

Lived Experiences of Cerebro Vascular Accident (CVA) Patients from Selected Physiotherapy Units of Calicut, Kerala

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Abstract

Objectives: The objectives of the study were to explore and describe the lived experiences of CVA patients and to find the functional independence in activities of daily living of CVA patients. **Methods:** Data collection tools include demographic and clinical proforma, Standardized Barthel Index and a semi-structured interview with a lead question, "Could you tell me what happened when you had the stroke?" The ethical principles of informed consent, anonymity and confidentiality, beneficence and justice were acknowledged and addressed in this study. Pilot study was conducted among three patients with CVA attending Nandi's Rehabilitation Centre, Quilandi, Calicut and the study design was found to be feasible. Main study was conducted among 10 patients attending Malabar Rehabilitation Centre, Nadakkavu, Calicut, Kerala. Purposive sampling technique was used till data was saturated. Average of 45 minutes to one hour were taken to complete each interview. The interviews were audio recorded for analysis. The transcribed data was translated into English; the themes were derived and submitted to three experts for validation. **Results:** The major themes derived from the study were adaptation to life after stroke, living in a restricted world, dealing with trapped emotions, living with altered perception of self and life as rehabilitation... post stroke stage. **Conclusion:** Study concluded that CVA patients find different ways to adapt to their life after stroke. Providing them with opportunities to narrate their experiences and feelings to persons outside the home context might be helpful. Implementing measures to improve function and prevent disability will help to improve their well being.

Keywords: Living with CVA; Stroke; Experience; Qualitative Research.

Introduction

Cerebro Vascular Accident (CVA) is clinically defined by World Health Organization (WHO) as an acute neurological dysfunction of vascular origin with sudden or at least rapid occurrence of symptoms with signs corresponding to the focal areas of the brain resulting in loss of function [1].

More often disabling than fatal, CVA is the leading cause of severe neurologic disability and resulting in loss of productivity [2]. The 2004 estimate of Indian Council for Medical Research showed that stroke

accounts for 41% and 72% of death and disability respectively among the non communicable diseases.³

Surviving stroke may leave one in a state of stressful feelings and emotions on one's current and upcoming life. Majorities need health care and become dependent on others. The dilution in care of a stroke survivor occurs following discharge from the hospital to their house (National Board of Health and Welfare, 2002).

A qualitative study was conducted on experiences, perceptions and challenges of stroke survivors in New Zealand Stroke Foundation. A semi-structured interview was conducted among nine stroke survivors. The data was analyzed using general inductive approach and the themes derived from the data were journey to the new me, moving forward- the highs and the lows, a big learning curve; a whole new life. The study concluded that careful interpretation of the experiences and perceptions of stroke patients provide insight into post-stroke recovery and to give individualized care. 10A limited

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number of qualitative studies were done to explore patients' perceptions of their health status, after stroke. Health status measures are repeatedly used to quantify patients' perceptions [4].

For complete understanding of all the dimensions of life following CVA, it is vital to realize how patients and their family view the effect of CVA on patients' lives and on their recovery [5]. Varied emotional reaction to stroke occur like loss, confusion, grief, anxiety, frustration, fear and even elation where people are "just happy that they survived". So approaching people who had experience of stroke is needed to assess their varied perceptions.

The current study aims at studying the lived experiences of stroke survivors, which depicts their perspectives on post-stroke life. A qualitative approach was considered most suitable for this research study as interpretation of one's lived experience is purely subjective. This approach is concerned, not with uncovering a pre-existing truth, but with uncovering meaning i.e. how people make sense of their lives, and their experiences. This study is, therefore, an important exercise in advocacy for older people with a disability. The findings from this study can be used to support relatives and family members of stroke patients and to enhance their supportive role in rehabilitation efforts and thereby improve the quality of life.

The objectives of the study were to explore and describe the lived experiences of CVA patients using phenomenological approach and to find the functional independence in activities of daily living of CVA patients by using Barthel Index.

Methods

The research design adopted for the study was Descriptive phenomenology. Colaizzi process was used to analyse phenomenological data. The sample consisted of patients who were diagnosed with CVA attending Malabar Rehabilitation Centre, Nadakkavu, Calicut, Kerala. A total of 10 participants were included in the study as the data saturation was achieved. Patients diagnosed with CVA for a period of at least 6 months prior to interview, between ages of 40-80 during the period were selected purposively for data collection.

The data collection tools were used in the study: Demographic and clinical proforma of patients with CVA to acquire the background data and the clinical data of the patients., Barthel Index measures functional independence in the domains of personal

care and mobility and Semi structured interview to explore the lived experiences of the CVA patients.

