

CHALLENGES IN LIFE AFTER STROKE: A METASYNTHESIS

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ABSTRACT

Stroke being one of the major chronic illnesses world-wide, needs to be addressed by the health-care organizations. Stroke can affect virtually all human functions, and unlike other disabling conditions, the onset of stroke is sudden, leaving the individual and the family ill-prepared to deal with its sequel. A single qualitative study is not adequate to understand effect of stroke on stroke survivors. Thus the present review was conducted to identify, compare and synthesize published qualitative evidence to have in depth understanding of quality of life after stroke. Published articles were identified from the Medline, CINAHL, Social Sciences Citation Index, PsychInfo, a hand search through selected journals published since 2005, and from references lists. The articles were assessed for their relevance to the focus of interest and appraisal for rigour. The key themes were extracted from the data and were summarized, compared and synthesized. The search identified 64 papers with potential relevance to the review question, of which 6 articles met the review criteria for relevance. A total of 84 samples aged between 18 to 77 years from 6 studies were recruited for data collection. The themes identified were social relationship, psychological status, physical status and environmental impact and coping strategies. The results of research review supports that stroke clients were having a good coping in spite of having a strained social relationships, psychological distress, poor environmental and family support with various degrees of physical deficits. The results of research review supports that stroke clients were having a good coping in spite of having a strained social relationships, psychological distress, poor environmental and family support with various degrees of physical deficits. In order to enhance a positive coping further, they need special education and training focusing on their emerging needs. Social interactions need to be improved to overcome impact of psychological distress. Health care facilities should be made available, accessible and strengthened with skilled manpower to serve the stroke clients in a better way. Family members need to be made aware and trained to meet various needs of the clients. Regular follow up and counseling services should be strengthened for both stroke clients and family members for their changing needs, roles and functions.

Key words: CINAHL, Social Sciences Citation Index, Stroke.

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INTRODUCTION

Stroke is one of the major chronic illnesses world-wide that health-care organizations need to address for the next several decades. Stroke can affect virtually all human functions, and unlike other disabling conditions, the onset of stroke is sudden, leaving the individual and the family no time to be prepared to deal with its consequences [1]. According to existing research, 15 million people worldwide are diagnosed with stroke annually and five million of them remain permanently disabled (WHO, 2011) [2]. Stroke is the third most common cause of death in developed countries. Although

stroke is more common among men, women become more severely ill. It is supposed that stroke prevalence will increase due to the ageing population in the industrialized countries even though incidence of stroke is declining due to better control of high blood pressure and decreased use of tobacco in these countries (WHO, 2011) [3].

Low and middle-income countries shoulder 80% of the disease burden but research on stroke appears to be insufficient or lacking in developing countries. A rising incidence is suspected in developing countries as these countries struggle with increasing prevalence of risk



factors, especially diabetes (Feigin, 2005) [3].

According to the National Stroke Association (2009): 10% of stroke survivors recover almost totally, 25% recovers with minor impairments, 40% experience moderate to severe impairments that require special care, 10% require care in a nursing home or other long-term facilities, 15% die shortly after the stroke and approximately 14% of stroke survivors experience a second stroke in the first year following a stroke [4].

The social, physical and psychological consequences of stroke are devastating. These consequences are described by studies that elaborate Quality of Life (QOL) [5]. The patient's personal evaluation is important in the assessment of physical and social outcome of the disease, i.e. quality of life [6].

Various studies investigating stroke outcome focused on physical functioning or functional abilities in terms of activities of daily living. In recent years there has been interest in an expanded range of outcomes in the study of recovery, including health status, social participation or quality of life and the use of an increasing number of patient-centered assessments. A meta-synthesis of existing qualitative studies can provide direction for nursing practice and research in this area. Thus the researchers decided to identify, compare and synthesize published qualitative evidence to have in depth understanding of challenges of life faced after stroke.

Objective

To identify, compare and synthesize published qualitative evidence to have in depth understanding of challenges of life after stroke.

METHODS

The process of meta-synthesis comprised of 3 steps: (a) identifying the published papers for inclusion and determination of their relevance. (b) Quality appraisal and data extraction and (c) summarizing and synthesis.

