Perceptions of Caregivers about Long–term Care Services in Bangladesh: A Qualitative Descriptive Study

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Abstract: Long-term care demand for stroke survivors has increased in Bangladesh and other parts of the globe. Family caregivers play a significant role in continuing care for their relatives who are stroke survivors. Still, little is known about their experiences using long-term care services. This study explored the perceptions of Bangladeshi caregivers regarding long-term care use of family members with stroke. A qualitative descriptive study was carried out in the Rangpur division of Bangladesh between February and June 2020. A purposive sampling method was performed to select 15 participants from eligible family caregivers who met the inclusion criteria. Participants were interviewed face-to-face using semi-structured questions and recorded with a digital recording device. The duration of each interview ranged from 60 to 90 minutes. Data were analyzed using content analysis.

Four major themes emerged: 1) Understanding of long-term care, 2) The challenges of providing care, 3) Long-term care services as essential support, and 4) Facilitators and barriers to using long-term care services. The findings informed that nursing and multidisciplinary long-term care is needed for stroke survivors in the institutions and at home. The study finding has important implications for the front liners in health sectors, especially for nurses, clinicians, nurse educators, and policymakers to develop specific care units for stroke survivors and train family caregivers to ensure quality long-term care.

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Introduction

Worldwide, life expectancy is increasing consecutively because of demographic transition. However, non–communicable chronic diseases are increasing due to increased life expectancy, lifestyle changes, industrialization, and work stress. These include cancer, coronary artery diseases, stroke, and liver disease.[1] According to estimates of the Global Stroke Factsheet released in 2022, over the last 17 years, the lifetime risk of developing a stroke has increased by 50% because of high blood pressure. Moreover, one in four people is estimated to have a stroke in their lifetime.[2] Stroke is a diseased condition of the brain; globally, it affects 17 million people annually. It was the second most common cause of death in the world.[3] Globally, stroke burden substantially increased from 1990 to 2019 as 70% was combined stroke incidence, 43% of deaths were due to ischemic and hemorrhagic stroke, 102% was total

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stroke prevalence, and 143% was disability-adjusted life years (DALYs) due to all types of stroke. In lower and lower-middle-income countries, 86% of deaths and 89% of DALYs were from stroke.[4, 35]

In many countries, long-term care is increasing dramatically and may cause a crisis over the next several decades. Individuals and policymakers should be aware of long-term care issues before they become more severe.[5] Long-term care covers a wide range of services and situations with basic daily life activities such as bathing, dressing, meals, or more complex health-related services, at home, in private clinics, or care within a hospital setting. Stroke survivors need immediate hospitalization as a medical emergency and require individualized long-term care. They are often admitted to a long-term care institution, which is a challenge for their families.[6,7] Like other low and middle-income countries, stroke is also acute morbidity in Bangladesh. However, many preventable deaths occur yearly due to stroke, Bangladesh's third leading cause of death.[8] The most common risk factors observed for stroke in Bangladesh were hypertension, diabetes, ischemic heart disease and tobacco use.[9] In existing healthcare settings in Bangladesh, provision for acute care and outpatient departments for long-term care are available when stroke survivors stay at home. However, formal provision of home-based long-term care by trained professionals for stroke survivors in Bangladesh is not yet available. Usually, untrained family caregivers provide support for stroke survivors when they are at home.[9]

Therefore, it is time to set a policy to deal with the upward trend of stroke prevalence by developing comprehensive care for all.[10] Bangladesh has studies on the prevalence of stroke, but studies with relevant factors related to stroke survivors' long-term care use from family caregivers' experiences are limited. Additionally, related factors of stroke survivors' long-term care use from family caregivers' perspective are still unknown in the Bangladeshi context. Exploration of associated factors of stroke survivors' long-term care use in Bangladesh might need to establish a new policy for them. Considering the existing care provisions for stroke survivors and ensuring their quality of life, it was necessary to explore related factors of long-term care use from family caregivers' perspectives. Therefore, this study explored the experiences of family caregivers of stroke survivors using long-term care in Bangladesh and addressed gaps in the literature.

