

The Burden of Informal Caregivers Resulting from Providing Care for Stroke Patients

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ABSTRACT

Background: stroke occurs when the blood supply to part of brain is interrupted or reduced, preventing brain tissue from getting oxygen and nutrients. Brain cells begin to die in minutes. **Aim:** to assess the burden of informal caregivers resulting from providing care for stroke patients. **Design:** A descriptive research design was used in this study. **Sample:** A Convenient sample equal 150 informal caregivers of patients with stroke. **Setting:** This study was conducted in stroke outpatient clinic in El- Kaser El Aieny at Cairo University. **Tools:** One tool was used; interviewing questionnaire sheet composed of 4 parts demographic data of patient, informal caregivers' knowledge about stroke, the reported practice of the informal caregivers about the stroke and assessing burdens of the informal caregiver for stroke patients. **Results:** the study result revealed 87.3% of studied caregivers have low level of knowledge related to stroke disease. While 8.7% of them had average level of knowledge related to stroke disease and 4% of them had high level of knowledge related to stroke disease, 78% of studied caregivers had inadequate level of practices, while 22.0% of them have adequate level of practices for caring stroke patient, 68% of studied informal caregiver had sever level of burden and 27.3% of them had moderate level of burden, while 4.7% of them have mild level of burden. **Conclusion:** The most of informal caregivers had a low knowledge about stroke however more than three quarters of studied sample reported inadequate practice about stroke and two thirds of informal caregivers had sever burden. **Recommendations:** Developing health educational programs that would help informal caregivers to improve knowledge, practice and reduce burden regarding patient with stroke.

Introduction

Stroke is a clinical syndrome that consists of the rapid development of the clinical signs of global or focal disruption of cerebral function that lasts more than 24 hours; and may lead to death without any obvious cause other than a vascular-brain-origin (Ahmed, et al., 2020). Globally, it is the 2nd leading cause of death and the third in low-income countries. Nevertheless, two-thirds of the deaths related to stroke happen in developing countries. Stroke can be subdivided into ischemic and hemorrhagic origins (Areshidze, et al., 2018)

Stroke (including ischaemic stroke and haemorrhagic stroke) affects 13.7 million people globally per year and is the second leading cause of death, with 5.5 million deaths per year (World Stroke Organization, 2019). An estimated 1 in 4 adults will experience a stroke in their lifetime and there are >80 million survivors of stroke globally (Feigin, 2018).

Informal caregivers means the family members, close relatives, friends, or neighbors who are not trained health professionals, but care for stroke survivor at home irrespective of time limitations and without any payment. The new role of "informal caregiver" is a challenge that creates many difficulties for family caregivers that are not explicit in most studies (Muditha, et al., 2018).

The informal caregivers' burden is linked to the patient's physical, mental, psychological, and functional condition. Depending on the degree of patient dependency, the possibility of the caregiver experiencing burden, depression, exhaustion, and generally poor health. Caregivers need basic caregiving knowledge and skills to care for stroke patients in view of the various disabilities and potential complications of the stroke. These include performing or aiding the patients in basic activities of daily living as feeding, mobilizing, toileting, bathing, and dressing (Bugge, et al., 2019).

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Informal caregivers play an essential role in stroke survivors' rehabilitation at home. Informal caregivers should ask the health care team about rehabilitation services right away to ensure that the stroke patient is on the road to recovery as soon as possible. Then the informal caregivers can talk to the health care and rehabilitation team about how to provide help with rehabilitation at home and otherwise assist with stroke survivors' recovery plan (American stroke association, 2020)

In Egypt, according to recent estimates, the overall prevalence rate of stroke is high with a crude prevalence rate of 963/100,000 inhabitants, and the incidence of stroke annually is approximately 150,000-210,000. The official national statistics indicate that diseases of the circulatory system, including stroke, are the primary causes of death in Egypt, where stroke accounts for 6.4% of all deaths and ranks third after cardiovascular and gastrointestinal diseases. In Egypt, it was relatively unchanged over the past 10 years (Aref, et al., 2021). In addition, although the percent of population aged above 50 is only 12.7%, yet there is a relatively high proportion of stroke in young reaching 20.5% in some areas as shown by a previous study. This might explain the high prevalence and incidence of stroke among Egyptians, despite the low percent of aged population (El Nahas, et al., 2019).