Identifying the published papers for inclusion and determination of their relevance

Published articles were identified from the Medline, CINAHL, Social Sciences Citation Index, PsychInfo, a hand search through selected journals published since 2005, and from references lists. The Key words used for search were 'Stroke', Cerebrovascular accident', 'quality of life' and 'challenges after stroke'. The suitability of the study for inclusion was determined by following screening questions: (1) Do the report findings of paper involve qualitative methods for data collection and analysis? (2) Is the focus of paper suitable to the synthesis topic? Studies focusing on qualitative methods to explore experiences of subjects living with stroke from the perspectives of individuals who had experienced stroke were included in synthesis. However the studies reporting focus from the perspectives of caregivers of stroke patients were excluded. Studies

reporting use of mixed method approach were also excluded.

Inclusion Criteria

- Qualitative studies with phenomenological, grounded and descriptive research design.
- Studies with adult stroke patients as participant.
- Recent studies for period of 10-12 years.

Exclusion Criteria

- Studies including subjects with significant language impairment, cognitive impairment, other major co-morbid medical difficulties, or with a past history of psychiatric problems.
- The studies reporting focus from the perspectives of caregivers of stroke patients.
- Studies reporting use of mixed method approach.

Quality appraisal and data extraction

Two main criteria were applied in the evaluation of qualitative research i.e. credibility and relevance. Studies meeting inclusion and exclusion criteria were subjected to further scrutiny using the following series of 7 questions:

Credibility

- Were sampling strategies and data collection methods explained?
- Was method of data analysis discussed and enough data provided to allow the reader to determine support of the data to the interpretations (auditability)?
- Did the authors acknowledge the influence of the research process and the presence of researcher including the role of prior biases, assumptions and experience, on the collected data (reflexivity)?
- Has appropriate attention given to negative cases and to contradictory data?
- Had the author explored alternative, plausible explanations for the data collected and incorporate a range of different perspectives (fair dealing).

Relevance

- Was information regarding participants, settings and context provided (transferability)?
- Did the author broadly discuss the findings, proposed generalization of findings and/ or suggested scope of future research (analytic generalization)?

Summarizing and synthesis

Condensing labels were used to summarize and list down the perspectives of various studies. Themes identified by researchers were noted, and cross checked against their cited data. After summarization of data in each paper by labels, these were charted under unifying headings. Concepts were developed that synthesized the findings of all the papers included in the meta-synthesis



using an inductive and deductive process.

RESULTS

Identifying the published papers for inclusion and determination of their relevance

The search identified 64 papers, of which 14 papers had potential relevance to the review question. Five papers of potential relevance were omitted because of use of mixed method approach with main focus on quantitative aspects. Further, 3 additional studies were excluded as they presented findings more in keeping with a topical survey; rather than thematic analysis and provided results as frequency of codable remarks rather than themes. Thus remaining six studies [7-12] were taken for the second step.

Quality appraisal and data extraction

All 6 studies satisfied the criteria for quality appraisal and data extraction.

Summarizing and synthesis

A total of 84 samples aged between 18 to 77 years from 6 studies were recruited for data collection. 27 were males and rest of them was females. Studies from 2005 to 2017 were included. There were 4 Phenomenological studies and 2 grounded theory studies. The method of data collection was self report technique, by using semi structured questionnaire, open ended questions, and in depth interview technique. The themes identified were social relationship, psychological status, physical status, environmental impact and coping strategies. (See figure 1 & 2).

Theme 1: Social relationship

Subtheme: a) Social support

Findings of the meta-synthesis reveals that stroke puts severe stress on social relationships. Patients reported stroke to often results in breaks with significant others, for example, spouses or children. Alterations in these relationships have a deep impact on both patient's social life and feeling of social security.

b) Communication

Patients mentioned experiencing extreme emotional reactions because of communication difficulties related to loss of speech as it have more direct impact on social relationships than do other stroke-related disabilities. Loss of speech was described as humiliating experiences especially lack of ability to speak to medical professionals. Patients also felt frustrated related to the difficulty of speech as they were being dependent on others.

c) Independence

Patients expressed frustration as they were not able to perform basic tasks. Although, they reported appreciating the support of their family and other

caregivers; however they didn't felt comfortable with their dependence on others.

d) Role changes

Subjects mentioned that their social roles were altered radically when they can no longer work. It was apparent from participant discussion that shifts in social roles often worsen relationships that are already stressed by the dependent status of the patient.

