

Role of Sex and Gender in Post-Stroke Care

A Study in Gandhinagar District, Gujarat

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Globally, stroke leads to 21.7 per cent of deaths among women in the geriatric age-group. For those who have survived it, it demands prolonged care-giving. A relatively longer life expectancy adds to the higher stroke burden among women compared to men. In a country like India with an aging population, a non-functional healthcare system, and a large number of people living in poverty, the burden of post-stroke care, in entirety, gets shifted to households. Within Indian households, women are seen as the primary caregivers, putting them at risk of physical and psychological stress. Patriarchal social norms also place women stroke survivors in severe disadvantage in many ways.

This paper aims to highlight how gender mediates treatment seeking, care receiving and caregiving in household settings in the aftermath of a stroke. A mixed-method study was conducted in two phases in Gandhinagar district, Gujarat. The quantitative component included a cross-sectional survey of 113 individuals in the age group 60 years and above, who had suffered stroke at least two years prior to the survey. The survey included a set of pre-tested tools to elicit information regarding participants' physical, social and mental problems, extent of disability and coping strategies. The qualitative component included in-depth interviews with a sub-sample of 30 individuals who were selected using 'maximum variation' and 'extreme cases' criteria.

Study findings point to the vulnerability of women as patients and as care givers. Among the patients, more women were widowed/separated/divorced (55.6 per cent) when compared to men (5.7 per cent); and more women (57.8 per cent) than men (45.6 per cent) were above the age of 70 years. A majority of caregivers were women, either the spouses or daughters-in-law; and most of them expressed prolonged sleep deprivation, depression, fatigue, body ache and raised blood pressure. Women reported having to undertake tasks such as physically lifting and supporting the male patients even though they were not fit to manage such tasks. Women caregivers often either gave up remunerative employment or were pushed to take up some remunerative work in order to make ends meet. Women stroke-survivors whose husbands were caregivers expressed a sense of helplessness, grief and guilt. An instance of a woman not being taken to hospital after stroke, too, was reported. Unlike some stroke-affected men who continued to be economically resourceful with pension, petty self-employment or owning property in their name, women stroke-survivors were often completely dependent on either their spouse or children.

Women, both as patients as well as care givers, are more adversely affected by stroke-related concerns than men. Apart from the problems rooted in the patriarchal arrangement the study also calls for a resilient and sustainable health care system which provides long-term rehabilitative care, to reduce the burden on women of post-stroke care-giving.

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I

Introduction

Stroke continues to feature as a public health concern for women across the world especially in old age (World Health Organization [WHO], 2009:63), both as individuals who are directly affected by the disease as well as caregivers for other stroke patients. Seshadri et al. (2006) observed that the lifetime risk of stroke is higher in the geriatric age-group, about 1 in 6 for men (14 per cent - 17 per cent) and 1 in 5 for women (20 per cent - 21 per cent) (p. 345). The burden of this disease was much higher among women than among men as women have a longer life expectancy. Although men had a higher risk of stroke, (Sealy-Jefferson et al., 2012:121), many studies have reported that the mortality rate is higher in women stroke patients as compared to men and that male stroke patients had better treatment outcomes than female patients (Wyller, 1999: 41). Stroke deaths account for approximately 22 per cent of deaths among women of the geriatric age group in middle-income countries like India (WHO, 2009:63). Studies have indicated that the effect of stroke is far higher in women, with fewer chances of recovery, affecting their quality of life and predisposing them to co-morbidities (Reeves et al., 2008: 915).

Stroke causes a wide range of physical and psychological problems and has a significant socioeconomic impact on the lives of survivors and their families. Post-stroke recovery is a slow and incomplete process causing irreversible impairments, compelling survivors to live the rest of their lives adapting to post-stroke disabilities. Many researchers have noted that only some stroke survivors recover entirely and regain their routine physical functions; however, approximately half of them have long-term mobility deficits and around a quarter to half of the survivors need some amount of assistance for their daily activities (Bonita, Solomon and Broad, 1997). In low and middle-income countries, poverty, poor healthcare infrastructure and limited access to care forces families of stroke-survivors to take care of survivors (Pandian, Srikanth, Read and Thrift, 2007: 3063).

Post-stroke-care entails a composite set of responsibilities shaped by factors such as the financial situation, cultural beliefs and gender norms of the household; interpersonal relationships within the family; and the presence of a competent healthcare system (Singla and Singla, 2016: 76). Disabled stroke survivors who need prolonged caregiving but are unable to afford the high cost of care and rehabilitation are often cared for by their families (Pandian and Sudhan, 2013: 128).

Many studies have reported that, within the household, women bear a higher burden of caregiving as compared to men as a part of their gender-role expectations, resulting in considerable physical and psychological hardship (Gosman-Hedstrom and Claesson, 2005; Pinquart and Sorensen, 2006; Banerjee and Das, 2016). A comparative study carried out to determine the improvements in quality of life (QOL) of stroke survivors and their informal caregivers, found that while the patients “appeared to adapt to new life situation and their QOL in socio-emotional and mental domains improved during the year between the follow-ups ... the caregivers were on a lower level in emotional and mental domains, and their most important determinants of QOL were the age of the caregiver and the patients’ functional status” (Ann-Cathrin Jonsson et al., 2005: 803). Apart from the physical and mental stress, the burden of financial expenses was also a significant stressor seen in 81 per cent of the informal female caregivers (Das et al., 2010).