The community health nurse help informal caregivers to facilitate and support patients with stroke to receive the right care in the right place at the right time, promoting best practice about why to deal with the patient, facilitating the pathway for patients potentially, administering medication, providing nursing care and continuous monitoring the patient, When the nurse improved awareness for the informal caregiver that's forward by positive for the patient (Green et al., 2021).

Aim of this study: - The aim of the study was to assess the burden of informal caregivers resulting from providing care for stroke patients

These achieved were done through the following:
Assessing the informal caregivers' knowledge about stroke disease.

Appraising the informal caregivers' reported practice regarding the care for patients with stroke. Estimating the informal caregivers' burden (physical, financial, psychological and social burdens) resulted from providing care for patients with stroke.

Research Questions:-

What is the informal caregivers' knowledge regarding stroke disease?

What is the informal caregivers' reported practice regarding the care for patients with stroke?

What is the burden on informal caregivers resulted from providing care for patients with stroke?

Subjects and Methods

Research Design: A descriptive research design was applied to achieve the aim of this study
Setting: Stroke outpatient clinic in El-Kaser El-Aieny at Cairo University in Egypt. The study was conducted at stroke outpatient clinic in first floor, this clinic provides treatment and follow-up services for patients suffering from stroke. So, choosing this place because it covers a large number of patients

suffering from stroke attended to stroke outpatient clinic.

Subjects: A Convenient sample was used to achieve the aim of the study.

Sample size: there were 150 informal caregivers with their stroke patients visit outpatient stroke clinic in El-Kaser El-Aieny and all of them were conducted in this study.

Tool for Data Collection:

One tool was used to collect study sample for achieving of study aim.

Tool : A structured interviewing questionnaire: This tool was developed by the investigators after reviewing the national and international related literature and contains four parts:

Part I: (A) Demographic data of informal caregiver, this part consists of 8 items as age, gender, place of residence, marital status, educational level, occupation, income residence and relationship degree.

B) Demographic data of patient with stroke, this part consists of 3 items as patient age, gender and date of informal caregiver providing the care.

Part II: Assessment of informal caregivers' knowledge regarding stroke.

This part concerned with informal caregiver's knowledge regarding stroke, and consisted of 7 closed ended questions, such as meaning of stroke, causes of stroke, signs& symptoms of stroke, types of stroke, treatment of stroke and complication of stroke.

Scoring system for knowledge questions, a correct answer was scored 2 points and incorrect answer was scored 1 point,

Total knowledge scores were classified as follows: High knowledge >75%, Average knowledge \geq 50% - 75%, and low knowledge < 50%

Part III: Assessment of informal caregivers' reported practice, this part consists of 13 closed ended questions as informal caregivers practice about patient's ability to swallow, informal caregivers practice about patients nutrition, Patient's sitting position while eating, patient's skin care, how to provide dressing for stroke patient, Pulmonary aspiration complication, how can you prevent constipation to stroke patient, how should you prevent UTIs for stroke patient, how to prevent muscle tension, positive and negative exercises should be done.

Scoring system of caregiver reported practices

These scores were converted into percentage score. The informal caregivers were considered done practice was scored one point and not done practices for patient with stroke was scored zero point. Total reported practice scores were classified as follows: Adequate practice \geq 60.0%. Inadequate practice <60.0%.

Part IV: Assessment of informal caregivers' burdens, this part consists of four sub items:-

1st: Assessment of the physical burden of an informal caregiver for stroke patients. 10 closed ended questions. As physical stress resulting from providing care for stroke patients, suffering from a lack of physical activity or eat balanced foods due to providing care for stroke patients, physical burdens resulting from preparing and providing proper nutrition stroke patient, physical burdens resulting from providing stroke patient's personal hygiene and physical burdens resulting from

transporting stroke patient from bed to chair or vice versa.

