

Examining the Lives of Young Adults with Sudden Mobility Impairment: Inputs to Counselling

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Abstract This study aims to gain deeper understanding on the inner feelings, coping strategies and experiences of a person who had sudden mobility impairment. Specifically, it focused on how the participants deal with life after surviving a neurological disorder. Using thematic analysis, the research yielded that three themes emerged from the verbatim interview data: the participants who suffered from neurological disorder not only struggle with physical adjustment but also face psychological and emotional turmoil; their condition created a major impact on how they view their future; and significant people and religious beliefs play an important role to the participants' recovery. This study showed the importance of strong emotional support in their road to recovery and building a positive self-concept. Counselling is recommended to possibly reduce the barriers brought by their mobility impairment.

Keywords: Adjustment, Coping strategies, Life Stories, Social Support, Sudden Mobility Impairment

Introduction

None of us knows what life has in store for us tomorrow or even in the next few hours. Anything can happen in a blink of an eye. And we will never know what that thing will bring to us, what our life will be or how it can be changed. Accidents happen anywhere and at any time; disease may occur suddenly and can strike people at any age, and they can have devastating consequences like living a life with physical disabilities.

Physical disability might come in many forms such as mobility impairment. Truscott's (2006) review of the Criteria for Physical Impairment report for the Department of Education, Training and Employment's (DETE) in Queensland defined mobility impairment as a dysfunction in neurological and/or musculoskeletal system, affecting the mobility of an individual. In fact, the most prevalent cause of serious physical disability is related to neurological disorders. Some have inborn disabilities while others developed during a person's lifetime and may come as a surprise. Coming to terms with any disability is not easy and might take a long time, especially when it comes as a sudden surprise.

Having the opportunity to meet and talk to different medical practitioners in the field, the researchers learned that the effects of a neurological disorder and length of recovery vary from one person to another. Brain injury depends on which area of the brain sustains the damage. Tilling, Sterne, Rudd, Glass, Ityk & Wolfe, (2001) explicate that some disabilities and impairment of body functions are secondary to neurological disorder, which may be mild and short-lived. For others, disabilities could be more severe and long-term.

Mobility impairment brings significant changes on a person's life. It greatly affects relationships, career, daily activities and expectations for the future (Creed, 2010).

People who suffer mobility impairment brought about by neurological disorders may have complex needs not only with their physical functioning but also with their emotional and psychological facets. More painfully, the sudden change in one's lifestyle can be difficult to endure. Hopeful thoughts of the future may turn into despair as disability seems to add another obstacle to their dreams. Disability greatly affects both the physical functioning and the mind and spirit of a person.

Every individual has unique valuable experiences to share. Each person deals with struggles, hopes and aspirations. The researcher, who had been physically disabled by a massive brain injury at a very young age has been inspired to make use of this extraordinary experience to focus her study on to gaining deeper understanding and awareness of living in a life with sudden mobility impairment. A person with mobility impairment herself, she considered this study as an imperative part of her life. Hence, she aspires that this study be an instrument for telling her story and their stories to assist and provide inputs to educators and counsellors to help make it nearly normal and easier for students with mobility impairments included in general classroom settings while on physical and emotional recovery process. After all, education brings hope and self-empowerment.

The sense of life is threatened by the presence of a physical disability (Gourgey, 1994). The very ability to recover from a life-changing injury or illness might be the hardest thing to deal with and anyone would naturally feel down about it, yet with few changes come hope that one might still live life to the fullest, not to allow the feeling of limitation by a disability determine life and eventually develop coping mechanisms.

According to an analysis by Taguba and Mina (2011), studies in the Philippines on people with disabilities are very limited. The authors also conducted a field survey

in Rosario, Cavite where they interviewed 106 respondents from 31 barangays. And, only three out of 10 respondents are aware of the important legislations intended to improve their well-being. The mobility-impaired persons have the highest awareness rate.

Coping and acceptance

Intrinsic and extrinsic motivation

The first step of recovery is acceptance. Like what the ontological philosophy explained, people with mobility impairment need to understand how “things will be” and the “new reality” undeniably brought about by the existence of the condition. Simply speaking, it means that people deal not just with the existence of mobility impairment but also the later effect of it in one’s life. Accordingly, the “Disablement Process” of *Verbrugge and Jette (1994)* illustrates the effect of the mobility impairment on the physical functioning of the body, mental actions, and daily activities. They said that intrinsic and environmental factors may speed up or slow down the process of recovery.