This paper is the outcome of an exploratory study in Gandhinagar district of Gujarat. The study aimed to document the physical, mental and social problems faced by individuals with post-stroke disabilities and innovations made by patients and caregivers to cope with demands of everyday life. We found that technical innovations made in the built-environment, furniture or assistive devices were minimum. Innovations were mainly in the form of strategies of family reorganisation. These were to ensure the presence of one or more immediate family members to provide care over the prolonged period of recovery and rehabilitation after stroke. Gender was a factor that configured these strategies. This paper aims to capture how the sex and gender of the affected individual and caregivers becomes a critical dimension along which these strategies get shaped.

II

Materials and Methods

We conducted a cross-sectional, descriptive study with a mixed method approach. Community approach was adopted to identify stroke patients with the help of Anganwadi workers, Accredited Social Health Activists (ASHA) and residents of villages. The study was conducted between January 2014 and October 2015.

Research team

Besides the principal investigator and two co-investigators, the trained research team included two research associates with a medical background and five field investigators with a social work background. The research team underwent a two day-intensive training by a physiotherapist and a medical doctor, which introduced them to various terminologies used in the study tools, and to making an independent assessment of the mental health status, coping-behaviour and physical disability of stroke-patients. Field investigators were trained to administer questionnaires and assess responses under the supervision of research associates. Debriefing meetings with the principal investigator followed each field visit.

Research setting and Study population

The study was conducted in Gandhinagar district of the Gujarat state, India. The district has four blocks namely Mansa, Kalol, Gandhinagar, and Dehgam. The study population comprised stroke survivors in the geriatric age-group (60 years and above) who had suffered a stroke at least two years before the date of the survey in all four blocks of Gandhinagar district.

According to Census 2011, the total population of Gandhinagar district was 1,387,478 with 787,949 in rural and 599,529 in urban areas. The estimated number of stroke cases in the geriatric group for Gandhinagar district in Gujarat was calculated by using the age-specific prevalence rate of 8.47/1000 (Indrayan, 2005: 205). The population in geriatric age-group was 110,998 and hence, the estimated number of stroke cases was 940.

Study design

The study had two components – quantitative and qualitative. The quantitative component included a survey of stroke-survivors and/ or their caregivers to whom a set of pre-tested tools were administered. The qualitative component comprised of in-depth interviews with a sub-sample of participants drawn on the basis of theoretical sampling from those sampled for the survey. In addition

to the in-depth interviews, details of the living space of stroke-survivors and the innovations they or their families had made to cope with disabilities were captured.

Sample size and sample selection

The sample for the survey was selected through population proportionate sampling method. We selected 14 villages through systematic random sampling, aiming to draw two participants from each village. We repeated the process for all the four blocks in the district. Fifty-six villages/urban wards were selected in Gandhinagar district, 14 villages from each block. From these locations, we included 113 individuals in the survey and carried out qualitative in-depth interviews with a sub-sample of 30 individuals from this group.

Selection criteria for participants

For the quantitative survey, all the individuals in the geriatric age-group, who had suffered a stroke at least two years before the date of survey, were selected. For qualitative in-depth interviews, we drew a sub-sample of 30 participants from the quantitative survey, using the ‘maximum variation’ and ‘extreme cases’ criteria. The dimensions considered for selection of participants for the qualitative component of study were gender; whether professional support was received or not; type of disability; availability of a toilet within the house; family support (presence of spouse, other immediate family members or complete neglect); effect on livelihood and/or adjustments made by family members to deal with care-giving for stroke-survivors.

Those who had developed disabilities due to reasons other than stroke; those who had suffered stroke less than two years before the date of survey; and those who were not in geriatric age-group were excluded from the study.

Study tools

For the quantitative component we used a set of structured tools including a customised tool to elicit socio-demographic and illness related information, the Brief Coping Scale to capture mental health status and coping behaviour of participants (Carver, 1997), the Scandinavian Stroke Scale (SSS) to assess the extent of post-stroke impairment (Scandinavian Stroke Study Group, 1985) and the Barthel Index (BI) to measure dependence in activities of daily living (Mahoney and Barthel, 1965). The tools were already validated for the Indian population (Mohanraj et al., 2014), and translated into the Gujarati language.

For the qualitative component, an interview guide with probes was prepared to interview stroke survivors and immediate family members. As the purpose was to capture the lived experiences of the patients and immediate family members, the interviews were relatively unstructured. Efforts were taken to have individual interviews, but often this was not possible, and the interview had to be conducted in the presence of other members of the family, with responses coming from them as well. As the study was also about caregiving, in situations where the stroke-affected member was not able to answer or was deceased, caregiver(s) or family members were interviewed. In other words, the unit of data collection and analysis in the qualitative component was the household as the dynamic unit that has been experiencing stroke and caregiving as an ongoing process. Interviews were audio recorded, and field observations were written. Photographs were taken to capture the living space and innovations related to post-stroke caregiving.

Data analysis

Data from the quantitative component was analysed using descriptive statistics and Pearson correlation. Gender differences on BI were assessed by Chi-square test. For the qualitative component, audio recordings of IDIs were transcribed and translated into the English language with all personal identifiers removed, and these were checked for accuracy. Transcripts were uploaded as primary documents in qualitative data analysis software and were coded for a pre-decided set of codes derived from the tool plus additional codes generated concurrently as the data collection proceeded, during debriefing meetings post each field visits, and during the process of familiarisation with data. Iteratively, five themes were identified, and the data was organised into these themes. Inter-relationships across themes were also explored.