2nd: Assessment of the financial burden of an informal caregiver for stroke patients. 5 closed ended questions. As does taking care of stroke patient cause financial hardship, does preparing and providing proper nutrition to stroke patient cause financial burdens and if there is a need to do a nursing or medical consultation at home.

3rd: Assessment of the psychological burden of an informal caregiver for stroke patients. 26 closed ended questions. As does caring for your patient cause you frustration, exhaustion or nervous tension, do you feel constant anxiety, have you noticed lately that you are getting a lot of sleep or not getting enough sleep, have you become irritable and do you get angry about interactions with a stroke patient.

4th: Assessment of the Social burden of an informal caregiver for stroke patients. 7 closed ended questions. As does being with your patient make you socially isolated, do you accept the help of others in providing care for your patient, and do you feel that your social life has suffered because of my involvement with a stroke patient

Scoring system: The answers to these questions were scored as "2" for always, "1" for sometimes, and "0" for seldom.

Total burden scores were classified as follows:

Sever burden >75%, Moderate burden \geq 50% - 75%, and Mild burden < 50%

II- Operational Item:

Preparatory phase:

It was include reviewing of past, current, national and international related literature and theoretical knowledge of various aspects of the study using books, articles, internet, periodicals and magazines to develop tools for data collection.

Pilot study:

The pilot study has been conducted to test clarity of questions, applicability and understanding of tool. It has been conducted on 10 % of the sample (15) sample. The results of the pilot study helped in refining the interview questionnaire and to schedule the time framework. The participants of pilot were included in the main study sample.

Field work:

Data collection of the study was started at the beginning of May 2022 until the end of July 2022. The investigators introduced themselves to the patients and their informal caregivers, explained the aim of the study and its implication and how to fill in knowledge questionnaire, and ensure their

cooperation. Informed consent was obtained from the participants. Interviewing patients and their caregivers was carried out in specialized room in the outpatient stroke clinics in El- Kaser El Aiemy at Cairo University. The sheet took about 30 -45 minutes to complete. Data was being collected at 2days/week (Monday and Thursday) from 9am to 12 pm) every week within 3 months. Interviewing sheet was completed by the investigators for each informal caregiver.

Ethical considerations:

An official permission to conduct the proposed study was being obtained from the Scientific Research Ethics Committee at faculty of nursing Helwan University. Participation in the study was voluntary and subjects was be given complete full information about the study and their role before signing the informed consent. The ethical considerations was include explaining the purpose and nature of the study, stating the possibility to withdraw at any time, confidentiality of the information where it was not be accessed by any other party without taking permission of the participants. Ethics, values, culture and beliefs was be respected.

III- Administrative Item:

A written approval letter was being issued from Dean of Faculty of Nursing, Helwan University. The letter was directed to the director of El- Kaser El Aiemy hospital Clinics for conducting the study. After explanation of the study aim and objectives, an official permission was obtained from the Dean of faculty of nursing and the general manager of El-Kaser El Aiemy hospital asking for cooperation and permission to conduct the study.

IV-Statistical Item:

Data collected from the studied sample was revised, coded and entered using personal computer (PC). Computerized data entry and Statistical analysis were fulfilled using Statistical Package for the Social Science (SPSS) version 24. Data were presented using descriptive statistic in the form of frequencies, percentages. Chi-square was used for comparisons between qualitative variables. Spearman correlation measures the strength and direction of association between two ranked variables.

Significance of the results:-*
 Statistically significant $p < 0.05$,*
 Highly statistically significant $p < 0.001$,*
 Not significant $P < 0.0$.