Demographic proforma consisted of total of 12 items to collect information on name, age, gender, marital status, address, contact number, type of family, place of residence, educational status, occupation prior to attack of CVA, monthly family income, and distance of physiotherapy unit from patients home.

Clinical Proforma contains total of 7 items to collect information on date of diagnosis of CVA, Duration of illness, current symptoms, specific activities, comorbidities, frequency of visit to the physiotherapy unit and current medications of the patient.

Barthel Index is a 10-item ordinal scale which is standardized that measures functional independence in the domains of personal care and mobility. The Barthel includes 10 personal activities: feeding, moving from wheelchair to bed and returning, doing personal toileting, getting on and off toilet, bathing self, walking on level surface (or propelling wheelchair if unable to walk) and ascending and descending stairs, dressing, controlling bowel and controlling bladder.

The response categories of disability in an activity were defined and rated in scale steps (0, 5), (5, 10), (5, 10, 15), (0, 5, 10, 15) dependent on the item. The Barthel can be administered via interview by asking the patient, friends/relatives as the sources or by observation of the patient's performance in a specific setting (observation is not mandatory), or by asking the patient to demonstrate an activity. In this study, interview technique was used to collect data. An overall score is formed by adding scores on each rating. 5-point increments are used in scoring, with a maximal score of 100 indicating that a patient is fully independent in physical functioning, and a lowest score of 0 representing a totally dependent bed-ridden state. It is stated that the higher the score is, the higher the degree of independence is. There is no classification of score into categories.

Permission was obtained to use and translate the Barthel Index from the Maryland State Medical Society. The translation process of the tool into Malayalam was done as recommended by the Mapi Trust. The forward translation of tool to Malayalam was done by two experts independently. By having a discussion between both these translators and the researcher, a reconciliated version is produced. The resulting version was translated back to English by an English expert. A comparison of backward version with the original version was done by the researcher on meeting with English expert. This version was administered to five CVA patients attending Nandi's

Rehabilitation Centre, Quilandi, Calicut, on 2nd December 2013 for cognitive debriefing. This was done to determine clarity of the items, difficulty in understanding, the time required for the interview. There was difficulty in understanding a translated word in Barthel Index, which was modified. The test took approximately 3-5 minutes to complete. Proof reading of the final Malayalam version was done.

The reliability of translated tool was established by giving the tool to 20 individuals diagnosed with CVA attending 'Physiocare', Physiotherapy unit, Narikkuni, Calicut, Kerala from 7th-9th December 2013 after taking administrative permission from the authorities. The reliability of translated tool was calculated by Cronbach's alpha method and was found to be 0.88. Hence the tool is reliable.

Semi Structured Interview

Based on the purpose of the study and after reviewing ample literature extensively, a semi-structured interview was drafted. It comprised of a lead question and 13 open ended question to explore the lived experiences of the CVA patients. The lead question was "Could you tell me what happened when you had the stroke?" The order and type of the probe questions depended upon the answer provided.

To ensure the content validity, tool along with the problem statement, objectives and criteria checklist were given to 6 experts. Experts were selected from the field of Nursing, Psychology, Public Health Research and experts from various stroke organizations. The experts were requested to give suggestions and opinions regarding the relevancy, adequacy and appropriateness of the item. One of the significant suggestions was that before validation, the lead question was "What are your experiences related to your disease?". Based on the suggestion the lead question was changed to "Could you tell me what happened when you had the stroke?" after validation. The necessary modifications and additions were done as per the expert's suggestions and the tool was finalized. Language validity was established by translating the tool from English to Malayalam and retranslation to English by language experts.

Pretesting

Prior to conducting interviews, as a beginner of qualitative research, a practice session was piloted with a physiotherapist not involved in the study, using a draft interview guide to obtain practice and feedback on the process and content of the interview.

Following the insights and feedback that emerged from this pilot session, questions were made more specific and open ended in order to facilitate flow and transition during interviews.

Reliability

Reliability or consistency of the data was done in method of data collection itself. It was ensured by using audio recorder for collecting the data. The researcher went back to the narratives to check the originality of the data. "Member checking" was achieved by getting agreement from the participants on the emerged results. Verification of verbatim was done as well as clarity of the unclear information or incomplete materials were ascertained. Review of the emerging ideas through discussions with the study guide was also done and an additional cross checking of the whole analysis process was done by the guide.