Ethical consideration

Ethical approval for the study was obtained from the institutional ethics committee of the host institution. During the fieldwork, members of the research team were made aware of the practical issues of research ethics. Stroke-survivors and their family members were informed about the study using a participant information sheet, were assured of anonymity and confidentiality and were informed about their right to withdraw at any point in time. Before seeking consent, consent forms were given to respondents who could read, and for those who could not read, the ASHA or Anganwadi workers or neighbours were asked to help explain the content of the form. For the qualitative component, consent was sought and obtained especially for audio recording and taking photographs. Photographs were taken in such a manner that respondents' identities were not divulged.

III

Results

Quantitative component

The following tables capture the result from analysis of data from the survey along the dimension of the sex of the stroke-affected participant. The first table captures the socio-demographic characteristics of participants. In terms of age profile, the mean age of male participants was 68.68 ± 7.41 , and for female participants it was 70.51 ± 7.82 . Distribution across age groups shows a greater proportion of men in 60-69-year age-group and a greater proportion of women in 80+ year age-group.

Table 1: Name of the Welfare Funds(WFs) and Year of Establishment

Variables	Categories	N (per cent) Male	N (per cent) Female
Gender	Number of Male and Female patients	68 (60.2)	45 (39.8)
Age group	60 – 69 70 – 79 80 +	37 (54.4) 24 (35.3) 7 (10.3)	19 (42.2) 17 (37.8) 9 (20.0)
Age (Years)	Mean Std. Deviation	68.68 7.41	70.51 7.82

Marital status	Currently Married Divorced/Separated/ Widowed	63 (92.6) 5 (7.4)	20 (44.4) 25 (55.6)
Residence	Urban Rural Suburban	13 (19.1) 54 (79.4) 1 (1.5)	12 (26.7) 33 (73.3) 0 (0)
Currently residing with	Spouse Immediate family members (with spouse) Immediate family members (other than spouse) With relatives other than family members	8 (11.8) 53 (77.9) 7 (10.3) 0 (0)	5 (11.1) 15 (33.3) 23 (51.1) 1 (2.2)
Education	No Schooling Primary Education High School Graduation Post Graduation and Higher	9 (13.2) 39 (57.4) 16 (23.5) 3 (4.4) 1 (1.5)	28 (62.2) 15 (33.3) 2 (4.4) 0 (0) 0 (0)
Current Employment status	Unemployed Part-time Full time Retired and pensioner Retired but not pensioner	48(70.6) 4(5.9) 1(1.5) 13(19.1) 2(2.9)	44(97.8) 0 (0) 0 (0) 1(2.2) 0 (0)
Monthly Household Income	0-1000 1001-10000 10001-20000 20001-30000 30001-40000 40001-50000	5(7.4) 47(69.1) 11(16.2) 0 (0) 4(5.9) 1(1.5)	3(6.7) 27(60.0) 15(33.3) 0 (0) 0 (0) 0 (0)
Person(s) from whom help may be sought when needed (with multiple response)	None Spouse Children Siblings Parents Other Relatives Friends	4(5.9) 34(50) 51(75) 1(1.5) 1(1.5) 4(5.9) 4(5.9)	0(0) 8(17.8) 37 (82.2) 0(0) 0(0) 3(6.7) 2(4.4)

A large number of female stroke survivors (55.6 per cent) were widowed, separated or divorced at the time of the survey. This proportion was comparatively very small (7.4 per cent) among the male participants. In terms of residence, only 44.4 per cent women resided with their spouse while close to 90 per cent of stroke-affected men lived with their spouse. Further, 50 per cent of male participants reported that they were dependent on their spouses when in need of help; whereas only 17.8 per cent of female participants reported that they depended on their spouse when in need of support. Female participants were financially more dependent or vulnerable as most of them were unemployed (97.8 per cent) and a large number of them (62.2 per cent) had no formal

schooling. In contrast, at least one-fourth of the men had some source of income and relatively higher levels of education.

In other words, men as stroke survivors were relatively better-off in terms of their educational level, economic independence and co-residence of and caregiving by their spouses. Women stroke survivors were in a much more vulnerable situation, being economically dependent and often without their spouses for support. This also suggests that most of the caregivers are women, an assumption corroborated by the qualitative component of the study.

Tables 2 and 3 are based on BI score for disability and various activities. The data shows that almost similar numbers of male and female participants suffered severe to mild disabilities with a few very severely disabled patients (Table 2).

Table 2: Information on Illness-related Characteristics and Treatment Seeking

Variables	Categories	N (per cent) Male	N (per cent) Female
Sex	Number patients	68 (60.2)	45 (39.8)
Barthel Index (BI) Score	Very severely disabled (0-20 score)	2 (2.9)	3 (6.7)
	Severely disabled (25-45 score)	10 (14.7)	6 (13.3)
	Moderately disabled (50-75 score)	24 (35.3)	15 (33.3)
	Mildly disabled (80-95 score)	24 (35.3)	19 (42.2)
	Not disabled (100 score)	8 (11.8)	2 (4.4)
Advised for Physiotherapy	Yes	60 (88.2)	36 (80)
	No	7 (10.3)	8 (17.7)
Accessibility to Physiotherapist	Yes	47 (69.1)	28 (62.2)
	No	13 (19.1)	8 (17.7)