Review of Literature

Based on Andersen's Health Care Utilization Model, the researcher reviewed relevant literature to measure equitable access and develop policies for health care services in hospital inpatient services, dental services, and long-term care settings.[11] In the revised version of the model,[12] the family caregiver was included based on the assumption that directly and indirectly, the family caregiver influences the use of services determined through three major components, predisposing, enabling, and need factors adding family-level indicators.[11] However, this study concentrated on understanding how Bangladeshi family caregivers engaged in long-term care selection based on their knowledge, understanding, and decision-making.[13] Stroke is one of the leading causes of death globally. Annually, 15 million people are affected by stroke worldwide.[14] It was the second most common cause of death.[15] In the United States, a stroke kills someone every 3 minutes 17 seconds.[16] In India, the annual incidence rate of first-ever stroke was 123.15 per 100,000 persons per year.[17] According to the statistics of 2020, it was found that 7.08 million deaths occurred due to stroke worldwide.[16]

Stroke affects many people annually, creating the most significant burden in low- and middle-income countries.[17] Stroke is also a disease of younger people; almost two-thirds of strokes occur in younger adults. Stroke prevalence, death, and disability-adjusted life years (DALYs) remained much higher in developing countries.[7] Moreover, many stroke-related deaths (75.2%) occur in developing countries.[18] The percentage of deaths in younger adults between 1990 and 2019 increased, leading to a more significant burden of aging in developing countries.[4] In developing countries, many stroke-related DALYs (81.0%) occurred.[18] Family caregivers often face competing roles and responsibilities with seeking help.[19] Long-term care provided for them includes medical, personal, and rehabilitation support. Some studies suggested a lack of children to provide informal family care was a high risk for hospitalization.[20]

According to the global disease burden in the last two and a half decades, stroke survivors and stroke incidents increased from 50% to 100%.[2]Long-term care demand in Bangladesh has proliferated because of an increasing number of stroke survivors, their life expectancy, and their level of chronic disability. Although the need for long-term care is growing, there is little empirical evidence to guide policymakers in Bangladesh where the health care delivery system is a complex network including public health departments, non-government organizations and private institutions. The Ministry of Health and Family Welfare is responsible for formulating national-level policy, planning, and decision-making for healthcare and education. Across the country, from the national to the community level, the various implementing authorities translate the national-level policies, plans, and decisions into actions.[13] There are very few studies in Bangladesh indicate the relationship between family caregivers' burden on stroke survivors and their preference for long-term care provisions. However, the relationship between dependence and long-term care use in the country has not yet been explored.

Individuals who use long-term care along a continuum vary enormously in financial, emotional, and physical abilities and should have an affordable and accessible system to respond to their needs. Moreover, long-term care should change to effectively provide a continuum of care to the diverse population of Bangladesh. However, in the traditional Bangladeshi culture, the obligation to care for stroke survivors is primarily a family responsibility. Therefore, most health services were traditional healthcare facilities in Bangladesh. Moreover, very few articles addressed the issues of long-term care use and caregivers' experience of long-term care use. Therefore, this study included acute and chronic illnesses or disabilities due to stroke to focus on stroke survivors' long term care use. Despite many achievements, Bangladesh continues to carry a high disease burden, including non-communicable diseases. Therefore, this gap convinced the researcher to explore perceptions of using long-term care services for stroke survivors by their family caregivers in Bangladesh.

Methods

Design: This study used a qualitative descriptive approach to discover and understand the phenomenon of the investigation. This approach was a naturalistic inquiry in which the descriptions of experience and perception of the phenomenon are straightforward,[21] and therefore was appropriate to identify the subjective nature of the research problem. This approach enabled the researcher to understand in-depth information, feelings, and life experiences of Bangladeshi family caregivers with at least three months of caregiving experience. This study's reporting followed the Criteria for Reporting Qualitative Research (COREQ).[22]

Participants and Setting: Participants were 15 family caregivers of stroke survivors who lived only in the Rangpur division of Bangladesh and met the inclusion criteria for the best answer to the research questions.[23] Purposive-sampling method was used to select participants. Inclusion criteria included: 1) family caregivers aged 18 or above who cared for stroke survivors with moderate to severe dysfunction for at least three months or more, screened by the National Institutes of Health Stroke Scale (NIHSS)[24] with the cut-off point of more than four; 2) be a spouse, father or mother, or sibling; and 3) be willing to share their opinion, judgment, or any experiences using a long-term care service.

