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#### RESEARCH ARTICLE

#### Disabilities caused due to stroke

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#### **Abstract**

Background: Stroke is a non-communicable disease caused due to obstruction of supply of blood to the brain. It is one of the leading causes of disability adjusted life years lost. The aim of the present study was to consolidate the disabilities faced by stroke patients from the clinical experiences of the experts involved in giving care to the stroke patients. Materials and methods: A qualitative study design was utilised. All the participants were recruited from Kasturba Medical College, Manipal-Karnataka, through professional networks. Semi structured face to face interviews were conducted and oral informed consent was taken. Interview guide was developed through literature review and discussion with the research team. The interview sessions were carried out till the saturation was obtained and 15 participants were recruited. The International Classification of Functioning, Disability and Health core sets for stroke were considered as broad themes for amalgamation of responses. Deductive approach was used to analyse the data. Results: Majority of the participants claimed that motor disabilities were the most common followed by impairment in performing activities of daily living, language problems, difficulties of cognition and perception, psychological problems, caregiver burden, sexual and urinary problems. Conclusion: Each disability varies from person to person and has profound effect on patient's as well as caregiver's quality of life.

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## INTRODUCTION

Stroke is one of the non-communicable diseases caused due to obstruction of supply of blood to the brain, which can be caused due to bursting of a blood vessel or blockage due to a clot. Its consequences depend on the part of the brain involved and its severity which can range from transient ischemic attack to death. Leach year around 15 million people across the globe suffer a stroke, approximately six million deaths occur and five million suffer from life-long disability.

In South Asian region the prevalence of stroke is high particularly in young individuals, 4 studies in India have reported that 10-15% of stroke occurs in people under the age of 40 years. <sup>2,4,5</sup> Morrey and Lopez have projected that by the year 2020, 61 million disability adjusted life years (DALY's) lost can be attributed to stroke, 6 out of which 84% will be in the developing nations. <sup>2,6</sup>

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In developing countries there is an epidemic of stroke<sup>7</sup> and the incidence is increasing.<sup>3</sup> It is one of the leading causes of DALY's lost, <sup>7</sup> which is seven times higher in the developing nations than developed nations.<sup>2</sup>

Stroke is the fourth leading cause of disability in the world.<sup>2</sup> The disabilities caused due to stroke among a large proportion of younger population causes a mammoth burden on the society.<sup>5,6</sup> Among the stroke survivors only around one-third can independently perform activities of daily living (ADL) while more than one-fourth are bed ridden.<sup>5</sup> Further one fifth of the stroke survivors require institutional care after three months and 15-30 % suffer from life-long disability.<sup>2</sup> The common disabilities which are caused due to stroke are loss of vision and/or speech, paralysis and confusion.<sup>3</sup> The period prevalence rate of mild cognitive impairment caused due to stroke was 13.88% in a study conducted in Kolkata-India.<sup>8</sup>

Disability according to International Classification of Functioning, Disability and Health (ICF) framework, is defined as "an umbrella term for impairments, activity limitations and participation restrictions which denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)." The ICF core set for stroke includes the following four components: body function, body structure, activities and participation; and environmental factors. <sup>10</sup>

Although there is enough evidence on the different types of disabilities caused due to stroke, there is lack of literature on the disabilities suffered by stroke patients in Udupi district, Karnataka, India. Also there is not much evidence on experiences of various professionals working in the domain of stroke in Indian context. Therefore the aim of the present study was to consolidate the disabilities faced by stroke patients from the clinical experiences of the experts involved in giving care to the stroke patients.

#### **Materials and Methods**

A qualitative study design was employed. Participants who were employed in the study were experts involved in giving care to the stroke patients, they were from the field of neurology, physiotherapy, occupational therapy, speech and hearing therapy and clinical psychology. All of them were recruited from Kasturba Medical College (KMC), Manipal-Karnataka, through professional networks. It was decided to recruit the participants till saturation of information is achieved, based on this, 15 participants were taken up for the study.