Results

Table (1): Frequency Distribution of Demographic Characteristics of Studied Caregivers (n=150)

Demographic characteristics		No.	%
Age (years)	Mean ± SD	37 ± 11.77	
Sex	Male	27	18.0
	Female	123	82.0
Residence	Urban	39	26.0
	Rural	111	74.0
Marital status	Single	30	20.0
	Married	87	58.0
	Divorced	28	18.7
	Widow	5	3.3
Educational level	Unable to read and write	25	16.7
	read and write	40	26.7
	Basic education	70	46.7
	Secondary education or technical diploma	15	10.0
	University education and more	0	0
Occupation	Employed	25	16.7
	Farmer	52	34.7
	Worker	53	35.3
	House wife	20	13.3
	Other job	0	0
Income	Save and enough	13	8.7
	Enough	35	23.3
	Not Enough	102	68.0
Age of stroke patient	Mean ± SD	52 ± 21.34	
The gender of stroke patient	Male	95	63.4
	Female	55	36.6
Since when is the care for a stroke patient	Mean ± SD	2 ± 11.04	

Table (1) shows that the mean of studied informal caregiver age is Mean ± SD 37 ± 11.77, 82.0% of them are female ,also 74.0% of them are live in rural area, 58.0% of them are married, in addition 46.7 of them are having basic education, 35.3% of them are worker, 68.0% of them not have enough income, furthermore 36.6

of studied caregivers are wife of stroke patients, the mean of the studied patients age are Mean ± SD 52 ± 21.34, also 63.4% of the studied patient are male and the mean of duration from care for the a stroke patient is Mean ± SD 2 ± 11.04.

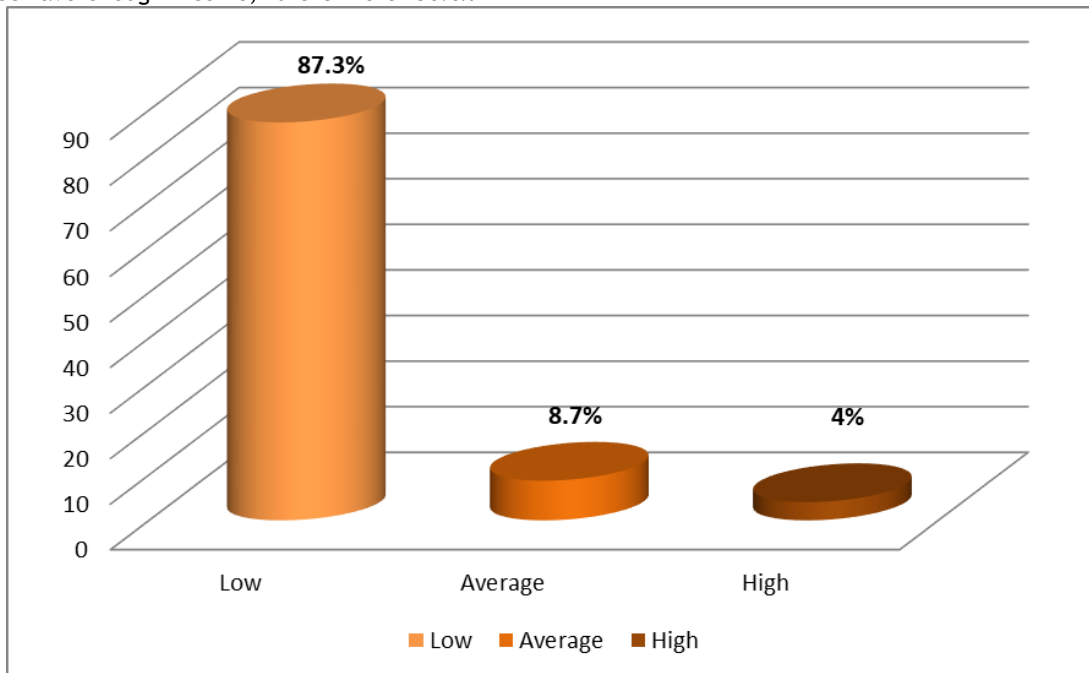


Figure (1) Percentage Distribution of Total Level of Knowledge among the Studied Informal Caregivers Related to Stroke Disease (n=150).