Before the data collection, the investigator attempted to bracket her own knowledge and experience about the phenomena under the study. The data collection was from the month of December to January 2014 which was collected by the investigator. The data was collected from CVA patients attending Malabar Rehabilitation Centre, Nadakkavu, Calicut, Kerala after obtaining prior permission from authorities. The recruitment approach was whereby the chief physiotherapist in the centre identified appropriate CVA patients through the records. The patients were contacted by telephone and the date of their next visit to the centre was collected and informed that they will be interviewed in their next visit.

CVA patients who met the sampling criteria are approached by the researcher in the clinic. Privacy was assured by collecting data in a separate room where the conversation was not disturbed by telephone or other patients or staff and family members if possible. The investigator introduced her to the participants and rapport was established. The objectives of the study were explained to the participants. Assurance of confidentiality of their response was given and anonymity was maintained throughout the study by giving them pseudonyms. Informed written consent was obtained from participants. Patient information sheet was given to participants. Permission was taken from the participants to visit their homes if any need arises.

Following this, participants were interviewed, each lasting for an average of 45 minutes to 1 hour, where the participants were allowed to talk freely about their lived experiences. The researcher started by asking

participants to tell his/her experience about what happened when they had the stroke. Language of communication was either Malayalam or English. At the very end of each interview, background data was obtained using Demographic Proforma and Clinical profile by using Clinical Proforma and functional independence in activities of daily living by using Standardized Barthel Index. Audio recording continued during this phase of the interview session to capture any further information that may have been revealed.

At times the patient's own language styles were adopted, and their own comments re-stated and incorporated into further questioning. In addition to the main interview questions used which initiated and guided conversation, some of the probe questions asked were "How has the stroke affected your life?", which clarified responses and encouraged elaboration. Nine patients were interviewed twice, and were free to stop the interview at any time. A simultaneous audio recording was done using a tape recorder/mobile recorder. Immediately following the interview, impressions, reflections, observations such as if they were tearful or had a depressed affect, any notable features of the surrounding environment such as noise or interruptions, rapport between the researcher and participant was written down in order to identify non verbal communications which could help to depict the meaning of participant's experiences. As the researcher found that same information and content was repeated and data saturation was achieved, data collection was limited to 10 participants.

The data collected from the interview was transcribed by the researcher. The duration of first interview was approximately for one hour and the investigator had to go back to the participants to confirm the verbatim. None of the participants changed their transcripts. Transcribed data was translated to English. The themes were derived and were submitted for validation to three experts.

Results

The findings of the study revealed that majority of participants 5 (50%) belongs to age group of 41-50 years and had high school education. Majority 9 (90%) were males and were from rural area. All the participants 10 (100%) were married. About 8 (80%) were from joint family. About 3 (30%) has a monthly family income of Rs 15,001-20,000. Majority 7 (70 %) of participants lived within five kilometers from physiotherapy clinic.

It was found that out of the 10 participants, 8 (80%) were independent in feeding and walking on a level surface. All 10 (100%) had control of bowels and bladder. Majority 8(80) need help in getting on and off toilet and in bathing. Most of the participants 7(70%) can ascend and descend stairs independently and can move from wheelchair to bed and return. Most 7(70%) need help in personal toileting and in dressing.

Based on the objectives of the study and the analysis of the verbatim from the CVA patients, five themes were identified. Open Code 4.2 version software was used for coding the data.

The Themes and Subthemes Derived were

1: Adaptation to Life After Stroke

The formulated meanings are:

- CVA is a chronic and self limiting disease, which affect quality of life. Patients have a lot of physical disabilities like-difficulty in walking due to paralysis and weakness, unable to perform self care activities, unable to go for job and find it difficult to adapt to these changes
- Patients felt their life like being plucked and planted somewhere else and were not able to do anything or act freely.
- Patients expressed that they were able to do their self care activities much better compared to previous and believe that it would improve further with physiotherapy
- Patients expressed that their relief from being recovered from stroke even when they are left with certain disability
- Patients tries to adapt to their disability by using walking stick, footwear with straps, eats with left hand, use stool for toileting and bathing etc
- Majority have very positive feeling towards with treatment they receive from physiotherapy clinic and says they are improving
- One patient expressed that they cannot do religious rituals- bending and kneeling down during 'niskara' (praying method of Muslims) becomes difficult and he uses an improper way of praying due to his disability.

1.1 Being Plucked and Planted... a Transition in Life

- Participant 7: I never haven't been so annoyed like this.....I was very sad for three months...it

was horrible...very young children, you know?...My daughter studies in 7th and son in 5th....and why...it happened in this young age.....I feel automatically I'm being plucked and planted somewhere else...

