation étroite entre rétablissement émotionnel et physique, la durée du processus de rétablissement d'un accident vasculaire cérébral et le besoin pour les survivants de choisir délibérément de se rétablir.

survivors' experiences. Some of these theoretical findings are supported by previous research by others. "Becoming normal" illuminates the close relationship between physical and emotional recovery, the duration of the stroke recovery process, and the necessity of making a deliberate choice to recover.

Literature review

When using grounded theory, the initial literature review is conducted to sensitize the researcher to the phenomenon of interest without biasing or blinding the researcher to emerging concepts. Upon analysis of the research data and the emergence of relevant concepts, a more in-depth literature review is conducted. This process facilitates researcher openness to emerging concepts, as revealed by the participants (Chenitz & Swanson, 1986; Glaser, 1978; Morse & Field, 1995; Streubert & Carpenter, 1999). Others may argue that an initial literature review may bias the researchers and blind them to emerging concepts (Glaser, 1978).

For the purpose of this research, an initial sampling of the literature related to the topic of emotional issues in stroke was undertaken to provide an overview of the current state of the knowledge. The following concepts were identified as being of particular concern in the examination of emotional recovery following stroke: post-stroke depression, self-worth, hope, crisis and chronic illness. Indeed, there has been research conducted that examined the importance of depression, self-worth, hope and crisis on the emotional recovery from chronic illness. However, emotional recovery post-stroke is still not clearly understood, although feelings that were identified as important, such as depression (Robinson & Price, 1982; Robinson, Starr, Kubos, & Price, 1983; Robinson & Bolla-Wilson, 1986), self-esteem (Chang & Mackenzie, 1998; Doolittle, 1991; 1992; Hafsteinsdottir & Grypdonck, 1997), hope (Hafsteinsdottir & Grypdonck, 1997; Popovich, 1991), and crisis (Backe, Larrson, & Fridlund, 1996; Nilsson, Jannson, & Norberg, 1997), were examined individually within separate studies. There was no evidence of inter-relationship, or of their essential significance in emotional stroke recovery (Bennet, 1996; Kelly-Hayes, et al., 1998). There was sparse literature available concerning the process of emotional recovery from the stroke-survivor's perspective (Doolittle, 1991), although many authors noted that the perspective of the stroke survivor was critical to nurses' understanding of and aiding emotional recovery from stroke (Bays, 2001; Bennett, 1996; Hafsteinsdottir & Grypdonck, 1997; Kirkevold, 1997). It is also evident that stroke is multifaceted and can be viewed from different lenses, such as stroke as a crisis or stroke within a chronic illness trajectory. However, no evidence of substantial work from these perspectives was found.

The process of emotional recovery from stroke is poorly understood and under-researched. As such, it would be premature to force the information gained from a study of emotional recovery into an existing theoretical framework. The potential to lose important information related to stroke recovery while trying to fit research findings within an inappropriate framework could be significant (Glaser, 1978).

Ethics approval

Ethics approval was obtained from the local university, as well as the provincial branch of the Heart and Stroke Foundation of Canada. Research did not begin until written approval was received. The executive director of the Heart and Stroke Foundation received a copy of the research proposal for their board to review as the initial sample for this study was a convenience sample of stroke survivors recruited from a list of participants in a stroke recovery program. The facilitators for the program sent letters of invitation to past participants of the program. Those who agreed to be interviewed mailed a letter of intent, they were contacted and, following a full explanation of the study with an opportunity for questions, arrangements were made to meet in person and obtain consent.

Study participants

Nine stroke survivors ranging in age from 42 to 82 years and living in Atlantic Canada participated in this study, conducted in 2004, and were representative of a variety of stroke types, ages, marital and family circumstances. One had been locked in, three aphasic, four had right-sided weakness and four left side. All were highly motivated people who were eager to do whatever it took to recover from their stroke, as well as to share their experiences.