Semi-structured interviews were conducted at a place which was convenient for the participants with a prior appointment. Oral informed consent was taken from each participant before the interview and entire conversation was audio recorded. Interview guide was developed through literature review and discussion with the research team. The questions were open ended in nature and were meant to capture the experience with regard to disabilities caused due to stroke. It was decided that the interview sessions would be carried out till the saturation is achieved. The participants were allowed freely to put forward their opinion and were not interrupted. They were not given any incentives for participating in the study.

Data analysis: The first step of data analysis was to transcribe the audio recording in to a written format into a single document. Following which broad themes were developed by "deductive approach" using four components of ICF core sets for amalgamation of experiences of the participants. <sup>10</sup> Specific codes were allotted for each theme manually in order to facilitate easy amalgamation.

### **Results**

Data collection was carried out in November 2014, which lasted for two weeks. On an average, duration of the interview lasted for 40 minutes, maximum being one hour thirty minutes and minimum being 18 min. The study included 15 one to one sessions involving two expertise from the field of neurology, seven physiotherapists, two occupational therapists, three speech and hearing therapists and one clinical psychologist. Out of the 15 participants two were females. Five of them were professors, five associate professors, two assistant professors, one senior resident and two research scholars.

Majority of the participants claimed that motor disabilities were most commonly seen in KMC hospital followed by impairment in performing ADL, language problems, difficulties of cognition and perception, psychological problems, caregiver burden, sexual and urinary problems.

Amalgamation of responses: The responses were amalgamated based on the ICF core set for stroke as follows: *Theme 1: "Body function"* 

The theme body function was subdivided into seven sub themes: disabilities related to motor functions, speech, cognition, perception, psychological, sexual functions and urinary functions. Each of them has been elaborated below:

 Motor disabilities caused due to stroke included disabilities of muscle power, muscle tone, muscle endurance, motor reflex, involuntary movement reaction, control of voluntary movements and gait pattern functions. The upper limb motor disabilities included impairment of hand function/ dexterity/ upper limb function. Whereas, the disabilities concerned to the lower limb were problems related to ambulation, gait, balance, other loco-motor related abnormalities and difficulties in walking on even/ uneven ground/climbing.

Motor disabilities can occur with or without speech problems depending on the affected side of the brain. Lower limb disabilities tend to recover faster while the upper limb disabilities are chronic in nature and hence require early therapy. The ultimate goal of all interventions for any kind of motor disabilities is to improve ADL.

- 2. Speech related disabilities: It included disabilities of voice, articulation and fluency; and rhythm and speech functions. On an average, one in five to one in three stroke patients experience speech related disabilities. The common speech related disabilities are dysarthria and apraxia. Dysarthria is a condition which is characterised by an impaired production of speech sounds due to muscle weakness wherein the patients are aware of what is to be spoken, but their muscles do not support them to perform this activity. Apraxia is where the patients are unable to make voluntary movement of the muscles. It also affects motor functions and is usually associated with aphasia. Both dysarthria and apraxia are most common in cortical stroke; however few cases of the former can also be seen in cerebellar stroke.
- 3. Cognition related disabilities occur in almost all patients whose right hemisphere is affected. The participants did not divulge much details pertaining to cognition related disabilities.
- 4. Perception related disabilities are seen to occur in patients whose left hemisphere is involved. Patients experience neglect issues or hemi neglect, being able to perceive only one half of whatever they see. These disabilities add to the burden of patients having motor disabilities and thus affecting the prognosis.
- 5. Psychological problems include emotional dysfunctions such as anxiety, depression as well as fear of death. Anxiety is related to performance of the patient and might be caused due to misconception of the disease, underestimation and negative cognition which are activated after the event. Depression is commonly seen one and a half month post stroke; is mostly related to hopelessness. Psychological problems in turn affect prognosis of the patient.
- 6. Sexual dysfunction is the disability that is ignored most of the times. It affects the self-esteem and self-efficacy of the patient which in turn hampers their quality of life.
- 7. Urinary incontinence is also one of the disabilities noticed in some patients. This disability affects a patient the least.