1.2 Recovery Leads to Relief

Patient expressed his concerns on being ill, and relief of being improved from the previous condition

Participant 1: When I got up, I had headache....then my limbs got paralyzed like this...right hand side....she brought the tea...couldn't hold it... ..I was paralyzed....does physiotherapy now...paralysis has been cured...now I do exercise at home also....Earlier a little spilled from the glass...now it is OK.

1.3 Adaptation to Disability

Participant 2: ... physiotherapist advised me to walk freely... Now I walk with a walking stick...this physiotherapist offered it for me... I am disappointed of being like this.....a little I can walk freely...within the house...still walking stick is a must.. I find difficulty at the toilet...takes bath sitting on a stool...Find problem to bend..

1.4 Rays of hope for future from stroke experience, situations and similar survivors

Participant 1: I was a KSRTC driver...got retired....now I don't go...I drive vehicles... I usually go out to Mukkam, REC and all, in car along with younger brother. He used to take me. I have a jeep too... First I drove...I searched for clutch, brake...a confusion like that...It was like driving in a second phase...practiced like that..Now I m OK...Planning to take school children to school next year...As I have my own vehicle...let me see...if it is possible only...

1.5 Nature of support and care from family and friends

Participant 10: As I'm not cured for so far, everyone took it as their matter...all speak only about my arm...that why doesn't get cured...so and so....they would say it is because I don't do therapy....that I don't pay attention...that I don't shake my arm...they will ask me to do it strongly.... Everyone count it as a permanent disease....

My family suggest for 'ayurvedam'. My brother wanted me to consult Aryavaidyasala, Ayurvedic medicines...warming the body...Thus it would be cured....doctor suggests physiotherapy...

1.6 Spiritual adaptation

Participant 8: ...Now I don't go to Mosque also...can't bend down for 'niskara'. I can't pray at the proper manner...after sitting...I bend down my head to a chair....I keep a chair in front of me....worried of not having a proper niskara..

2: Living in a Restricted World

Formulated meanings are

- Patients were not able to do anything or act freely. Even though they have desire to do, their dependency on others and disability in walking prevents it
- Some of the patients were not attending social gathering or festivals and do not go for social functions like marriage
- Some expressed their inability to attend work due to disability and felt it as occupation by default
- Many patients were diabetic, hypertensive and try to control their diet for betterment.

2.1 Being Housebound

Participant 8: I don't go out...always remain at home...because I can't go out. If I fall, it will be worse...Now I don't go to Mosque also...can't bend down for 'niskara'.

2.2 Adjusting to the Restricted Dietary Patterns

Participant 1: ...Earlier I used to drink...Now it's stopped...Made a change in eating habits...no fried items now...eat very less now...not eat at night.. now I have one fourth food of what I used to have eaten..

2.3 Adjusting to the Restricted Occupational World

In this study participants were earning members prior to CVA, and they feel disappointed now.

Participant 3: I'm president of Mahila..and the Committee member of Kozhikode district.... Now I don't go...If it is needed I will ring...they don't have much idea.....though it happened to me...they didn't dismiss me.....recently I attended meetings of woman's committee and area committee...that also was by using a vehicle...couldn't avoid that...So I went...if I'm cured once, I want to continue...

3: Dealing with Trapped Emotions

The formulated meanings are:

- The chronic nature of the disease and dependency

caused variety of emotional problems for the patients.

- Some patients experienced increased anger, frustration about their condition without any solid reason
- Patients had number of physical disabilities, they were unable to do their activities themselves and are helpless to meet their needs
- Every human being has the desire to fulfill their basic needs. Patients have a feeling of causing burden to others, when they have to depend on others for these needs. This cause parallel suffering to family members, friends etc
- Patient expressed that during the initial periods of stroke they had vivid memory. They were unable to recognize even their wife, daughter and the surroundings. Some were unconscious and had memory loss.

3.1 Coping with Emotional Disturbances

In this study the investigator found that majority of patients manifested a variety of emotional problems

Participant 7: I often get angry...particularly to wife... whatever she says I get angry telling 'the other'...I never haven't been so annoyed like this...When she speaks.. I'm about to beat...that much angry... I'm very sad...for three months...it was horrible...very young children, you know? Daughter studies in 7th and son in 5th..that why...it happened in this young age...

3.2 Feeling of Helplessness

Participant 2: I find difficulty at the toilet...takes bath sitting on a stool...Find problem to bend...feel difficult to wear trouser...do shaving by myself...If shaving is not proper...wife will say it is not over...then I will shave that also...helpless to meet my needs...I feel I'm sick

3.3 Feeling of Causing Parallel Suffering to Family

Participant3: ... In kitchen I will do nothing by gas...won't go to stove.....I will sweep the floor...clean it...won't wipe...Now I can arrange my hair... Previously my husband will do all these....he does everything.....He (Husband) hasn't gone for work for 13 months... he does painting.