The study setting was two tertiary-level medical college hospitals in the Rangpur division of Bangladesh. The rationale for selecting the study settings was that over half of urban facilities in Bangladesh provide services for cardiovascular diseases like stroke compared with 13% of rural facilities. The interview was performed in the hospital ward, hospital cabin, or at home according to the participants' desired location where they felt comfortable.

Ethical Considerations: Permission for conducting the research was obtained from the Institutional Review Board of Thammasat University (the Ethical Review Sub-Committee Board for Human Research Involving Sciences, Thammasat University, No. 3). The project was approved on 24 January 2020, and the project code was 147/2562. Informed consent and anonymity of family caregivers were ensured. A consent form included family caregivers' agreement to participate in the study and acknowledge their protected rights. To ensure privacy and confidentiality, access to the identity of the participants was limited to the primary investigator (PI). All study data were kept in a locked metal file cabinet in the PI's office and will be destroyed after three years.

Data Collection: Data were collected from February to June 2020. The PI was a doctoral candidate with qualitative nursing research training and experience. He conducted face-to-face interviews using an interview guide with open-ended questions. One participant was interviewed on the hospital grounds, one at the hospital cabin, and 13 participants at their homes. All participants selected the place of the interview as their desired location and felt comfortable. The objective of the research background and purpose was explained before the interview. All participants received a letter of invitation and signed informed consent before the interview. The interviews were recorded with the prior permission of the family caregivers of stroke survivors. A previous discharge certificate was used[25] to validate the data during interviews. Eight interviews needed to be done again to probe for more information. All the interviews were conducted in Bengali language and recorded with digital recorders. Field notes were taken after each interview to record the participants' gestures and body language. Reflections were used to write down the PI's thoughts and feelings during the study and data analysis process. When PI found no new information, no further interviews were conducted. The duration of the in-depth interview was at least 60 to 90 minutes.

Interview guide: Focused on Andersen's healthcare use model,[11] an interview guide was developed by PI, including open-ended questions as required.[25] Advisors rechecked the accuracy and appropriateness of the questions. Pilot interviews were conducted with two participants before formal interviews for revision and were not included in the final analysis. Examples of semi-structured questions were: 1) Please tell me about the health service that you use for stroke survivors, 2) Which one of the services do you mean as long-term care service and why? 3) What things inspired you to use this service? And 4) Why do you think this service is essential for stroke survivors? Before the interview, the PI made rapport with the family caregiver to gain in-depth information to explore related factors of long-term care use from their actual experiences.

Trustworthiness: In the qualitative design, the researcher seeks believability based on coherence, insight, instrumental utility[26] and trustworthiness through a process of verification rather than through traditional validity and reliability measures. For example, a discharge certificate from the hospital was checked to confirm their hospital admission and validate the data's findings and credibility.[23] The PI was engaged longer to collect data and used persistent observation as he explored details of long-term care service use by family caregivers. To achieve dependability, PI provided the data collection, analysis, and interpretation method to keep tracking as an audit trail. To achieve transferability, the PI provided detailed, thick descriptions by probing questions to get the quality of data saturation. To achieve confirmability, the research team discussed the findings and checked and rechecked participant data analysis. This was documented by a transparent coding scheme that identified the codes and patterns in the analyses. The transcripts and findings were given back to the participants to clarify for accuracy.

Data Analysis: In the qualitative analysis, data collection and analysis proceed simultaneously. The steps in the qualitative analysis undertaken in this study included 1) preliminary exploration of the data by transcripts transcribed by the PI; 2) data coding by segmenting and labeling the text; 3) aggregating similar codes together; 4) interrelating themes; and 5) constructing a narrative.[27] Based on this analysis, the PI provided a detailed case narration. Therefore, data were analyzed for themes that were either common or different. This showed the extent to which identified factors have a similar or distinct effect on the study participants regarding long-term care use.

Findings

Fifteen participants were family caregivers caring for their relatives who were diagnosed stroke survivors. Among them, eight were female, and seven were male. Participants were 19 to 50 years old, with an average age of 28.13 years. The participants' average caregiving duration was 29.6 months for their stroke survivors' long-term care. Seven participants were sons who cared for their fathers and a mother (6 for fathers and 1 for mother). Four participants were wives taking care of their husbands. Three participants were daughters taking care of their mother and a father. One participant was a daughter-in-law who took care of her father-in-law.