Data collection came from individual formal unstructured interviews and one focus group session where the emerging theory was presented for discussion and confirmation. All participants were invited to attend a group session when the analysis was approaching completion and the substantive grounded theory developed. The focus group interview was held in order to provide a test of credibility (did the emerging theory resonate with the group and explain their response to stroke). Five stroke survivors and their families attended the focus group, which was held six months after the final interview.

Each person was interviewed at least once. Subsequent interviews to clarify content obtained in the first interview occurred. Participants were informed of this prior to obtaining consent, and the formal consent contained a statement that indicated the researcher might wish to speak with the participant more than once. Participants were encouraged to contact the researcher in the event they had something further to ask or had questions or concerns. In addition, provisions were in place to provide participants with an opportunity to receive support if they had concerns or problems at any time during the project. The researcher agreed to contact each participant following the interview to ensure there were no problems or issues.

Four participants contacted the researcher following their interviews, as they felt they had something further to contribute and gave information that added to clarification of the process of "becoming normal". Participants were informed that the aim was to hear the story from their perspective and that the interview should preferably take place in a quiet, private setting. Four participants had family present during their interviews. At times family members interjected but, for the most part, were silent observers.

Stroke survivors who participated in the study sustained a stroke that left them with a level of physical impairment that required admission to a rehabilitation unit following admission to an acute stroke unit. Each was living at home at the time of the interview. The period of time from their stroke event to interview ranged from as recent as six months to four years for one participant. The median time was one year post stroke.

Half of the participants had some degree of aphasia during their initial acute stroke period, but all were able to communicate during the time of the interview. It was interesting to note that participants who experienced aphasia reported significant events and turning points unique to their stroke recovery where they recognized their inability to communicate, but were fully present and aware. They shared their reactions and impact on recovery.

Methodology

The process of emotional recovery post-stroke is underexplored, particularly from the stroke survivors' perspective and, therefore, poorly understood. Grounded theory is considered an ideal research method to employ when examining a relatively unstudied process related to a social psychological problem. The goals for this study were 1) to determine the central issues for stroke survivors' emotional recovery, 2) identify the basic social process that accounts for stroke survivors' emotional recovery, and 3) to consider implications of this emergent theory for nursing education, practice, and research.

For the purpose of this study, grounded theory, as defined by Glaser (1978), was utilized. Grounded theory is a qualitative, inductive methodology that serves to explore how people manage problems (Glaser, 1978). Grounded theory is based on symbolic interactionism (Blumer, as cited in Annells, 1996), which has three premises: 1) Human beings act towards things on the basis of the meanings those things have for them, 2) Such meanings arise out of the interaction of the individual with others, and 3) An interpretative process is used by the person in each instance in which he must deal with things in his environment.

Within that structural context, the purpose of the method is to generate a theory that explains the basic problem, what is going on around that problem, what factors are present, how they relate, and how participants process that problem. The stroke survivor population is very large. It is estimated that in Canada there are 300,000 stroke survivors (Hakim, Silver, & Hodgson, 1998; Lindsay et al., 2008), and little has been examined regarding the emotional experiences of recovery from the perspective of the survivor. Therefore, the initial study findings may have limited applicability. Furthermore, the theory that arises from this study may be modified as other future studies are conducted and, therefore, can be useful as a starting point for generating further theoretical support (Wuest, 2000).

In grounded theory methodology, data collection and data analysis occur concomitantly. The analysis is often referred to as circular and the search for emerging concepts and themes begins from the moment data collection begins (Glaser, 1978; Morse & Field, 1995; Polit & Hungler, 1999). Data analysis consists of concept formation, concept development, identification of a core variable and formation of a grounded theory (Glaser, 1978). In this study, all interviews were coded line by line with three levels of coding utilized: Level I (open coding), Level II (categorizing), and Level III (Basic Social-Psychological Process Identification (Glaser, 1978).