3.4 Vivid memory...an altered mental state at acute phase

Participant 1: That time I couldn't recognize her and my daughter...could recognize others of family...it took 1-2 week to be improved...know only old events...

Living with Altered Perception of Self

The formulated meanings are:

- Patients were upset and sad because of their dependency on family members even for self care activities like unable to go to toilet or bathroom alone.
- Some patients experienced low self esteem because of difficulty in talking due to facial deviation, concerned about the appearance of face and they keep silence in majority of situations

4.1 Living with a Body in Need of Support

All the patients were dependent on others for their self care activities.

Participant 2: ...can't board a vehicle...If I want to get into an auto, someone should lift my leg...I don't climb up steps...still I manage to get in home...I'm feared...whether I would fall down...

Participant 4: Always need help to go to toilet and all...to wipe body and to pour water...can't bend down and take a bath....I sit on a stool for bath...shaving...at barber shop...

4.2 Body Image Disturbance

Participant1: 7 months before I got stroke.....even now speech hasn't become OK...So I keep silence... All my friends know, close friends comes frequently...Will come here...Will chat...Will dine...when they come I speak a little...

5: Life as Rehabilitation...Post Stroke Stage

The formulated meanings are:

- The patient expressed that they had spent lot of money for physiotherapy, and are having low family income.
- One patient expressed that he was not aware of physiotherapy and its benefits and no one has given any information on such clinics
- Majority have very positive feeling towards with treatment they receive from physiotherapy clinic and says they are improving

Most of the patients expressed that rehabilitation through physiotherapy was essential to recover from stroke.

5.1 Lack of Resources

Participant 4: physiotherapy made a change...now for a month it is not regular...comes often, not

continuous...difficult to reach here...too far...needs a vehicle...almost 5 kilometers....no one to accompany...

5.2 Inappropriateness and Timing of Information

Participant 9: Physiotherapy has been started for the past two months...For the first six months we didn't do it...from hospital we were asked to do it at home...we were not aware of visiting a clinic...Some said that it will help walk...thus we went

5.3 Experiences with Physiotherapy...a Recovery Stage

Participant 10:I was admitted there for 10 days....returned home. I noticed that my limbs is not moving...they prescribed physiotherapy...thus came here...doctor also said...that physiotherapy is the only remedy...so to continue that itself.....therapy adds an energy to body...it is only for one day....if it is continued at the next day, then only that energy will sustain...now I have completed one year like this...

Discussions

One of the formulated meaning in the present study was patients felt their life like being plucked and planted somewhere else and were not able to do anything or act freely.

The present study finding has being supported by a phenomenological study by Simone Setal. to explore the lived experiences of 15 stroke survivors who attended various rehabilitation centers in Rome and Naples. The findings of the study revealed that patients experienced a 'deeply changed life'. Not only had life changed for survivors but it was deeply changed [6].

A study was done by Lipka-Blachly J to explore and capture the individual experiences of stroke from six survivors. The study findings suggest that many patients expressed that they move independently in their home but spent most of the time at home and described it as loss of independence. All the participants expressed how their inability to drive completely impacted their independence and that they were dependent on others to take them out [7].” This supports the findings from the present study which identified one subtheme as being housebound.

Altered mood is common after CVA. The subtheme derived in the present study feeling of helplessness and feeling of causing parallel suffering to family. A grounded theory study done to describe experiences with mood changes at 1, 3, and 5 years after stroke in Australia. The four main categories identified in this

study were feelings of frustration, reduced self efficacy, dependency, and loss. The participants were required to rely on other people for assistance, which contributed to their experience of low mood. It is shown that mood changes continued well beyond and enhanced services were needed to monitor and address low mood [8].

A qualitative study done by Lawrence M and Kinn S in UK to explore stroke experience and the rehabilitation needs, priorities and desired outcomes. The phenomenology of Merleau-Ponty was used in the study. Up to four interviews were done on 10 adults over two years. The study found that survivors seek to return to normal, ie to a life as they knew it before stroke through rehabilitation [9]. These findings were contradictory with the present study were no one expressed that they want to return to a life before stroke, but a need to improve further.

This study concluded that CVA patients finds different ways to adapt to their life after stroke. Providing with opportunities to narrate their experiences and feelings to interested and qualified persons outside the home context might be helpful. Implementing measures to maintain, regain or improve function and prevent disability among patients and providing assistance and support will help to improve their well being.

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