Table 3: Sex differences on Barthel Index (BI) Activities

Barthel Index (BI) Activities		Gender		Chi-Square Value p
		N (per cent) Male	N (per cent) Female	
Feeding	Dependent	12 (19.1)	9 (20.0)	0.7811
	Independent	55 (80.9)	36 (80.0)	
Bathing	Dependent	28 (41.2)	16 (35.6)	0.5485
	Independent (Or in the shower)	40 (58.8)	29 (64.4)	
Grooming	Needs help with personal care	33 (48.5)	25 (55.6)	0.4644
	Independent face/hair/teeth/shaving (Implements provided)	35 (51.5)	20(44.4)	
Dressing	Dependent	21 (30.9)	17(37.8)	0.3883
	Needs help but can do about half unaided	16(23.5)	6(13.3)	

Bowels	Incontinent, or catheterized and unable to manage alone	22 (32.4)	13 (28.9)	0.6966
	Continent	46 (67.6)	32 (71.1)	
Bladder	Incontinent, or catheterized and unable to manage alone	21 (30.9)	10 (22.2 per cent)	0.312
	Continent	47 (69.1)	35 (77.8)	
Toilet use	Dependent	14 (20.6)	8(17.8)	0.8157
	Needs some help, but can do something alone	19 (27.9)	15 (33.3)	
	Independent (On and off, dressing, wiping)	35 (51.5)	22 (48.9)	
Transfers	Unable/Major help	12 (17.6)	12 (26.6)	0.3815
	Minor help (Verbal or physical)	24(35.3)	17 (37.8)	
	Independent	32 (47.1)	16 (35.6)	
Mobility	Dependent	28(41.3)	19 (42.2)	0.912
	Independent (But may use any aid; e.g., stick) > 50 yards	40 (58.8)	26(57.8)	
Stairs	Unable	23 (33.8)	15 (33.3)	0.9569
	Needs help/Independent	45 (66.2)	30 (66.7)	

Differences across the dimension of sex on various BI activities were tested to assess the functional disabilities by Chi-Square test (Table 3), which showed that there were no significant ($p > 0.05$) differences across sex for ability to perform activities of daily living.

Qualitative component

Thirty participants were selected for in-depth interviews of which, 11 (37 per cent) were women, and 19 (63 per cent) were men (Table 4). In-depth interviews focused on physical, social and mental aspects of coping with the after-math of stroke in stroke-affected individuals and their caregivers. For those participants who were completely cognitive-impaired or who had expired following the survey, caregivers and other household members were interviewed to capture the dimensions of coping and caregiving, ‘as perceived and reported’ by them. Analysis of this data brought out many themes including changing social relationships, financial hardship, caregivers’ stress, coping strategies and access to rehabilitation services with a cross-cutting theme of ‘role of sex and gender in shaping the care-receiving/giving experience’.

Table 4: Profile of Participants Selected for Qualitative In-depth Interviews

Participants for in-depth interviews	N (per cent)	N (per cent) Male
Participants selected	19 (63)	11 (37)
Deceased	3 (15.7)	5 (45.4)
Completely cognition- impaired	1 (5.2)	2 (18.1)
Partially cognition impaired	3 (15.7)	0 (0)

Sex of the patient and experiences around care

As indicated by Table 4 among the 30 patients who were followed up for this component of the study 19 were men and 11 women. As we shall see through some of the narrations below, sex of the patient had a role in shaping who gets or provides care and the strategies of reorganisation adopted by households.

Table 4 suggests another important possibility. Out of the thirty patients who were followed-up from the initial survey, 11 had unfortunately expired before the qualitative study began. Three times as many women had expired as men. It is probable that age played an important role in this. The average- reported- age of women and men stroke-survivors were 74 and 69, respectively. The average- reported- age of patients who had expired was 81 for women and 76 for men. In addition, other factors like co-morbidities, the severity of stroke, families' economic status etc. may have played a role. Yet, the higher mortality observed among women patients could also indicate a difference in the quality of care received by women as compared to their male counterparts.

In the following paragraphs, we look at narrations from households with female patients and a few from households with male patients to illustrate the differences – if any - in care received by them respectively.

Harishbai

Harishbhai⁴, age 70 years, had a stroke about 14 years ago and another one subsequently. He is paralysed on the left side of his body. He is being taken care of by his second wife and an unmarried son. Earlier he used to manage to go to the toilet by himself outside in the fields, but his condition had worsened over the past three years. He is bed-ridden now and has urinary incontinence and no bowel control.

“Can’t say about bowels (lacks control) ... that’s the only thing he can’t tell. Even if we ask many times, he will still pass it (in bed) ... earlier he was not able to eat ‘roti,’ but now he can eat it.”

His wife does all the work for him, but cannot easily lift him; she therefore does whatever possible, and beyond that, she waits for the son to come. His son can lift him up to bathe him or wash him once in three or four days and massage. The son is still unmarried and in search of a wife who would be ready to come and live with his family. “I don’t want to live separately. After my father dies, then I may I live (separately)”.

⁴ All names are pseudonyms

His wife narrated:

“I feel tired, not able to sleep in the nights and my limbs ache. But who will do for us? My daughter-in-law lives nearby but if we ask her ‘please give me some water,’ she would answer, ‘I have no water in the house how I can come to give to you.’ Then we have to help ourselves”.

“I don’t go to anybody’s house ... Even if I went to my brother’s house; I would leave at 10 o’clock and would be back by 2 o’clock. I don’t even visit my children’s homes.”

One of their neighbours added,

“His wife cares for him. Whatever he wants, she would make it for him. They keep his bedding separate, two pairs of bedding. Every day she washes the beddings and his bed. Sometime, if he has diarrhoea, she serves him all day. She uses nappies made up of clothes...like we do for young kids... On some days she would feel like resuming work in the fields, but she also has low BP problem. She feels dizzy... is it advisable to go and work?”