Figure (1) illustrates that 87.3% of studied informal caregivers have low level of knowledge related to stroke disease. While 8.7% of them have average level of knowledge related to stroke disease and 4%

of them had high level of knowledge related to stroke disease.

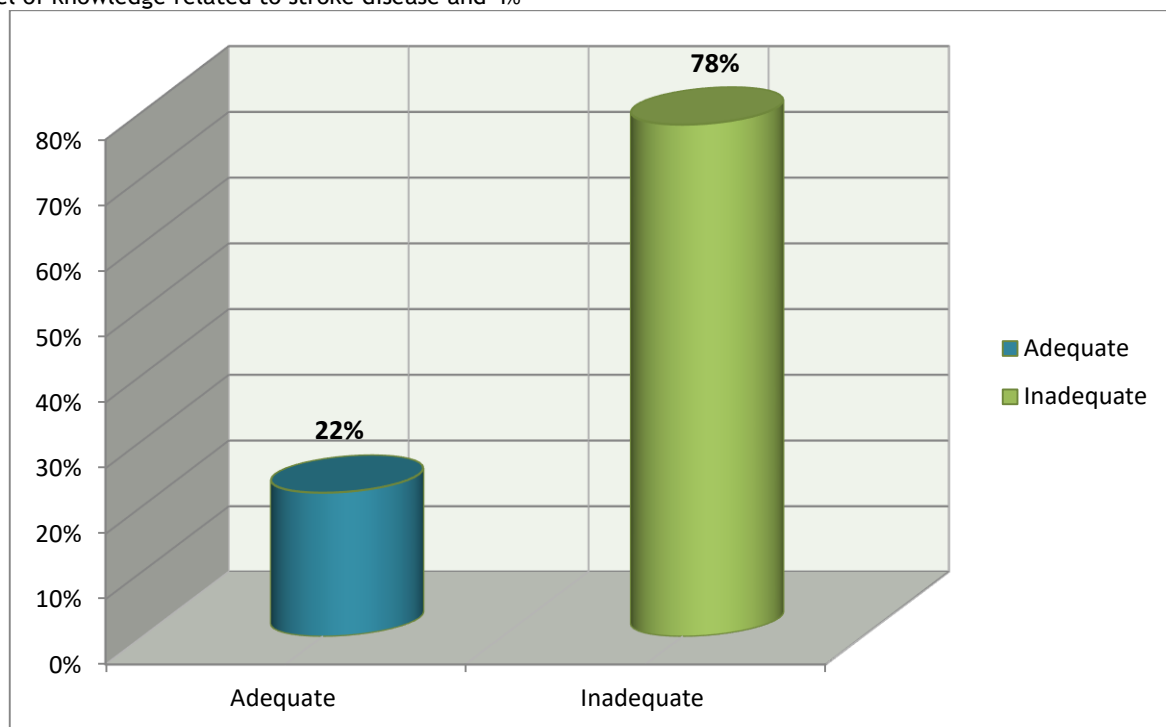


Figure (2) Percentage Distribution of Total Reported Practices Level among Studied Informal Caregivers Regarding Caring of Stroke Patient (n=150).

Figure (2) illustrates that 78% of studied caregivers have inadequate level of practices, while 22.0% of

them have adequate level of practices for caring stroke patients.

Table (2): Frequency Distribution of the Financial Burden of the Informal Caregiver for Stroke Patients (n=150).

Financial dimension	Always		Sometimes		Seldom	
	No	%	No	%	No	%
Does taking care of your patient cause you financial hardship?	62	41.3	80	53.3	8	5.3
Does preparing and providing proper nutrition to your patient cause you financial burdens?	27	18.0	19	12.7	4	2.7
Did you have to take unpaid leave from work to take care of your patient?	28	18.7	22	14.7	0	0.0
Do you bear the cost of medicines and consumables needed to take care of your patient, causing a great financial burden?	128	85.3	22	14.7	0	0.0
Did you have to do a nursing or medical consultation at home?	19	12.7	92	61.3	39	26.0

Table (2) indicates that 85.3% of the studied informal caregivers agree that always “the cost of medicines and consumables needed to take care of your patient, causing a great financial burden”

and 81.3% of them agree that sometimes “take unpaid leave from work to take care of your patient”.