Furthermore, an individual has intrinsic and extrinsic motivations that aid him or her to adapt in the changes of his or her world. Coping is an intrinsic appraisal-based motivation of a person to draw meaning from the adversities of life. It draws courage and motivation during difficult moments from one’s set of beliefs (e.g. spiritual), values (e.g. attitude), and existential goals (e.g. purpose of life) (*Lazarus & Folkman, 1984*). Hence, positive and adaptive coping skills help a lot in the recovery process. On the other hand, the extrinsic aspect comprises of the individual’s environment and significant people around him or her.

Regulation Theories

The Relational Regulation Theory (RRT) of Lakey and Orehek (2011) explain the effect of perceived support to mental health and physical health (Uchino, Cacioppo & Glaser, 1996). The theory proposes that people deal with stress and adversities by regulating their emotions through usual social interactions and shared activities ***with other people***. Those with highly perceived-support adhere to their family and friends to provide quality assistance during tough times. Hence, personal relationship maintains a healthy emotional well-being, since it boosts one's morale and self-efficacy (Lakey & Orehek, 2011). Another theory that links social support and health is the Life-Span Theory of Uchino et al.(1996),as they help strengthen adaptive personality traits, such as low neuroticism, optimism and coping skills. Social support and one's adaptive personality traits promote healthy lifestyle and practices (e.g. exercise) and help in dealing with health-related stressors (e.g. job loss). People with low social support are at high-risk of developing sickness or worsening one's condition.

Furthermore, self-regulation is an ability to adjust one's behaviors to meet the social and situational demands (Carver & Scheler, 2007). People who suffered from a neurological disorder which led them to acquire mobility impairment need high self-regulation to meet the situational demands of their current condition. Self-Regulation Theory of Baumeister and Vohs (2007) proposes that patients have an active role in their own healthcare management. The practitioner and healthcare providers acknowledge the responsibility of patients in coping with the experience, complying with treatment regimes, providing self-care and with all aspects of the experience. Baumeister and Vohs (2007) also believe that self-regulation works effectively alongside with high motivation. They argue that motivation

is an important ingredient of a high self-regulation. Simply put, self-regulation behavior would not work if a person has no motivation at all. To this effect, Heckhausen, Wrosch and Schulz (2010) explain in their “A Motivational Theory of Life-Span Development” that an individual has an intrinsic ability to overcome major life course challenges. People have a deep sense of active involvement in managing their own lives, acting in accordance to the pursuit of their goals. And even when confronted with failure or obstacles, they have an ability to bounce back and maintain a sense of self-preservation.

Framework of the Study

In line with this idea, Filipinos are known to be resilient during times of misfortunes (Villafuerte, 2009). They always have their ways of solving their problems, become socially competitive, independent, and know their sense of purpose and belief in a better future. Apparently, spirituality is one of the major factors present in the concept of Filipino resiliency (Aliga, 2007). Having faith and being religious enables Filipinos to grasp and genuinely accept the nuances of hardships in context of God’s will and plan. Additionally, finding meaning in life can be brought by self-reflection and analysis of past experiences. The modified framework for this study (Figure 1) shows the experience of disability by viewing it, not just as a health condition, but as a universal human experience.