### Theme 2: "Activities and participation"

The theme activities and participation had two sub themes namely ADL and language problems.

- ADL is also known as activities of self-care or functional disabilities. It can be classified as basic which
  includes activities such as dressing, bathing, combing, eating etc. and instrumental like doing complex
  tasks such as going for shopping, driving, writing etc. Depending on the requirement of assistance; ADL
  can also be categorized as no assistance needed, partial assistance needed, assistance needed and bedridden.
  - Interventions are usually targeted to restore basic ADL first in order to make patient independent, followed by instrumental ADL. After the patient is able to perform both basic and instrumental ADL, then efforts are made to help the patient get back to his/her work. Patient recovery is faster if he/she is motivated to become independent from the very beginning.
- 2. Language problems: Whether a stroke patient will develop a language problem depends on the side and area of the brain affected. One of the most important neurological related language problems is aphasia wherein patient is unable to communicate. It is most commonly seen in cerebellar stroke. Not being able to communicate is a major barrier to the stroke person.

### Theme 3: "Environmental factors"

Even though there are many sub themes under environmental factors as per ICF, responses were obtained only pertaining to caregiver burden.

Caregiver burden: Stroke is a burden not only on the patients but also on their entire family. Stroke patients become entirely dependent on their caregivers, due to which caregivers face economic and psychological constraints, also they are forced to compromise on their time and mental health thus reducing the quality of life. The degree of caregiver's burden is directly proportional to the disability of the stroke patient. Rehabilitation should target both the patients as well as their caregivers.

None of the participants mentioned any disability which could fall under the 'body structure' component of ICF core set.

#### Discussion

In the present scenario, stroke is one of the prime causes of DALY's lost in developing nations<sup>7</sup> and is on the priority list of healthcare providers. Out of 15 million stroke cases annually, around one third of them are disabled for life.<sup>3</sup>

Thus the present study was intended to find out the disabilities caused due to stroke, which are most commonly seen by the experts who were professionals involved in giving care to stroke patients. It was a first of its kind study to be conducted among the experts who were involved in management of stroke patients in Udupi district. Fifteen semi structured interview sessions were conducted; the responses were collated and consolidated on the basis of themes constructed on the framework of ICF core set for stroke which includes body function, activities and participation; and environmental factors.

All the participants claimed that the disabilities vary from person to person, and each of them has an intense effect on the individual and his/her family which in turn has a profound effect on the quality of life. Stroke management strategies are customized considering the individual's needs and disabilities.

Out of all, motor disabilities were deemed to be the most prevalent as well as severe followed by ADL. The "American speech-language-hearing association" report categorises the disabilities into physical, sensory, cognition, communication, swallowing and emotional but in the present study no mention was made about the sensory disability and dysphagia. Another report by "National Institute of Neurological Disorders and Stroke" divides the disabilities caused due to stroke into motor and sensory problems, difficulty in understanding language, problems of thinking and memory; and emotional disturbances. The findings of the present study are consistent with those of this report except problems of sensations. The report also mentions about some secondary problems which stroke patients might experience, none of which were cited by the participants of the current study.

Dementia is highlighted as one of the disabilities in the report given by the Stroke Association<sup>13</sup> which was not spoken by any of the participants in our study.

Major limitation of the study was that participants were recruited from only one medical college.

### **Conclusion**

This study highlights health professionals' experiences on the disabilities caused due to stroke, which they most commonly see in their clinical practice. These disabilities are motor disabilities, impairment in performing ADL, language problems, difficulties of cognition and perception, psychological problems, caregiver burden, sexual and urinary problems. Each disability varies from person to person and has profound effect on patient's as well as caregiver's quality of life.

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