The above is a situation in which a patient had a stroke over 14 years ago, was bed-ridden and is still being cared for. He was clean, and his room and surroundings were hygienic. The presence of his wife and an unmarried son – who has been delaying his marriage – has made a big difference in the quality of care he has been receiving. His son attends to the economic needs and supports in tasks that require physically lifting the patient, while the patient’s wife attends to chores connected to his care.

Shankarbhai

Shankarbhai, aged around 70 years at the time of the initial survey, had expired when the team visited for the qualitative interview. He had a stroke over six years ago. The family is economically better off, owed land and ran a private higher secondary school. He was the founder-owner of the school.

During the initial survey, the team found this person left in an almost unattended state, in a room with a strong stench. Toilet bins were left un-cleared, and the person was in a dirty state. When the investigators reached the site, his daughter in law and grandson hurriedly got his room cleaned and washed him.

His wife had heart attack four years before his stroke and was not in a position to take care of him. She subsequently passed away after his stroke. After that, he was being taken care of by his daughter-in-law and his grandson. He used to walk without a need for a stick, but he fell and broke his hip and after that, his condition began to deteriorate. During the last six months, he was entirely bedridden.

According to his daughter-in-law,

“My son and I have been taking care of him. Sometimes he would have diarrhoea. But my son and I would clean him. I would hold on one side and on the other side my son would hold and would make him stand by the support of the walker. ... His daughters are there (in the village, a few kilometres away). So he used to go to stay for 10 to 15 days there in between.”

Here, the individual affected was economically affluent and commanding respect in the family. However, as he had lost his spouse and his married sons and daughters were not in a position to take care of him he was shunted between his son’s and daughter’s houses for care. Meanwhile, he became

bedridden, and the situation became worse. He was left entirely unattended and didn't survive long.

Tulsiben

Tulsiben was 80 years old and had a stroke about four years prior to the survey. She had expired by the time the team went for an in-depth interview with her. She had been utterly dependent on her son's family that had a reported monthly income of Rs.1500.

At the time of her stroke, there was the family was in the midst of a wedding. Because the family feared that the marriage may be called off if her illness was known, they made her sit-up to greet the guests. She was not taken to a hospital. Instead, a doctor from a private clinic was called home to attend to her. The doctor had told the family that nothing could be done for the patient. Her son and daughter-in-law told us that because of the poor prognosis according to the doctor, they did not take her to a hospital.

The stroke affected Tulsiben on her left side and she was unable to walk independently. She used to drag herself around the one-roomed space she had been given under the government's free housing scheme.

She was not able to communicate properly, had mood swings and behaved erratically. She sometimes took off her clothing. She often woke up three or four times in the night asking for water, and was awake from 4 am onwards. She did not allow her daughter-in-law to touch her. She preferred to have her daughter, who lived nearby, or her grandchildren to come over to bathe her.

Her son and daughter-in-law narrated,

“We faced many difficulties. ... In everything...In feeding her, in lifting her...We had to feed her, give her a shower, and change her dress ... We could not go for our farming work leaving her alone at home ... The whole day we had to keep giving water to drink at frequent intervals.”

Here, probably the economic situation of the patient's family and the severity of the stroke had shaped the caregiving situation. Yet, the fact that she did not have a living spouse and was completely dependent on children who had their own family responsibilities also appears to have made a major difference.

These cases illustrate the importance of the presence of the spouse or a male member who could attend to care; economic affluence of the household, and the household's ability to adapt to caregiving situation in shaping the quality of care received by the stroke patient. It is certainly difficult to tease out these factors. Nevertheless, it may be said that the sex of the patient and the presence of a female -principal caregiver did ensure better caregiving.

Changing social relations

Most of the narrations by participants and family members referred to changes in social relations following the incidence of stroke in a member of the household. The stroke caused severe stress in relationships especially with spouses and children and made a profound impact on the emotional well-being of patients and caregivers.

The IDIs captured the conversations about how families, friends, and neighbours supported or denied support to stroke survivors after the illness. In some situations, the patient experienced considerable discrimination.

A female stroke survivor who lived alone, described the discrimination she faced from her brother and other relatives,

“In such times (when one suffers from a stroke), relatives are not going to do anything...if something happens to me, my neighbours help me... My brother visits only to check the house as I live in his house...and never helps financially for medicines or livelihood...rather he would say I should die.”

Another female survivor, having her spouse as the principal caregiver, expressed intense guilt and a sense of helplessness. During the interview, her husband told us,

“At times I feel like poisoning her food to get rid of her. I am tired of caring for her.”

Contrary to this, in some households, stroke survivors were well taken care of irrespective of their gender.

A granddaughter, as a chief caregiver, described how her family cared for her grandmother, a stroke-survivor with cognition-deficit issues

“My grandmother used to sell vegetables, but after her illness my mother sells vegetables...My grandmother is never quiet, and keeps talking on and on...we let her speak...we have to be patient with her because she is an elder, have to be patient as long as she lives.”

A male stroke survivor shared his experiences about a change in his social role after stroke:

“I used to sell vegetables earlier...but now my wife and son are managing the occupation... Earlier I was the decision -maker but now my wife and son...they do it. They usually ask me before doing anything...I have to guide them...”

The IDIs also captured societal attitudes towards aging-related diseases. We observed that society easily accepted age-related illnesses and gradually the survivors and their families started preparing themselves for the patients’ death. In spite of such societal attitudes, most of the families sought immediate medical care after stroke to save their elderly. However, as an exception, an instance of a woman not being taken to the hospital was reported. Her son told us,

“We did not take her to a hospital as she was not able to speak or stand up and she was aged...one usually does not recover in old age...we asked my sisters also, they said that she will not recover even if we spent money.”