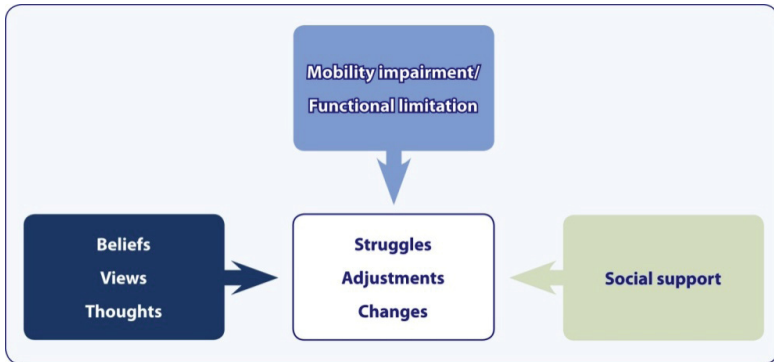


Figure 1. Research Paradigm

Figure 1 depicts the framework of how an individual suffering from a mobility impairment brought by a neurological disorder endures and regulates the changes brought by the impairment in his or her daily activities and future life goals. The individual's ways of coping with the sudden change in life are greatly influenced by his or her intrinsic values (e.g. beliefs, views and thoughts), social support and methodological understanding of his or her real condition. Similarly, the individual, having known that he or she is in a diseased state, will have to contemplate and arrive at the point of acceptance. The acceptance of one's condition is primarily dependent on what he or she believes and thinks of. In the process of gaining understanding, social support will play a significant role to help an individual endure the struggles brought by his or her condition. This is explained by the Relational Regulation Theory (RRT) of Lakey and Orehek (2011) and Life-Span Theory of Uchino et. al. (1996) where the individual's intrinsic set of beliefs, the moral support from the environment and the thorough understanding of the condition constitute the overall coping mechanism of the person --- to keep on struggling and fighting, making the needed adjustments, controlling social setting when doing an action and observing changes that happen after actions are given.

Statement of the problem

With an aim to gain deeper insights into the impact of sudden mobility impairment in the life of individuals, this study tries to examine the inner feelings, coping strategies and experiences of a person who had sudden mobility impairment as they lived. Specifically, it seeks to answer the following questions: First, What are the struggles of a person with mobility impairment beyond human awareness, those that cannot be communicated and invisible to the naked eye? Second, What are the adjustments and changes made after surviving a neurological disorder? Third, How do people, environment, and religious beliefs affect views of themselves and mobility impairment? And lastly, What vital pieces of information could serve as inputs in the counselling program in the tertiary level of education based on the given findings?

Methodology

Research Design

In answering the problems of the study, a qualitative method of research, specifically the life story method was utilized. The method allowed the participants to tell their stories as to illuminate the life of an individual living in sudden mobility impairment and how they perceived their physical condition to show what we do “see beyond mere appearance.” Hence, the researcher’s purpose is to understand their experience, as manifested mainly within their life narrative during the sudden mobility impairment.

Participants of the Study

The participants of this study were three Filipino professionals, who have been all mobility impaired by a neurological disorder. They are survivors of Stroke, Brain

surgery and Traumatic Brain Injury caused by car accident from referrals and recommendations by the Physical Therapy and Rehabilitation professionals of Asian Hospital and Medical Center in Alabang, Muntinlupa City. The eldest participant was 28 years old while the youngest 24 years old, who have been mobility impaired for six months to three years. All three young Filipino survivors are college graduates from reputable schools, from middle-class family and have successful professional careers before their mobility impairment. They were all undergoing medical treatments and rehabilitation during the time of the study.

Research Instrument

This study used semi- structured interview questions patterned after McAdams’s life story interview model focused on one specific event that occurred during the participants’ life story, which is after surviving the neurological disorder. The model asserts that people living in the modern societies provide their lives with unity and purpose by constructing internalized and evolving narratives of the self (McAdams, 2001). Sample questions included in the interview are shown in Table 1 below.

Table 1. Semi-structured interview questions adapted from McAdams Life Story Model of Identity

CATEGORY	QUESTIONS
Disability & Identity	How has your disability influenced/changed your life?
Life experiences:	
Low Point;	Could you think of a scene in your life that stands out as the lowest point from onset of the neurological disorder up to this day?
	What happened in the event, where and when, who was involved, and what were you thinking and feeling these?

Dreams, Hopes and Plans	Did the sudden mobility impairment change your plans, dreams, or hopes for the future? What do you hope for in the future? Dreams? Plans?
Interactions with Others	Do you feel comfortable talking about your mobility impairment? What has been the role of others in regard to your disability? Family? Friends? Community?

Data Gathering Procedure

In using the interview questions of the adapted McAdams Life Story Model of Identity, the researcher consulted three experts in the field of education, counselling and medicine. The participants were subjected to purposive sampling procedure in this study. An informed consent form was provided and signed by the participant before proceeding with the interview, the answers provided to the researcher were handled with high confidentiality. Hence, pseudo names were used and no pertinent data revealed the identity of the participants mentioned in this study.