In qualitative research, researchers pursue rigour through establishing the trustworthiness of their interpretations (Guba & Lincoln, 1985). Trustworthiness is evaluated using the criteria of credibility: dependability and confirmability, and transferability (Guba & Lincoln, 1985). Glaser (1978) describes credibility as having fit, grab and work. This means that a theory "should be able to explain what happened, predict what will happen and interpret what is happening in the area of substantive or formal inquiry" (Glaser, p. 4). The final test of credibility lies with the subject groups. If the theory fits, the group will give evidence of the theory's acceptability (Glaser, 1978), hence the need for the focus group session to test the emerging theory.

An audit trail was maintained so that others could examine the assumptions made by the researcher and attest to their trustworthiness. The audit trail allows for the traits of dependability of the data over time (stability) and confirmability of data (objectivity) to be measured (Polit & Hungler, 1999).

Transferability is a feature related to providing enough description to allow for determining if the findings from the data can be transferred to other groups in similar situations (Glaser, 1978; Polit & Hungler, 1999; Streubert & Carpenter, 1995). As identified by Glaser (1978), thick description is a hallmark of grounded theory methodology utilized to ensure transferability of data. In a brief journal article it is often difficult when working within content restrictions to include significant thick description.

Findings

See Figure 1 and Table 1.

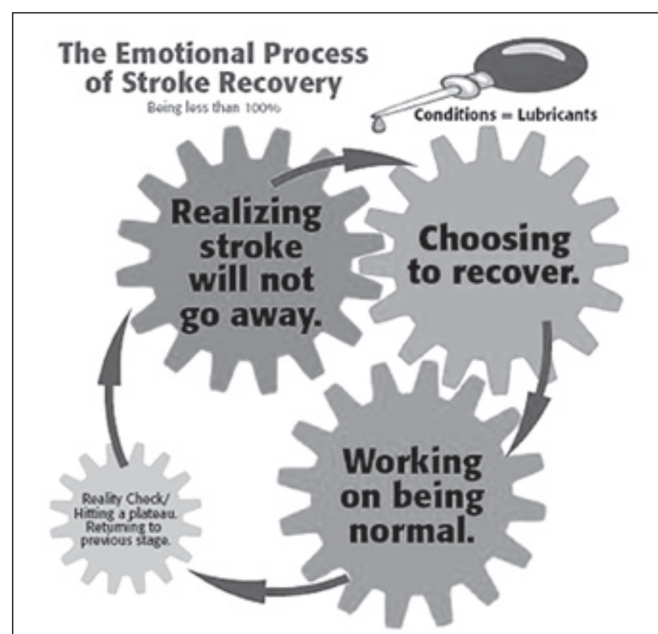

Figure 1. Model of becoming normal

Central problem

The central problem experienced by these stroke survivors was being less than 100%. This refers to a change in personal identity rooted in physical changes that prevent survivors from carrying out activities that they see as self-defining. It is not about losses but about *being less*. The effects of their stroke changes who they are and affects what is central to their individuality and what makes them feel worthwhile. They feel less than 100%. Their personal identity is inextricably tied to being able to do certain things. These tasks are important to the roles they perform in what they identify as normal life and being normal; recovery of these personally critical skills is vital for emotional recovery. In this sense, both physical and emotional recovery is intertwined.

> *Mr. E: I guess I'm not very good at explaining things, but I began to feel that these things that I had all these years were being taken away from me, I didn't have any control over it. Then you mean to tell me that the disease doesn't take over? Well, it takes over up here (pointing to his head). You are conscious enough to know that something is being taken away from you.*

Being less than 100% is similar to the loss of self-concept identified by Ellis-Hill and Horn (2000) and Dowswell et al. (2000), as participants described this aspect as "lives turned upside down" and related to past and present self-concepts.

Basic social process

The basic social process used to address this central problem of *being less than 100%* is "becoming normal", which is composed of three stages: recognizing stroke will not go away, choosing to work on recovery, and working on being normal (see Figure 1). Each stage has several phases (see Table 1). Becoming normal is influenced both positively and negatively by the following conditions; personal strengths and attributes, past history of stroke or adverse events, family support, professional support, faith, and comparing self to peers.