Table (3): Frequency Distribution of the Social Burdens of the Informal Caregiver for Stroke Patients (n=150).

Social dimension	Always		Sometimes		Seldom	
	No	%	No	%	No	%
Does being with your patient make you socially isolated?	52	34.7	91	60.7	7	4.7
Do you accept the help of others in providing care for your patient?	22	14.7	59	39.3	69	46.0
I feel that my current situation with a stroke patient does not allow me as much privacy as I would like	90	60.0	60	40.0	0	0.0
I feel that my social life has suffered because of my involvement with a stroke patient	116	77.3	27	18.0	7	4.7
Do you set aside a fixed time in your day to talk to friends?	4	2.7	10	6.7	136	90.7
Do you dedicate once a week to entertainment?	3	2.0	19	12.7	128	85.3
Do you find suffering in attending social events?	129	86.0	9	6.0	12	8.0

Table (3) displays that 86.0% of the studied informal caregivers reported that always “find suffering in attending social events” and 60.7% of them reported that sometimes “being with patient make you socially isolated” while 90.7% of them agree that

seldom “set aside a fixed time in your day to talk to friends”,
 Figure (3) Percentage Distribution of Burden Level among Studied Informal Caregiver (n=150).

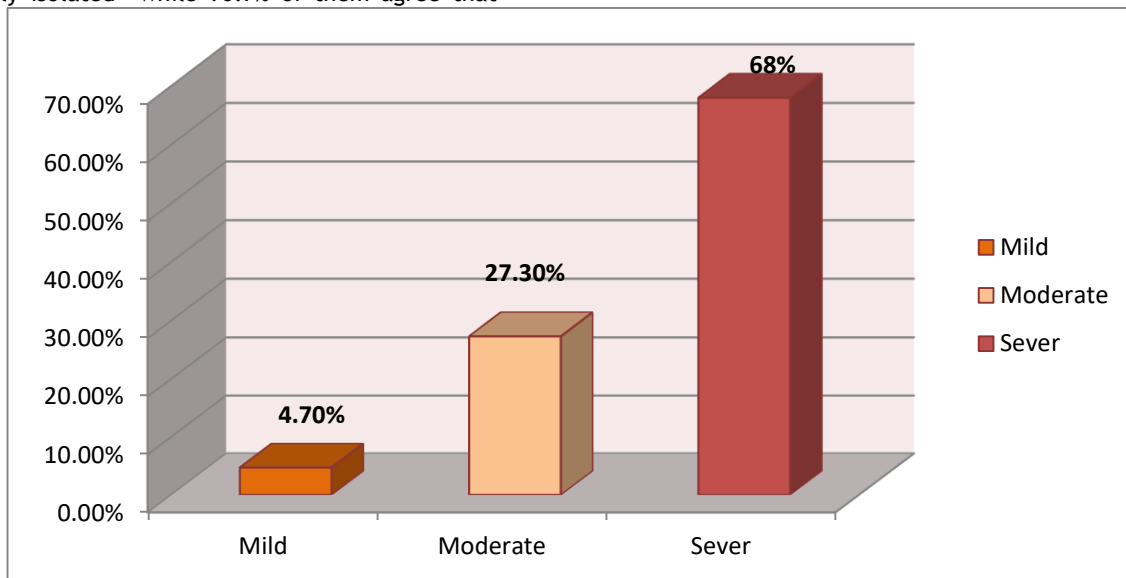


Figure (3) shows that 68% of studied caregivers have severe level of burden and 27.3% of them have moderate level of burden, while 4.7% of them have mild level.