Data Analysis

Analysis for this study was developed around passages directly from the interview data. Thematic analysis was used to reveal themes from the interview data collected in this study. The analysis involved obtaining an overview of the verbatim transcription, the researcher identified patterns emerging from the interviews. In this regard, Braun & Clarke (2006) stated that a theme captures something important about the data in relevance to the research questions, and represents a patterned response as it gives meaning within the data. Several steps were taken to construct themes, most of which were visibly seen and others emerged upon further analysis. Each theme was labelled based on its content and tediously

reviewed several times in an effort to reduce researchers bias and own interpretations upon the findings

Results and discussions

The participant's responses were clustered into themes generated from the verbatim interview data. The main themes are directly derived from the three research problems of the study: 1) Struggles and emotional experience after the sudden mobility impairment; 2) Adjustment made and changes after surviving the neurological disorder; and 3) Family, social support and beliefs influenced in their recovery. Under each theme, the sub-themes that emerged during the thematic analysis are presented. The gathered sub-themes from participants during the interview session and then pieced together to obtain a comprehensive view of their experience.

Struggles and emotional experience after the sudden mobility impairment.

The struggles include the non-physical effect of the neurological disorder to the participants as stunned by the sudden change in their lives. Three themes were derived from the data analysis relevant to this section the experience of having survived the neurological disorder and living a new life with mobility impairment, as they deal with depression, anxiety, and patience.

Emotional explosions and waking up with depression

Depression was one of the first sub-themes that became evident. According to the American Psychological Association (APA) (2008), it can badly impair the ability to function effectively in everyday situations. All the participants admitted having experienced depression with a perceptible peak on the first few months of their mobility impairment, a common reaction among the participants of

this study. Kan, Barakat, & Sourdif (2011), said that at least one person out of four people will experience depression after stroke. Furthermore, Hackett, etal. (2000) believed that there were risks of occurrence on the onset, middle, and late stages of stroke recovery. The participants felt a sense of grief for activities they were able to do before. For one, there was the feeling of being alone, the feeling that nobody could understand the ordeal much less a feeling of anger.

They felt a sense of uselessness, especially when failing to do the usual activities they were capable of before their impairment. One of the participants shared that she was undergoing psychotherapy, while the other revealed that she suffered from post craniotomy syndrome on the onset of her impairment. The feeling of being a stranger in one's own body also piercingly by struck the participants as much as the feeling of losing control of one's own body contributed to a sense of loss of identity and depression. They underwent to the extent of questioning life and themselves. More excruciatingly, they asked, "Why and Who I am" and started to ponder their self, as they experienced loss of physical abilities through their activities, life as it was before and their independence.

Some of the participants expressed anger and blame God for their condition. Gordon (2011) and Dye (2011) reported that there were people who admitted getting angry at God because they believed that HE had allowed the negative events in their lives. Furthermore, all participants shared the same sentiments that they felt that nobody really understood what they were going through.

A scary fall and days of anxiety

The sub-theme anxiety was also visibly seen. Anxiety is a feeling associated with apprehension, dread and uneasiness that stems from fear of what might have

happened (Sanchez, Abad & Jao, 2000). The participants expressed unease on the loss of functional ability and feared for a complete recovery, the majority worry about not being able to function as they did before the neurological disorder and becoming a burden to others. These include concerns about how they will completely recover. Most of the participants confessed their fears of experiencing another life threatening attack, their dependence on family/caregivers, and helplessness for their sordid condition.

One of the participants also shared her experience of being evidently anxious when being left alone even for a short period of time. Gallozi (2009) said that loneliness poses a danger of developing anxiety and depression. Another participant revealed that he closed himself to the world, confessing that he did not talk to anyone in the first two months of his condition, as he dealt with fears and confusion.

Dealing with Patience

Patience was often mentioned by the participants. The sub-theme of Patience emerged in consonance with frustration, as all the participants underwent rehabilitation at the time of interview. The slow recovery was frustrating on their part, they shared that recovering from a neurological disorder could be very frustrating, as they also dealt with adjustments at home and from an active lifestyle before their sudden mobility impairment. Simple skills like walking, eating, taking a bath, and dressing had become complicated.

Most of them are having long period of therapies without an assurance from their medical team of regaining their normal body function. The participants further shared that the “length of time that it takes to recover from their condition depends on the extent of the damage to their brain.” The participants all agreed that they need to sustainably exert patience on the process of recovery. It is also usual that people

who suffered from neurological disorder feel frustrated about not being able to do what they want to do (Landau, 2011).