Table 1. Stages of becoming normal and steps within each stage

Central Problem: Being less than 100%
Social Process: Becoming Normal

Stages and Phases (Themes and subthemes)		
Realizing stroke will not go away	**Choosing to recover**	**Working on being normal**
• Being vigilant • Being knocked off • Being flabbergasted • Becoming aware	• Identifying losses • Looking at options • Choosing to work on recovery	• Making the list • Rehabbing self/taking risks • Having success and moving on • Getting a reality check/hitting a plateau

Stroke survivors work long and hard on stroke recovery. Similarly, Kirkevold (2002) in her "unfolding illness trajectory of stroke" study noted: "Adjustment to stroke is a process that is gradually evolving and prolonged over the most of the first year following the stroke" (p. 887). Findings of this study show that this process continued far beyond the first year.

Stroke survivors identify that becoming normal is their goal and they continue to work toward this goal long after their period of acute stroke. Indeed, they are willing to invest time and energy on personally ascribed meaningful recovery, which speaks to the critical nature of collaborative goal identification with stroke survivors.

A number of conditions are considered important to the process of becoming normal. Personal strengths and attributes, past history, family support, professional support, spiritual faith and comparing self to peers are instrumental conditions for the process, but will not be discussed in this article.

Recognizing stroke will not go away

This stage of stroke recovery begins with the first stroke symptom and ends with awareness that stroke will not go away. It takes place in three phases: being vigilant, being knocked off, and being flabbergasted and becoming aware.

Being vigilant

Being vigilant is a process of purposefully observing one's feelings and how one's body is behaving during the stroke event and relating these observations to someone who can seek help. It is a process that is in operation until personal safety, identified as receiving medical help is established. Eaves (2000), in her study of stroke survivors' experience of stroke, which specifically focused on the initial impact of stroke, defined a similar stage to being vigilant, which she named discovering stroke and delaying treatment.

> *Mr. H.: I came indoors and very soon after, I felt peculiarity in the right hand and arm didn't lose it, but it was not normal and then my lips began to tingle. Then I realized; I knew it was a stroke. So, as soon as my family got home from work, we got in the car and went to the hospital.*

Being knocked off

Being knocked off is a state of relinquishing control to others while barely being able to take in what is happening. This phase begins with admission to the emergency department and ends when stroke survivors become completely aware of what has happened. The paradox is that while patients were so vigilant during the initial phase of the stroke, they were distanced from subsequent events for a period of time.

> *Mrs. D.: Well, then they took me down for an ultrasound and then they did a cat scan and one thing or another like that, but uh, I don't know, I just seemed to be a party to it, but in the distance like. It wasn't really real to me.*

White and Johnstone (2000) describe a passive stage early on in stroke recovery. They surmise that the survivors want to put their faith in experienced and trusted experts who will help them make sense of the event. The survivors in this study reported being unaware of events at this time and, thus, were not looking at experts to help them make sense of this event.

Being flabbergasted

Being flabbergasted (an in vivo phrase one stroke survivor used that eloquently described to others how they too felt) is a process of being astonished and dismayed by functional changes that stroke causes. It is characterized by distress and fear, which intensifies with the recognition that one's independence has been compromised. This is different from being vigilant. They are now looking at what they cannot do versus observing their weakness.

> *Mrs. D.: I realized by then that this wasn't game time, just things that you take for granted that you are doing for yourself and you just can't. It is a low blow.*

Ellis-Hill et al. (2000), in their life narrative study of eight couples noted a similar phase, which they called self-body split. In their study, stroke survivors who experienced dysphasia were excluded, as the first interview occurred in the immediate acute stroke interval. In this present study, conducted in the post-acute phase of stroke recovery, being flabbergasted was present and could last longer in those who initially experienced dysphasia.