Patients with communication difficulties due to loss of speech/slurred speech showed intense emotional reactions, perhaps because the ability to speak and express is an important factor in maintaining social relationships. The wife of a male stroke survivor who had been fond of singing bhajans (religious prayers), shared with us that he would often cry at his inability to speak.

Financial hardship

Nearly all households experienced significant financial impact of the catastrophe brought about by the stroke. As a stroke attack is usually sudden, most participants/families said that they were unprepared and were unable to manage the crisis. Due to the acuteness of the illness, priority was given to immediate treatment, which was generally very expensive. To meet the emergency, many families had to borrow money from relatives. Consequently, the families ran short of money for further medications and long-term rehabilitation services.

Some incidents were noted where women caregivers had to take up some form of employment to make ends meet, besides care giving. A daughter-in-law shared her financial problems after her husband went absconding, leaving her to take care of his mother.

“My husband, who used to sell vegetables in market, ran away last year after his mother’s illness...he left us and his mother and did not return even for her death ...so I started working to earn our living ... As I could not afford to spend on her medications, we stopped her medications after my husband ran away.”

There were also situations where many women had to give up their jobs in order to take care of a stroke-affected member, causing economic vulnerability. The families were further burdened by societal norms requiring them to perform post-death rituals:

“I used to work and earn Rs.5000-6000; but after my mother-in-law suffered a stroke, I had to leave my job, because my sister-in-law was not able to manage things alone...As per the custom in our caste, we performed some rituals after her death, the expenses for which were about Rs.15000 to 20000.”

In another case, a woman expressed guilt at getting back to work with her husband in home after a stroke,

“I went to work for three days as a labourer thinking that since he was better I could go out to work and earn to feed him better...but in the meanwhile he had an insect bite and developed boils on his back. I felt bad, and my sons also scolded me for going to work when he had to be taken care of. Then I decided to never work.”

The immediate and long-term household economic impact of stroke are most often overwhelming. Many households are rendered impoverished and indebted. Depending on specific life situations, members have to reconfigure their roles vis-a-vis employment. Some give up their jobs, and some freshly take up employment, and the decisions are often mediated by caregiving roles and gender norms.

Caregivers’ stress

This theme captured physical and mental stress that the caregivers had to endure as they carried out their care giving responsibilities, whether willingly or unwillingly. In most households, members mentioned that caregiving was the responsibility of women members of the household - wife, daughters-in-law, or granddaughters. Interviews with these members brought out the enormity of this responsibility and their feelings of helplessness because these responsibilities were seldom shared by other members of the family. As discussed in the previous section, some women were compelled to take up remunerative employment along with caregiving; while some had to give up their employment to meet the caregiving requirements. In both situations, the women caregivers experienced high levels of physical and mental health issues such as fatigue, body ache, sleep-deprivation, high blood pressure, infections, and depression.

Two daughters-in-law narrated their care giving experience for a bed-ridden mother-in-law,

“We faced a lot of physical difficulties but what could we do? ...Being available for her all day, we used to get feverish, tired and dizzy...we were not getting adequate sleep....sometimes we used to think, ‘when will the God call her now?’.. God should either free us or her. She would soil her clothes every day...We used Dettol soap for her and put some Dettol in warm water to give her a bath. We had a good relationship with our mother-in-law, but we feel good now (as she is no more).”

They also added that:

“A male cannot do such things...if a male is disrespectful and insensitive; he may not take care of his wife but would rather get rid of her by throwing her out of his life.” “Who will serve a female? ...only those who feel pity on them...their daughters and daughters-in-law [not sons or sons-in-law].”

Another daughter-in-law and a wife shared their experiences of taking care of a male stroke survivor in their family:

“He used to remove his clothes and expose his body parts to all of us (in a luring manner) ... While taking him for a bath, we used to face great difficulties as he would never cooperate in removing his clothes...he would beat us and would use abusive words... Nobody would tolerate such behaviour, but we tolerated for eight years.”

Although the study identified mainly women as the principal caregivers, in a few cases some male patients had their sons playing this role, and these men faced a similar burden. A man who had survived stroke had this to say about his son taking care of him:

“I was suffering from [disability due to] stroke at that time too (when my wife was alive), but my condition was better...but I lost my courage after my wife’s death... My son is a daily wage labourer...he comes in the afternoon and cooks food for me...Sometimes he gets frustrated...he comes from work and has to cook and take care of me so naturally, he gets frustrated.”

Taking care of individuals affected by stroke is physically and emotionally intense and often a full-time responsibility. It can wear out the caregivers and other family members physically and psychologically, and in addition they may have to face financial vulnerability and indignity. Caregivers themselves need support to cope with such extreme yet enduring situation.

Coping strategies

During the interviews, patients and their caregivers commonly discussed patients’ strategies to cope with the impact of post-stroke illness. Depending on their socio-demographic environment, patients developed their own coping strategies to deal with the physical and mental trauma. There were no significant gender differences found in coping strategies as elicited from structured instruments. Nearly all the participants accepted their stress and disabilities to retain their psychological and social wellbeing. Religious coping was one of the most frequently used strategies. Most of the survivors accepted their illness with an attitude of seeking forgiveness and spiritual support; however, a few patients showed extreme forms of negative religious coping.

“I have lost my faith in God (crying)... I am a widow since childhood. God has done this to me. God has nearly killed me. I don’t believe in God now. I don’t worship God now.”