All the participants shared their journey and common emotional experience of dealing with depression, anxiety and patience which had an understated impact in their lives. There is far more beyond the physical sufferings of a person with mobility impairments. Certain literatures support the claim that depression (Robinson, 2000) and anxiety (McCoy, 2006; Ramsden & Taylor, 1988) are usual for patients with neurological disorder and mobility impairment. In one study, it was revealed that frustration was observed to stroke patient (“Caregiver Introduction”, N.D.). The researcher further suggested that depression often leads to blaming and hostile behavior.

Adjustment made and changes after surviving the neurological disorder.

Admittedly, the participants were having difficulties adjusting not just physically but emotionally to the changes brought by the mobility impairment. Accordingly, Barton, Miller & Chanter’s study (2002) revealed that creating a therapeutic group would greatly help stroke patients to process their emotions and eventually adjust from their disability. The young survivors shared how they worked on accepting their disabilities as they progress in their therapies. They hope to relearn loss function, body movement and skills necessary for daily living that the neurological disorder had taken away. They narrate how they slowly increase confidence, develop control and maintain a positive self-esteem.

Forced to change life’s plans and dreams

Before being impaired, each one of the participants had set a trail for future plans—the mobility impairment created a major impact in their lives, as they were forced to

change and make adjustments on their plans and dreams. A stroke, for instance, is considered to be an unexpected and traumatic life-changing event (Donnellan, Hevey, Hickey, & O'Neill, 2005).

Most of the participants described themselves as outgoing, active and spontaneous. They shared their lifestyles and plans before impairment. They expressed their dismay over the lack of independence as they are now very dependent on their caregivers, all of the participants were assisted and accompanied by their caregivers during the interview session. They were forced to change their lifestyle and dreams due to their mobility impairment. Considering their limitations, the research reveals that the goals they had set before their impairment may appear to be impracticable.

Coping strategies

Following Taylor's (1998) definition of coping strategies, this sub-theme emerged as the participants showed "individual efforts, both behavioral and psychological to master, tolerate, and minimize the stress of the life-altering event in their lives."

Furthermore, there are evidences that suggest that adequate coping skills are likely to predict success of rehabilitation (LeMaistre, 1999). This theme illuminates how the participants showed determination to regain normal function showing interest in the world, building their self-esteem, and maintaining connections to others. Some of the participants enjoy and at the same time struggle to maintain an active and outgoing personality. They expressed how communication and diversion make them feel better. It became a strategy in terms of coping with their mobility impairment. They admitted that it is a relief to talk it out, spend some time out with family and friends and do something productive than their normal routine of attending their therapy sessions.

All the participants take pride in resuming activities, as they make them feel able. Even smaller limited function than before their neurological disorder were regarded as great improvements like winning off the wheelchair, taking measured tiny steps, moving one finger, bathing, and travelling to nearby places.

Positive Outlook

The sub-theme positive outlook was noticeable and unexpectedly seen throughout the participants during the interview sessions. From the rich qualitative data, researchers deduced the sub-theme “positive outlook” through participants’ sharing of their optimistic thought in life and high hopes for full recovery.

Furthermore, the participants similarly shared that the negative feelings toward the condition improve, as they slowly recover and appreciate their physical developments. Their positive outlook in life blazes desire, affirms determination and hopes for full recovery. They manage to bounce back and use every strength they have to cope with the adversities brought by their sudden impairment. While the road to recovery is not guaranteed to be a smooth trail yet, with their regaining esteem and confidence, they gradually develop optimism and future goals in life.

Change in beliefs and perception.

This sub-theme emerged as the participants shared their different views on health, faith, certain social issues and life in general after their sudden mobility impairment. They narrated how the experience and condition had been an eye opener to them: it made them realize that life is short and their idea of death changed. One of the participants defined death as a painful end. He felt that he was not ready for it, though he acknowledged it is in God’s plans, and that he

had not fulfilled yet his roles in life. Equally, one of them justified that life is full of uncertainties and that it's not the mobility impairment alone but also wanting to have God in the center of her life now. A deeper sense of faith in God after the mobility impairment had a great effect on her moral views and values.

In one statement, a participant further shared that no amount of money, success, achievements can make up for health. They learned to value health more. All participants confessed that they look at other people with disability differently now they feel more compassionate towards them as much as acknowledge that patience is of most important value to them at the moment.