Becoming aware

This is an extension or continuation of being flabbergasted. This is the time when stroke survivors recognize stroke effects. This includes both internal acknowledgement of existing stroke effects and awareness of the potential permanence of these effects. Becoming aware often occurs simultaneously with being flabbergasted.

> *Mr. C.: When I was at the centre (rehabilitation centre), maybe about two weeks or so, it certainly hit me like a bolt of lightning, the reality of what I had. I am locked in! It certainly got through to my brain, when I suddenly realized that I might even stay this way.*

Similarly, other researchers have discovered that awareness of the consequences of stroke is critical for recovery and this confrontation had to occur before patients could be ready for rehabilitation (Lewinter & Mikkelsen, 1995; Kirkevold, 2002). Until there was awareness that the stroke would not go away, there was no movement to the next stage, which is choosing to recover.

Choosing to recover

Choosing to recover is a process of purposefully making a decision to engage in stroke recovery work. It is a turning point in "becoming normal" and a deliberate thoughtful decision antecedent to stroke work. This was a finding unique to this study. The decision to recover is a personal decision, although family support influences the choices stroke survivors make. It takes place in three phases: identifying losses, looking at options, and choosing to work on recovery.

Identifying losses

Identifying losses is a process of detailing functional losses that occur as a result of stroke and threaten to change stroke survivor's identities. Stroke survivors reflect on who they are, what is important to them, and how functional losses can affect that identify. It is a process of internal personal reflection.

> *Mr. A.: I have a workshop in the basement and I do home repairs and so on. I would sure miss being able to go down to the workshop and cut up a piece of wood. If I was unable to do that, it would be a real pain.*

Similarly, identifying losses is reported frequently in the literature and that stroke survivors tally losses in relation to what is important to them, as persons (Boynton De Sepulveda & Chang, 1994; Doolittle, 1992; Dowswell, 2000). As in this study, they noted that health professionals often did not question stroke survivors about their feelings regarding stroke effects and what was most disturbing to them. Stroke survivors felt this information would be helpful for appropriate professional support.

Looking at options

Looking at options is a process of examining various courses of action and their consequences. Stroke survivors identified three possible courses of action as being: doing nothing, contemplating suicide, and working on recovery. According to other researchers, stroke survivors who did nothing, in effect waited for the stroke to pass, did not do well in overall recovery (Boynton De Sepulveda & Chang, 1994; White & Johnston, 2000). All stroke survivors in this study rejected this option.

Choosing to work on recovery

In this study, deciding to work on recovery was noted to be a specific decision unto itself. It was described as an epiphany-like event and all participants could identify when they personally arrived at this decision. It is possible that goal-setting by stroke survivors, which has been identified elsewhere, implicitly includes deciding to work on recovery. However, in this study it seemed to be a separate juncture and all participants made this decision.

> *Mr. H.: This is one of the experiences of life where you've got to learn to deal with and that's not easy to deal with. You did, you operated in a certain way and at a certain level and, for me, I don't willingly accept the idea that I am going to live at a lower level.*

The phenomenon of stroke survivors making a conscious decision to recover is a new finding that adds to our understanding of the stroke recovery process. It is possible that goal-setting by stroke survivors, which has been identified elsewhere, implicitly includes deciding to work on recovery. However, in this study, deciding to work on recovery was a very specific decision.

Working on being normal

Working on being normal is the process of engaging in stroke work to become normal and is a sustained process that goes on for a long time. Stroke survivors define what "being normal" will be for them. Although some may accept a lower level of recovery or less than 100% recovery, for the majority of stroke survivors, being normal is being the same person as before the stroke. For the most part, stroke survivors were intent on achieving 100% recovery and many were working towards that goal beyond one year post-stroke.