Theme 2: Psychological status

Subtheme: a) Fear of stroke

The unanticipated onset of stroke that denies the individual a period of adjustment seems fundamental to understanding this fear. With lack of an opportunity to be prepared physically or psychologically for the onset of stroke, participants mentioned feeling vulnerable, exposed or caught unaware by stroke. This tends to boost the experience of stroke as threatening and terrifying. The event of stroke was crucial in bringing awareness of mortality to their lives, with the time post-stroke perceived as 'borrowed time'. Participants described the impact of stroke as unleashing 'the fear of the unknown.

b) The loss of self

Participants perceived the stroke to steal their core sense of identity from them through the loss of former activities, lifestyles and roles, and made them to struggle to forge a new sense of identity. Subjects were frustrated while delineating two versions of self: the person pre-stroke and the person post-stroke: the coping styles used in the past were no longer helpful to them and left them feeling vulnerable. They identified loss of their former roles as parents, or breadwinners, or caregivers. Loss of energy and loss of youth were described by majority of the subjects as significant hindrance in returning to their pre-stroke selves. Many reported stroke to be responsible for their loss occupational role; and thus their sense of identity and self worth.

c) Sense of loneliness/isolation

Participants experienced a sense of external isolation as they lost their engagement in previous lifestyle and roles. The necessity to cope alone with stroke without previous social support was enhancing sense of internal isolation. They expressed desire of other people to understand impact of stroke for them; although they also colluded with other people in not exposing their vulnerabilities.

Theme 3: Physical status

Subthemes: a) Deterioration of health

The majority of participant revealed being left with some residual deficits including weakness or paralysis on one side of the body, speech difficulties and vision loss. Subjects also reported difficulty in mobility and walking. Most patients despite having a stroke deficits



managed to hold a positive concept of their health and perceiving themselves to be healthy. Subjects with more severe disabilities felt less independent as they had to depend on their spouse/ partner or nursing staff to undertake the activities of daily living. A few patients reported regain of independence in physical functions such as walking after immediate stroke rehabilitation period was over. Most of the stroke survivors try to adjust to changes brought by the stroke by having positive outlook and trying to make best of their retained functions.

b) Lack of Personal Care

Participants revealed to experience lack of knowledge and skills; subjects and their families had no idea about how to deal with the new situation. They perceived problems in transferring, lifting, feeding, and drug taking; without receiving appropriate information and education. This lack of knowledge was believed to be resulted in loss of energy, increased family burden and delays in recovery. On occasion patients acknowledged that their physical problems placed limitations on their routine activities. However; Patients tried to learn to adapt to their physical limitations.

Theme 4: Environmental Impact

Subthemes: a) Inadequate rehabilitation Services

Participant described long travel times to the centers and inappropriate transportation and public facilities aiding in difficulty to use existing services and the rehabilitation services in the community. Rehabilitation services mainly offered in public rehabilitation centers was perceived to be usually relied on students as the work force causing lack of satisfaction among patients. Majority of the patients were depended on family, friends or neighbors to drive them to access rehabilitation services. Few of the rural area subjects reported that there was local transport available to collect

people at their homes and take them to day-care centers, but this service was also rare.