Family, social support and beliefs influenced in their recovery

The changes imposed by the loss of independence from mobility impairment, creates an impact on all areas of the participants lives equally affecting their family, friends and beliefs. The sub-themes on this last theme emerged as the participants indicate what appears to be a contributory factor to their recovery and view of themselves. This last theme illuminates the importance of support, encouragement and understanding in the life experience of having a sudden mobility impairment which was considered to be significant to the participants of this study. According to Dr. Grattan, the stroke patients with supportive family and friends had adjusted successfully after a year of having stroke (Levitt & Seiler, 2002).

Immediate family

All the participants shared how supportive and protective their family are for them. Lakey's and Orehek's (2011) Relational Regulation Theory (RRT) explained that

perceived support from the significant people around the people with mobility impairment would be a great help for them to adjust adequately with their impairment.

“*Stroke* can be described as a family illness, because *life changes* that occur *after* a *stroke* affect all family members,” as reinforced by Kitzm’ller, Asplund and H’ggstr’m (2012). Most of the participants also admitted that it is hard for their family to understand and become used to their condition. The illness of a family member, for instance, will affect the emotional well-being of the other member of the family (Warleby, Moller & Blomstrand, 2001). More evident in the interview transcript the participants narrated how their family deals with the medical finances, frustration, depression and uncertainty, as they help the participants recover and gain back independence in activities of everyday lives.

Friends, social support and the medical team

The participants shared how they value the support and encouragement that they get from most of their friends, and the community even to those strangers that they meet whenever they are out.

The participants commented on the value of offering support to each other to give them a sense of usefulness and of giving help to others which had a positive impact on their self-esteem and hope. They also spoke how their friends, the community and medical team affected their view of their condition and also contributed in frustration.

Religion and faith

The participants recount the strength they get from religion and faith. About two-thirds of stroke patients turn to the comfort and solace of religion on a regular basis (Levitt

& Seiler, 2002). This sub-theme shows its positive role in the life of the survivors after the mobility impairment which influenced the way they experienced depression, anxiety and frustration.

People with mobility impairment get strength and power to continue living through the significant people around them. Social support affects mental and physical health of a person (Uchino, 2009). The support of the family members, friends and the people community strengthens adaptive personality traits such as optimism, coping skills and low neuroticism of people with disability. Also, people with low social support are at higher risk of developing sickness or worsening one's condition.

Spirituality is one of the major factors present in the concept of resiliency for Filipino (Aliga, 2007). Their faith enables them to make sense and genuinely accept their condition and offer it to God.

Conclusions and Recommendations

The struggles in experiencing sudden mobility impairment caused by a neurological disorder, is far more beyond the physical sufferings, it has understated impact on the lives of the young Filipino professionals as they share common emotional experience of dealing with depression, anxiety and patience. Equally, the emotional well-being of the other member of the family and caregivers of the mobility impaired participants are affected adding to the emotional struggles of the person with mobility impairment and affecting their self-concept.

As in every other circumstance, we're never prepared for disability. Yet students who experience sudden mobility

impairment have the right to continue learning, receive strong education and pursue their dreams. This study gives deeper understanding not just on the physical effect of the mobility impairment but also the experiences, feelings and thoughts about their inability to function as they used to. The researcher believes on the importance of strong emotional support in their road to recovery and building a positive self-concept. In view of the findings, the study provides inputs to the counselling program in the tertiary level of education. To accommodate the specific needs of students who are also suffering with sudden mobility impairment.

Thus, a counselling program should be able to prepare them to be resilient towards adversaries that will surely come along the way. It may also give importance on self-care behaviours and coping strategies as well as building social support from family, teachers and classmates that will help boost confidence, motivation for schoolwork, and positive well-being. This will help them make sensible adjustments in personal, social and academic requirements to possibly reduce the barriers brought by their mobility impairment in meeting school demands and in their day to day living.

The severity of the effect of neurological condition indicated significant differences in the coping strategies. Hence, the program should greatly focus on activities that would encourage them to be more open about their feelings and embrace their vulnerability. It could also promote collaborative effort together with the school community and family to build a positive support system for the students with mobility impairment. Equipping them with strategies on helping the person deal with the challenges of the condition would be valuable to further establish his or her well-being. Lastly, the program should also provide training on how to handle school demands and prepare them attain jobs in the future.

It is vital to understand the students suffer from the non-physical or emotional effect of their sudden condition. The functional limitations of their physical condition, ongoing medical and rehabilitation needs require considerable assistance, support and school adjustments that an effective and responsive counselling program can give to students with mobility impairment.

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