> *Mrs. D.: (talking about finally being able to shower independently) I had the stroke three years ago this March, about this time. It took a long time, so I just had to give it a try one day because I had tried it many times. So, now I lean against the wall and haul my bad leg up and over.*

The stroke survivors' goal of becoming 100%, as discovered in this study, has been supported by other researchers (Bur-

ton, 2000; Dowswell et al., 2000). Conversely, other researchers report finding stroke survivors adapt to stroke losses and accept a lower level of functioning (Eaves, 2000; Lewinter & Mikkelsen, 1995). Still others have reported this goal lasted for only one year (Dowswell et al., 2000; Lawlor et al., 1999). These reported findings of acceptance of lower levels of recovery contrast with the process of becoming normal discovered in this study.

Stroke work is both physical and emotional. Emotional work is related to determining what level of recovery is acceptable and pushing oneself to go on over a significant length of time. It is an iterative process that consists of three phases: making the list, rehabbing self, and having success and moving on.

Making the list

Making the list is the process of naming what skills are important for personal identity and then prioritizing the list. It is composed of taking inventory and determining what is important. There is a tallying of losses that need to be overcome in order to regain identity and become normal. The purpose of this inventory is to look at losses in order to develop priorities for recovery work.

Determining what is important is the process of establishing priorities among the losses listed for regaining identity. Emotionally, this is a critical stage. What was identified as being important was as diverse as the individuals who participated in this study. Whatever was deemed most important to recover was worked on more diligently and at the expense of other gains. Doolittle's (1992) longitudinal descriptive ethnographic account of the experience of stroke recovery noted that, as in this study, participants expended energy on restoring function to areas of their bodies that performed functions that mattered to them and that gave them their identity.

Stroke survivors treasured health care professionals who identified what was important to them and their need to start on these tasks. It should be stated that being able to participate in basic ADL skills were often initial goals and that personal priorities followed as next goals. However, once basic needs are met, there is often incongruence between what therapists set as goals and what stroke survivors set as priorities. Depending on the degree of incongruence, the outcome for stroke survivors is frustration with the team focusing on what are, to the survivor, unimportant goals (Burton, 2000; Doolittle, 1992; Dowswell et al, 2000; Lawler et al., 1999; Hafsteinsdottir & Grypdonck, 1997). Conflict also arises when stroke survivors hold unrealistic expectations for recovery due to their comparative inexperience with the stroke recovery trajectory and require support from the team to help determine priorities.

> *Mr. F.: I had set goals for myself, as far as the recovery, some of which I never met. But, in time, I found, I discovered, they were realistic. I kind of broke down one day in Physio … So, finally, my physiotherapist helped me through it and said "Look, you are doing very very well, don't set unrealistic expectations." Well, I stopped beating myself up about that I think, mentally and set a more realistic expectation.*

Similarly, Lawlor et al. (1999) identified the critical role nurses can play in working with stroke survivors in mutual goal-setting. They found that when stroke survivors set goals that were not realistic, nurses did not intervene to help set more realistic goals due to the concern that they might discourage survivors and set them back. In this study, there were nurses who diligently worked with stroke survivors to assist them with setting realistic goals that were meaningful to the survivor. These nurses were treasured by the stroke survivors.

Rehabbing self

Rehabbing self is the process of taking the list and working purposefully on achieving the tasks according to priority. This process continued until "being normal" was accomplished. Rehabbing self is also a process of moving from a passive dependent recipient of therapy to becoming totally independent in rehabbing self. Being independent in "rehabbing self" often marked the true beginning of this phase. Stroke survivors became, for the most part, independent in self-care and activities of daily living. They began to work on tasks on that list that were truly important and critical to their self-identity. Problem-solving skills and strengths were important conditions in this phase.

Taking risks: One aspect of rehabbing self that was reported by several participants was taking risks. This was a strategy employed in the phase of rehabbing self. It was identified as trying something without a guarantee that it was possible or would work. Often the risk was related to trying something that was important to the survivor and, for the most part, risks were thoughtfully taken. Stroke survivors relate that when they were restricted from taking risks they felt devalued and depressed. They truly appreciated individuals who would strategize with them and support their efforts. It was also noted that even when these attempts met with failure, for the most part they resolved to try again at a later time. Risk taking was often described as a personal triumph and a feeling of taking control in recovery.