b) Financial problems

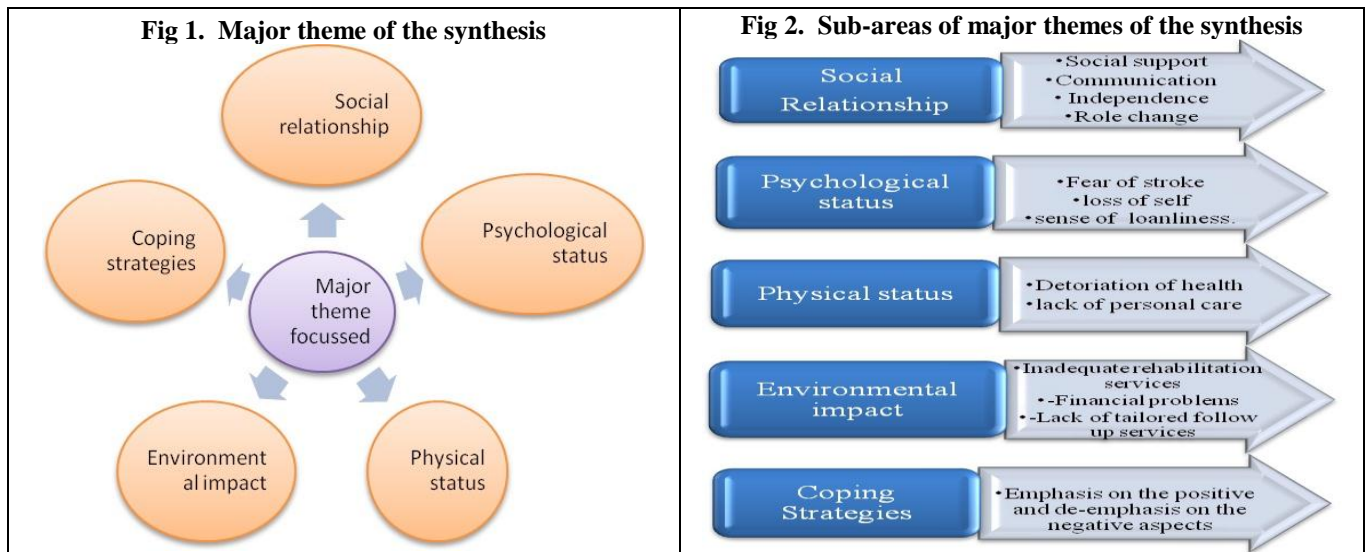
One major problem experienced was the inadequate social insurances for stroke survivors and their family caregivers, as they were perceived not to support the rehabilitation services sufficiently. Self bearing of expenses was a great burden to patients and family members. Patients living in their own homes were no longer able to go upstairs, use the bath or walk unaided because of their disability, increasing necessity to obtain modifications to the home environment and thus aiding to financial stress.

c) Lack of Tailored Follow-Up Services

Participant experienced that follow-up system was not tailored to their specific needs as stroke survivors. Lack of regular meetings, failure of coordinator to address personal questions and Lack of professional help were major concerns of participants.

Theme 5: Coping strategy

Subjects reported a persistent emphasis on the positive and de-emphasis on the negative aspects of their stroke to cope up with the situation. Practicing activities at home was felt useful for progress in relation to these three: personal care, everyday responsibilities and social functioning. Participants wished hard to return to their pre-stroke responsibilities. The majority of participants believed that they were lucky to have mild residual disability and believed in complete recovery. Various coping strategies that stroke survivors used to deal with the new life situation were sustaining the integrity of the family, taking spiritual help, gaining knowledge and skills regarding post stroke life and recovery, Medical follow ups, and using nursing care at home.



DISCUSSION

The main focus of the review was to find out challenges faced by stroke clients which were categorized in various aspects like social relationship, psychological status, physical status, environmental impact and coping strategies

When it is concerned about social relationship, stroke caused role changes and communication problems as well as made stroke survivors dependent that had deeper impact on their mental wellness, leading to extreme negative emotional reactions, frustration and stress.

Stroke was found to have devastating psychological impact on stroke survivors. Anticipated fear was not present as it was an unexpected event; however the seriousness of condition made them to perceive their present life as borrowed life. The stroke caused loss of identity as they were unable to preserve their former roles, lifestyles and activities, which inculcated sense of loneliness and external isolation among them.

The most common residual physical effect reported was motor dysfunction and communication problem. These motor changes made it difficult for the subjects to adapt to their daily routines. There was extreme need of special education and training. The perception of stroke clients regarding their health status varied depending on their level of residual effect. Most of the patient perceived themselves to be healthy as the effect were found to be less severe.

It was found that the availability and accessibility of rehabilitation and follow-up services was inadequate. Also those services were not rendered by trained and skillful professionals that caused poor satisfaction among stroke clients. This also put them under financial constrain. Subjects were found to be focused on positive aspects of present health status rather than the residual

defects, so their coping strategies were found to be healthy as most of the stroke client were having hope in their lives and positive hope on their recovery.

CONCLUSION

The results of research review supports that stroke clients were having a good coping in spite of having a strained social relationships, psychological distress, poor environmental and family support with various degrees of physical deficits. In order to enhance a positive coping further, they need special education and training focusing on their emerging needs. Social interactions need to be improved to overcome impact of psychological distress. Health care facilities should be made available, accessible and strengthened with skilled manpower to serve the stroke clients in a better way. Family members need to be made aware and trained to meet various needs of the clients. Regular follow up and counseling services should be strengthened for both stroke clients and family members for their changing needs, roles and functions.

STATEMENT OF HUMAN AND ANIMAL RIGHTS

All procedures performed in human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

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Nil

CONFLICT OF INTEREST

No interest

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