Table (4): Correlations between Total Knowledge, Practices and Burden among the Studied Informal Caregivers.

Variables	Total knowledge		Total burden		Total practice	
	R	P	R	P	r	P
Total knowledge	-	-	.029	.725	-.134	.02*
Total burden	.029	.725	-	-	-.203	.013*
Total practice	-.134	.02*	-.203	.013*	-	-

(*) Statistically significant at p<0.05. (**) highly statistically significant at p<0.01.

Table (4) illustrates that there are high statistically significant negative correlation between total studied informal caregivers burden and total practices. Also there are high statistically significant negative correlation between total studied informal caregivers knowledge and practices.

Discussion

Stroke is one of the major challenges facing healthcare being one of leading cause of death and

one of the major cause of disability and dependency in activity of daily living worldwide. Stroke rehabilitation has concentrated on patient-focused interventions to reduce severe disability and institutionalization, which has resulted in increasing number of disabled patients being managed at home (Kalavina et al., 2022).

Regarding demographic characteristics of the studied informal caregivers, the present results showed that the mean of studied informal caregiver

age is Mean \pm SD 37 \pm 11.77, the majority of them are female, also three quarters of them are live in rural area, more than half of them are married, in addition half of them are having basic education, one third of them are worker, two thirds of them not have enough income, furthermore one third of studied caregivers are wives of stroke patients, the mean of the studied patients age are Mean \pm SD 52 \pm 21.34, also three fifths of the studied patient are male and the mean of duration from care for the a stroke patient is Mean \pm SD 2 \pm 11.04. In the investigator point of view these results due to family structures and cultural attitudes toward caring for stroke patient.

These results were agreement with Wajnberg et al., (2022), who carried out their study about "Identifying Socio-demographic Characteristics Associated with Burden among Caregivers of the Urban Homebound" in United States and reported that the mean age was 37; 76% of them was female, live in rural education and have basic education. As same as these results agreed with Yakubu & Schutte, (2020), who carried out their study about "Caregiver attributes and socio-demographic determinants of caregiving burden in selected low-income communities in Cape Town" in South Africa. Who reported that 82% of the results study females, married and not have enough income.

These paragraphs answered the research question number1: What is the informal caregivers' knowledge regarding stroke disease?

Concerning about total level of knowledge among the studied caregivers related to stroke disease, the present study results illustrates that most of studied informal caregivers have low level of knowledge related to stroke disease. While one tenth of them have average level of knowledge related to stroke disease and few of them had high level of knowledge related to stroke disease. In the investigator point of view, these results due to most of studied caregivers lived in rural area and had basic education.

These results in the same line with Liu et al (2020) who conducted a study entitled "Effects of personal characteristics, disease uncertainty and knowledge on family caregivers" in China revealed that 89% of studied caregivers have low level of knowledge related to stroke disease. Also, these results in the same line with Lee et al (2020) who conducted a study entitled "A Survey of Caregivers' Knowledge about Caring for Stroke Patients" in the Busan area, Korea revealed that caregivers working at convalescent hospitals showed an only 17% of correct answers of knowledge related to stroke disease.

On the other hands, these results not in the same line with Tan, Hi & Azmi N, (2020) who conducted a study entitled "Caregiving Self-efficacy and Knowledge Regarding Patient Positioning among Malaysian Caregivers of Stroke Patients" in Malaysia revealed that 71% of studied caregivers have sufficient level of knowledge related to stroke disease. Also, these results not in the same line with Muhrodji et al (2022) who conducted a study entitled "Roles and Problems of Stroke Caregivers" revealed that 61% of studied caregivers have higher level of knowledge related to stroke disease.

The following paragraphs will answer the research question number 2: What are the informal caregivers reported practice regarding the care for patients with stroke?