Apart from these, self-distraction and substance use to ease the stress were also reported.

“I drink alcohol. Monthly I spend 200-300 rupees on it... If my body starts aching, I ask someone to bring alcohol, and I drink a glass of it...I offer the children (who bring me alcohol) one rupee to buy it for me...What to do as I don’t work now? I don’t take medicines. I want to die and go to God’s home.”

Smoking or chewing tobacco or using snuff was reported among both male and female stroke patients. One of the daughters-in-law reported that her mother-in-law smoked regularly, and continued to do so till the day she died.

As far as physical coping is concerned, patients/families innovated their own ways as they received

negligible help from the government. Post-stroke consequences caused loco-motor disabilities in survivors making them completely/partially dependent on others for daily activities such as defecation, transfer and walking. Such families reported the use of innovations like modifying a plastic chair/stool by cutting the seat from middle to use as a toilet chair and using a wooden/metal stick as a walking stick. However, innovations were very basic, and while they helped improve mobility to some extent, they hardly improved the quality of life of stroke-survivors.

Access to rehabilitation services

Affordability and availability were seen as barriers to accessing of rehabilitation services. Most people had to travel long distances and incur expenses on travel to access rehabilitation services. Households which were able to spend some money on rehabilitation continued it for some months after the stroke attack. For poor families, however, rehabilitation services were not affordable even from the nearest rehabilitation clinics. A lone woman patient, surviving on benefits from the government said,

“I used to go for exercise for six months by taking an auto rickshaw and spent so much money for auto rickshaw, but it has made no difference. Now I have no more money, so now I do nothing. How can I manage treatment and my living expenses in just 750 rupees?”

Accessing rehabilitation services demand cooperation from patients as well as caregivers and other family members. Patients or their family members often lost their faith in rehabilitation services and gave up as they perceived very little or no progress in the condition of the stroke-survivor despite spending money that they could ill-afford.

“My son earns 100-200 Rupees and he has four children to feed. I did not go anywhere for exercise ... I used to exercise for some days on my own, but then I got bored and stopped exercising.”

Unaffordable rehabilitation services often compelled stroke survivors to stay at home, increasing their post-stroke complications and severity of disabilities. Post stroke-complications and severity of disabilities amplified their rehabilitation needs.

IV

Discussion

In India, stroke survivors and their families are faced with enormous challenges during the course of post-stroke continuum of care – from the management of acute phase of stroke to immediate rehabilitation services to care at home. The present paper expands our understanding of how stroke affects the lives of survivors and their families by changing their social role and responsibilities affecting their social dynamics, their financial conditions, and their physical and mental well-being. This study reveals gender disparities prevalent in society negatively affecting women, both as stroke survivors and as caregivers.

Along the lines of previous studies (Bonita, Solomon and Broad, 1997; Carmo, Morelato, Pinto and Oliveira, 2015; Lynch et al., 2008), the present study illustrates that social relations are one of the major determinants of the quality of life of stroke-survivors. It has a significant influence on patients’ physical and psychological well-being. As many patients are dependent on their families for their day-to-day activities, surviving a stroke is not just limited to the physical effort, but it is a collective social effort as well.

Our findings are consistent with research that confirms the greater burden of illness among the female population as a result of longer life expectancy, resulting in a higher number of women stroke patients at an older age (Seshadri et al., 2006, Haast, Gustafson and Kiliaan, 2012). Further, the study highlights denial of immediate stroke treatment, rehabilitative services and home-based care for women stroke survivors especially when compared to support received by men stroke survivors. Like other studies, this study too brings out that gender disparities in stroke care are due to multiple reasons such as social values and norms around gender, residence, and economic situation of the stroke-affected individual and his/her family (Singla and Singla, 2016: 74).

Findings from this study illustrate gender differences in caregiving in a domiciliary setting. This has also been observed in previous studies (Das et al., 2010; Pinguart and Sorensen, 2006; Banerjee and Das, 2016). A majority of the primary caregivers are women, who consequently suffer from various physical and psychological hardships such as depression, disturbed sleep, fatigue, raised blood pressure, general body ache and financial stress.

Studies have also shown that there is a significant extent of unmet need for affordable stroke rehabilitation centres in India (Kamalakannan et al., 2016; Banerjee & Das, 2016; Pandian and Sudhan, 2013) and Gandhinagar district, Gujarat is no different from the rest. Although organised rehabilitation centres are available in the country, they are only limited to private hospitals in urban areas which are too expensive for the rural population who constituted our study sample.

V

Conclusion

In conclusion, our study shows that receiving emotional, physical and financial support from one's family is of greater importance to stroke-survivors than professional support. The study identifies women, as stroke patients and caregivers, to be in a more disadvantaged situation as compared to men. As caregivers, women are in dire need of other family members to share these responsibilities. Given the lack of rehabilitation services in Gandhinagar district in Gujarat, developing an affordable, accessible and patient-centred rehabilitative care is of utmost importance to reduce the post-stroke illness and burden of caregiving.

A major strength of this study is its mixed method study design which allowed us to obtain a rich understanding of stroke survivors' and their caregivers' needs. However, being a cross-sectional study, it does not provide insights into the process of coping with stroke and caregiving. A longitudinal or a more intensive ethnographic study may be useful as a follow up to this study.

Acknowledgements

We thank the Indian Council of Medical Research (ICMR), New Delhi, who provided us with funding and allowed us a great degree of freedom. We sincerely thank Dr. Geetha Menon for her constant support and guidance. We also thank all the colleagues from Indian Institute of Public Health Gandhinagar (IIPHG) who assisted in conducting the study.