> *Mr. H.: She realized it was important to me and she backed off and kept an eye on me. That was fine, she kept an eye on me, but she let me do things. I was willing to be careful, but I needed to be able to do what lay within my power, and if it wasn't within my power, I needed to be allowed to fail.*

Doolittle (1992) named taking risks "experiencing the possibilities" and noted, "What was so amazing about these risk-taking endeavours was the tremendous world of possibilities these situations opened up for the individuals" (p. 123). As in this study, it was reported that risk taking was often performed in secret, hidden from families or hospital staff. Reluctance to be reprimanded was the leading reason for these covert activities.

Having success and moving on

Having success and moving on is described as meeting one goal or accomplishing one task and then going back to the list and moving on to the next task. Like a cogwheel that moves one notch at a time, it is perpetual motion. Little time is spent on pausing, reflecting, or celebrating successes. Praise and recognition of accomplishments comes from family and professionals and is important to stroke survivors.

> *Mr. J.: She was very encouraging that way, and she didn't see me every day, and she would see me once a week and*

she would see the difference … those things are helpful and encouraging. I would think of different things the therapists here would say because they were a better yardstick than we are towards ourselves.

Stroke survivors need to have success and be recognized for it, even if they do not take the time themselves to pause and reflect (Lawlor et al., 1999; Pilkington, 1999). Having success and moving on is the most complex phase of the process and at times stroke survivors may fail to accomplish a task. Thus, getting a reality check and/or hitting a plateau can occur.

Getting a reality check

Failure to accomplish a task or the sudden realization that something the stroke survivor hoped to accomplish will not happen was another epiphany-like event. At that time, work on being normal halted. Some participants regressed to the stage of realizing stroke would not go away and it took time to move through the stages again. It was a devastating experience, but did not occur to all participants; indeed, often only to those who had experienced very devastating strokes.

Mr. C.: I remember going to the cafeteria for lunch and everyone was laughing. I wanted to holler out to them "don't you know I may never walk again!" My world stopped. After a while I realized I will walk again, just not now. I have other things to do now.

Getting a reality check is similar to being flabbergasted, but with a subtle difference. It is often time-oriented where the stroke survivor is not realistic on how much time and work is involved and is expecting success too soon. Getting a reality check has not been reported in the literature as a specific event, rather as part of having unrealistic goals. In this study it was a specific event. Those who experienced it recalled the instant when they recognized they were not going to be successful and described the circumstances, the setting and the people involved. It was an epiphany-like occurrence.

When they became aware they were not going to meet their goals, some participants regressed, necessitating they work through the stages of realizing the stroke will not go away, making the decision to recover and working on being normal again. A reordering of what was important occurred and, for some, getting this reality check was devastating; it took time to move through the stages again. Others were able to handle this philosophically and changed the yardstick they used to measure their progress.

Mr. J.: I guess my attitude is I will try it later. I would just have to lay it aside and come back to it later.

Hitting a plateau

Hitting a plateau is a phase in "working on recovery" where progress with completing the tasks on the list stalls, or the speed of progress slows. Some called it hitting a wall. They found that being forewarned that this may occur was what helped them keep things in perspective. In other words, they were expecting it to happen at some point. Those who were not prepared experienced increased anxiety and worried that their recovery had stopped. Looking back and looking forward were strategies used to overcome this period. Health care professionals and family members would identify where they were and how far they had progressed, and that allowed them to recognize accomplishments and gather strength to move forward.

Hitting a plateau is common in stroke recovery and, yet, many stroke survivors are not prepared for this and can become depressed when it happens (Burton, 2000; Doolittle, 1992; Dowswell et al., 2000). Doolittle stated: "We live in a culture where there is pressure for continuous progress. If this was not so, plateaus might be viewed in a more positive context as periods of stabilization where the body replenishes itself" (p. 123).