The present results demonstrates that most of studied caregivers have correct action regarding "best position that prevents the occurrence of pulmonary aspiration by saliva and the fall of the tongue", also half of them reported a good practice when helping in lifting the patient with difficult movements, while majority of them have incorrect action regarding "Swallowing test", and four fifths of them have incorrect actions to prevent constipation for their stroke patients. In the investigator point of view inadequate practice is due to most of studied caregivers lacked of awareness and low knowledge about stroke disease.

These results finding harmony with Hamzah, et al (2023) who conducted a study entitled "The Malay version of the caregiver assessment of function and upset instrument (Malay-CAFU): a translation and validation study among informal stroke caregivers" in Malaysia revealed that 84% studied caregivers know that best position that prevents the occurrence of pulmonary aspiration by saliva and the fall of the tongue.

The following paragraphs will answer the research question number 3: What is the burden on informal caregivers resulted from providing care for patients with stroke?

Regarding to burden level among studied caregiver, these results finding shows that most of studied caregiver have sever level of burden and one third of them have moderate level of burden, while few of them have mild level. These results finding corroborates with Bhattacharjee et al. (2021) who conducted a study entitled "Factors affecting burden on caregivers of stroke survivors" in The United States reported that 63% of caregivers for stroke survivors had sever level of burden and many factors contributed to this burden.

Also, Kalra et al. (2020) who conducted a study entitled "Training caregivers of stroke patients" in India revealed that 62% of informal caregivers had sever level of burden. These results discongruent with Nelson et al. (2019) who conducted a study entitled "Declining functioning and caregiver burden/health: the Minnesota stroke survey-quality of life after stroke study" in Kentucky, USA revealed that 71% of caregivers for stroke survivors had moderate level of burden.

Concerning about correlations between study variables, these results finding illustrates that there are high statistically significant negative correlation between total studied caregivers burden and total practices. Also there are high statistically significant negative correlation between total studied caregivers knowledge and practices. These results finding harmony with Huo, M., & Kim, K. (2023) who conducted a study entitled "Lasting impact of relationships on caregiving difficulties, burden, and rewards" in South Korea revealed that there are high statistically significant negative correlation between total studied caregivers knowledge and practices, Also, negative relationships with care recipients was only associated with increased difficulties for caregivers who had younger care recipients. In the investigators point of view these results due to lack of informal caregivers practice which make them malorganized and exert a lot of efforts in caring stroke survival.

These results finding discongruent with Wang et al. (2022) who conducted a study entitled "The positive aspects of caregiving in dementia" in China found

that positive relationships were significantly associated with increased rewards in caregivers whose care recipients had fewer disabilities. In the investigators point of view these results due to most of informal caregivers from married females lives in rural areas which have a lot of responsibilities with their large families.

Conclusion

On the light of results of the current study and answers of the research questions, it concluded that, the most of informal caregivers had low level of knowledge regarding stroke, while one tenth of them had average level of t knowledge regarding stroke and only few of them had high level of knowledge regarding stroke. Also, the most of informal caregivers had inadequate reported practice about stroke, while one fifth of them had adequate reported practice about stroke, there were most of informal caregivers had severe burden resulting from providing care for stroke patients. While, one third of them had moderate burden and few of them had mild burden. The most of informal caregivers had complained of physical and social problems, the majority of them complain of psychological and financial problems. In addition, there were a highly statistically significant negative correlation between total studied informal caregivers burden and total practice, Also there are highly statistically significant negative correlation between total studied informal caregivers knowledge and practice.

Recommendations

Based upon findings of the current study, the following recommendations were suggested:

- Providing health education by community health nurses to informal caregivers for engaging them in effective stroke care.
- Designing and hanging posters and brochures for informal caregivers of stroke patients in outpatient clinics.
- Informal caregivers of stroke survivors should be encouraged to present for regular check-up alongside with their care recipients.
- Provide workshops for informal caregivers to enhance informal caregivers practice in caring of stroke patients supervised by nurses.
- further local studies to explore the determinants of caregiver burden and depression among informal caregivers of stroke survivors, with the intent of providing clarifications, in order to enhance judicious utilization of available health resources.

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