References

- Banerjee, T. K. and S. K. Das,. (2016). Fifty years of stroke researches in India. *Annals of Indian Academy of Neurology*, 19(1), 1–8. doi: <https://doi.org/10.4103/0972-2327.168631>
- Bonita, R., N.Solomon, , and J. B. Broad, (1997). Prevalence of stroke and stroke-related disability. Estimates from the Auckland stroke studies. *Stroke*, 28, 1898-1902. doi: <https://doi.org/10.1161/01.STR.28.10.1898>
- Carmo, Julia Fabres do, , Renato Lirio Morelato, , Hudson Pereira Pinto, , Elizabete Regina Araujo de. Oliveira (2015). Disability after stroke: a systematic review. *Fisioterapia em Movimento*, 28(2), 407-418. doi: <https://dx.doi.org/10.1590/0103-5150.028.002.AR02>
- Das, S., A.Hazara, , B. K Ray,, M.Ghosal, , T. K.Banerjee, , T.Roy, , ... S. K. Das, (2010). Burden among stroke caregivers: Results of a community-based study from Kolkata, India. *Stroke*, 41, 2965-2968. doi: <https://doi.org/10.1161/STROKEAHA.110.589598>
- Gosman-Hedström, G. and L. Claesson, (2005). Gender perspective on informal care for elderly people one year after acute stroke. *Aging Clinical and Experimental Research*, 17(6), 479-85.
- Haast, R. A. M., D. R.Gustafson, , and A. J. Kiliaan, (2012). Sex differences in stroke. *Journal of Cerebral Blood Flow & Metabolism*, 32, 2100-2107. doi: 10.1038/jcbfm.2012.141
- Indrayan, A. (2005). *Forecasting Vascular Disease Cases and Associated Mortality in India. Background Papers: Burden of Disease in India*, New Delhi: National Commission on Macroeconomics and Health, Ministry of Health and Family Welfare, Government of India.
- Jonsson, A.C., I.Lindgren, , B.Hallstrom, , B.Norrving, , A.Lindgren (2005). Determinants of quality of life in stroke survivors and their informal caregivers. *Stroke*, 36(4), 803-808. doi: 10.1161/01.STR.0000160873.32791.20
- Kamalakannan, S., G. V. Murthy, A.Prost, , S.Natarajan, , H.Pant, , N.Chitalurri, , ... H.Kuper, (2016). Rehabilitation needs of stroke survivors after discharge from hospital in India. *Archives of Physical Medicine and Rehabilitation*, 97(9), 1526-1532. doi: 10.1016/j.apmr.2016.02.008
- Lynch, E. B., Z. Butt, A. Heineman, D. Victorson, C. J. Nowinski, L. Pere, D. Cella (2008). A qualitative study of quality of life after stroke: The importance of social relationships. *Journal of Rehabilitation Medicine*, 40(7), 518-523. doi: 10.2340/16501977-0203
- Mohanraj, R., V. Jeyaseel, S. Kumar, T. Mani, D. Rao, K. R. Murray, and L. E. Manhart (2015). Cultural adaptation of the Brief COPE for persons living with HIV/AIDS in Southern India. *AIDS and Behavior*, 19(2), 341-351. doi: 10.1007/s10461-014-0872-2
- Pandian, J. D., and P. Sudhan (2013). Stroke epidemiology and stroke care services in India. *Journal of Stroke*, 15(3), 128–134. doi: <https://doi.org/10.5853/jos.2013.15.3.128>
- Pandian, J. D., V. Srikanth, S. J. Read,, and A. G. Thrift (2007). Poverty and stroke in India: a time to act. *Stroke*, 38, 3063-3069. doi: <https://doi.org/10.1161/STROKEAHA.107.496869>
- Pinquart, M. and S. Sorensen (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *The Journals of Gerontology: Series B*, 61(1), 33-45. doi: <https://doi.org/10.1093/geronb/61.1.P33>
- Reeves, M. J., C. D. Bushnell, G. Howard, J. Warner Gargano P. W. Duncan, G. Lynch, ...L. Lisabeth (2008). A Sex differences in stroke: epidemiology, clinical presentation, medical care, and outcomes. *The Lancet Neurology*, 7(10), 915 – 926.
- Sealy-Jefferson, S., J. J. Wing and B. Sánchez (2012). Age- and Ethnic-specific Sex Differences in Stroke Risk. *Gender medicine*, 9(2), 121-128. doi:10.1016/j.genm.2012.02.002.
- Seshadri, S., Beiser, A., M. Kelly-Hayes, C. S. Kase, R. Au, W. B. Kannel, and P. A. Wolf (2006). The lifetime risk of stroke: estimates from the Framingham Study. *Stroke*, 37(2), 345-350. doi: 10.1161/01.STR.0000199613.38911.b2
- Singla, S. and R. Singl (2016). Stroke in India: Biosocioeconomic determinants. *Journal of Social Health and Diabetes*, 4, 71-76. Retrieved October 1, 2017 from <http://www.joshd.net/text.asp?2016/4/2/71/187993>. doi: 10.4103/2321-0656.187993
- World Health Organization. (2009). Women and Health in India: Today's Evidence Tomorrow's Agenda in Older Women. *WHO Report*, Ch. 6. p. 59-67. Retrieved January 5, 2015, from <http://whqlibdoc.who.int/publications/2009/9789241563857>
- Wyller, T.B. (1999). Stroke and Gender. *Journal of Gender Specific Medicine*, 2(3), 41-5.