Implications

This substantive theory of becoming normal adds to nursing knowledge with a new framework of stroke recovery that is grounded in survivors' experiences. Some of these theoretical findings are supported by previous research. "Becoming normal" adds to nursing knowledge by illuminating the close relationship between physical and emotional recovery, the duration of the stroke recovery process, and the necessity for survivors of making a deliberate choice to recover.

The process of becoming normal expands nursing knowledge by explicitly revealing how emotional recovery from stroke is grounded in regaining self-defining physical abilities, as opposed to functional capacities. The framework reveals areas where nursing practice may be tailored to support survivor priorities, leading to a more positive impact on stroke recovery. As well, findings reveal that stroke survivors' progress toward becoming normal is adversely affected by those who believe that stroke recovery is limited to time and discourage survivors in trying new things and setting long-term goals.

At times, nurses were viewed as being domineering, restrictive and detrimental to recovery. They felt that nurses would not allow them to try things and would restrict their independence. Often they recognized it was for safety reasons, but they felt nurses were over-cautious. According to Kirkevold (1997) nurses have the potential to be positive influences on stroke recovery. By virtue of their continuous presence, nurses should be perceived as being essential. They are present for 24 hours of the day, as compared to therapists and physicians who spend brief intervals with stroke survivors (Kirkevold, 1997).

Recognition of the stage stroke survivors are in and the key tasks they accomplish in each stage can be helpful to nurses in identifying critical strategies for supporting stroke survivors in their recovery process. For example, an important finding is that during most of the stage of *recognizing the stroke will not go away*, stroke survivors are unable to take in new information. *Being knocked off* is a phase where there is little recognition of stroke effects and what is going on. These findings suggest that this is not the time to focus nursing interventions on patient education. Rather, nurses need to be vigilant for patient cues that identify when the survivor is moving into the phase of *becoming aware*. At that time, nurses can provide support, information and hope for recovery.

As noted, *choosing to recover* is a deliberate thoughtful step and is a personal decision of the stroke survivor. The theory generated in this research suggests that rehabilitation efforts made by

health professionals are ineffective if stroke survivors have not made this decision. Stroke survivors in this study stated they made a deliberate choice to work on recovery and were able to tell others, if asked.

The majority of the stroke recovery work that was most meaningful to stroke survivors for becoming normal, occurred post discharge and with limited resources, and study participants noted that community reintegration and community resources are sorely lacking in helping them over the long term. Health policy initiatives should be developed to address this need.

Often hitting a plateau occurred after discharge. Stroke survivors who were prepared prior to discharge were able to anticipate its occurrence and were able to cope and move on.

Limitations

As with any grounded theory study there is opportunity for others to modify or extend the theory in further studies. The participants in this study were self-identified survivors who stated they wanted to recover and chose to work hard on recovery. It would be valuable to examine the perspective of those who did not choose to work. Recruiting from this population, however, may prove difficult. The study population in this research was recruited from an urban setting where rehabilitation units, as well as outpatient therapy were accessible. All stroke survivors were able to return to their own home. Stroke survivors who do not have access to therapy or who do not return home may also provide another view.

Conclusions

At the completion of the study, each survivor was continuing on "working on being normal" and identified that he/she has not reached the goal of becoming 100%. The role of the health professional in developing a meaningful therapeutic relationship is inextricably linked to recognizing what is important to the individual stroke survivor and their specific stage of recovery. For the most part, stroke survivors in this study did not identify nurses as essential players in the professional network supporting their work in becoming normal. Those nurses who shared their professional recovery experiences and supported stroke survivors in achieving goals that were important and encouraged them in risk taking as an exhilarating recovery action, were valued; indeed, treasured.

> *Mr. H.: I valued him (one rehabilitation nurse). He knew I needed to try and he let me. He said I know you are going to do it, let's figure a way to try it in a safe way.*

About the author

Patti Gallagher, RN, MN, CNS, Horizon Health Zone 2, New Brunswick. Email: ***patti.gallagher@horizonNB.ca***

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