Four major themes emerged from the data analysis and are discussed below:

Theme 1: Understanding of long-term care

Most participants (66%) explained that long-term care was using a care service for an extended period (more than six months). Participants used health and social services because their relatives with stroke needed care in different services—their relationship between family caregivers and family members with stroke-induced the use of long-term care. Most caregivers included daughters and sons who cared for stroke survivors who were their father and mother.

The types of long-term care services included physical therapy, speech therapy, and home health care service. Participants provided the meaning of long-term care use. For example:

> *"I think stroke survivors and cancer patients need long-term service because these patients need care for a long time. My father is suffering from a stroke, and we have been caring for him for more than 3 years."* (Daughter, 19 years)

> *"I think the service we are taking a long time is long-term care service. We are taking physical therapy now. Our doctor told us that we need a long time to be completely all right. So, it is long-term care."* (Daughter, 21 years)

Another participant indicated that after discharge from the hospital, she used physiotherapy for her family member as a different treatment option through hardship. Therefore, the meaning of long-term care was different for her. For example:

> *"Now we are using both neuro-medicine doctors in their private chambers and physical therapy doctors in their private chambers. Sometimes we go to the government hospital for physiotherapy, but not very often."* (Wife, 35 years)

Theme 2: The challenges of providing care

Participants managed care for family members. The care included health services from providers and full support care from participants. Stroke survivors needed the full support of caring in daily life activities, helping to take medication, and rehabilitation services, which increased caregiving challenges. Family caregivers care for stroke survivors by assisting with daily activities and social and environmental care. Almost all participants in this study expressed that their medical condition left them unable to meet activities of daily living. As a result, they visited the outpatient (OPD) department of a government hospital. Often, the person moved into the hospital because family members could not act as full-time caregivers. Many participants shared their experiences and the rationale for transitioning to a government hospital. For example:

> *"I need to do almost everything; I mean, some activities he can do by himself, but some he cannot do without my support. For example, during a bath, I need to wash his clothes, sometimes forget to take food timely etc."* (Son, 19 years)

> *"I have to do everything for him. From the morning to bedtime, I am always with him. He cannot take a bath alone, cannot take food alone, even during sleep, I have to do something for him."* (Wife, 45 years)

> *"I am taking care of him as his son. My mother is also helping me to take care of my father. She also helps him in all kinds of daily activities like bathing, eating, taking showers, going to take retirement allowance etc."* (Son, 27 years)

Family caregivers used long-term care services such as physical therapy and home health services in government and private hospitals. The problem of using long-term care services was dependent on the medical expense. For example,

> *"After discharge from the hospital, we get service from private and government hospitals. But since we were not rich enough to afford private services from a clinic, we had to go to the government hospital. We have used long-term care service for a long time, almost seven years."* (Wife, 35 years)

> *"After hospital, we are taking care of him through hardship. Handling such a stroke survivor was not so easy. We need to look after him all the time. We are using home health care service."* (Daughter-in-law, 23 years)

Theme 3: Long-term care services as an essential support

Most participants, 12 out of 15 (80%), stated that long-term care service was necessary for their stroke survivors for the length of their lives. Participants used such services to support the family members with stroke as treatment and rehabilitation. These services supported stroke care needs such as physical and psychological care needs. In addition, participants used long-term care services to support the activity of daily living, receive the proper treatment and care, and facilitate stroke survivors' rehabilitation to be dependent. Moreover, they preferred the services from a government hospital because that was less expensive than in a non-government hospital. For example:

> *"I think this service is important for the stroke survivor for many reasons. For example, after a stroke, most of the survivors cannot walk or cannot move like a normal person. So, they need to take service from the hospital for the rest of their life."* (Daughter, 24 years)

> *"Ah...this service is definitely important because a stroke survivor needs long-term service. Stroke survivors need whole-life treatment and care."* (Son, 27 years)

A participant shared the opinion that long-term care services support daily living needs. For example:

> *"I think this service is very important for my husband because he cannot do all works which he used to do it before. He needs help from others to perform his daily activities to survive. Even for going outside, we need to provide support to him."* (Wife, 35 years)

People often need long-term care when they have a severe and ongoing health condition or disability like a stroke disease. Most often, this need develops when people get older or their disability gets worse. However, participants were concerned about the expense of long-term care. For example:

> *"I think long-term care service for a stroke survivor is very important because this type of patient needs long time care. If there is no government hospital for stroke survivors, then many people could no treat their stroke survivors because private clinics are very expensive."* (Son, 30 years)

Theme 4: Facilitators and barriers to using the long-term care services

The participants described facilitators and barriers that made them decide whether to use long-term care services. Regarding facilitators to using these, participants reported low-cost or free health service charges in the government hospital. In addition, doctors' and nurses' behavior and a clean environment were related to patient satisfaction. The study showed that the behavior and attitude of the doctors and nurses reflect the overall stroke survivor's satisfaction status, for example:

> *"In the hospital, some doctors and some nurses are very good. They help me a lot. We can get services from the hospital with very minimum cost."* (Daughter, 21 years)

> *"Umm, hospital service is very good for us because we do not need to spend a big amount of money."* (Wife, 35 years)

> *"We come to the government hospital because of doctors and nurses availability... And we thought that maybe we need less money to get all services." (Wife, 45 years)*

For the barriers to using long-term care services, participants explained various obstacles to using care services, such as cost of services, quality of services, and healthcare providers' availability. These barriers reflected that participants were dissatisfied with the use of long-term care services of family members who were stroke survivors. For example:

> *"Umm...we are not satisfied with government hospitals because it is very troublesome to get free service in the hospital, and the service process is very complicated."* (Son, 30 years)

> *"Yet we are not highly satisfied because of staff's behavior and dirty environment. Everywhere there is a foul smell. So, I am not totally satisfied."* (Wife, 35 years)

In addition, the essential features for the family caregivers' dissatisfaction were a doctor-patient, nurse-patient relationship and shared responsibility in managing patients' illnesses. Some participants complained about doctors' and nurses' attention toward patients and other objections. For example:

> *"I am satisfied with the government hospital, but this hospital has some problems too. For example, dishonesty, staff's availability, delayed response etc."* (Son, 30 years)

> *"It is not easy to be satisfied because there are many things that will make you unhappy. Doctors and nurses are not available all the time. You will find them always busy. So they will spend very minimum time with you."* (Son, 22 years)

> *"We are somewhat satisfied with the hospital because we could not afford other places like private clinics."* (Son, 27 years)

Discussion

Long-term care for the dependent varies according to meeting their health or personal care needs to be independent. These services require professional paid caregivers or unpaid family caregivers to perform their daily activities because of physical illness or disability so they can live as independently as possible. In Bangladesh, unpaid family members have traditionally provided this type of long-term care at home because aged care homes or adult daycare centers do not exist in Bangladeshi communities.[6] Stroke survivors' needs vary according to activities of daily living dependencies, for example, if they need help around the home, shopping, transportation, or even counting money with family caregivers. The findings demonstrated that overall long-term care service quality was not very satisfactory. Because of distrust of hospital-based services and poor quality service, participants were unsatisfied and assured of the hospital services.

Understanding of long-term care

Andersen's behavioral model focuses on measuring equitable access to medical care[11], the model's primary goal. Access to care is defined as the actual use of health services equally based on personal characteristics and healthcare needs, including health service types. Caregivers perceived that long-term care was the health care services of stroke survivors who needed specific health care for a long time. However, the meaning of long-term care can be quite vague; many people might be uncertain exactly what this means. A general understanding of the term is the daily activities that one must do to take care of oneself.[29] In this study, caregivers perceived that long-term care was a variety of health services. That was because stroke survivors needed different services for more than one year. Practically, long-term care covers a wide range of services such as physical therapy, speech therapy, transportation, nutritional center, legal and financial service, hospice care, and adult day care. A systematic review revealed that the rehabilitation program, including physical and occupational therapy, was the most beneficial for stroke survivors.[30] In addition, the time of using health services for stroke survivors varied from six months to more than a year. No consensus about the time duration of using the long-term care service was presented. A systematic review reported that the multifaceted program of post-stroke complication, care management, rehabilitation, and counseling improved stroke survivors' quality of life and health function at twelve months.[31]However, in this study, no consensus was drawn about the specific time duration of service users regarding the meaning of long-term care.

The challenges of providing care

This study revealed that caring for stroke survivors is challenging for family caregivers. The care for stroke survivors in a family needs time and lots of support, such as daily activities, medication, and rehabilitation. In addition, this study revealed that healthy long-term care need was essential for caregivers who decided to use long-term care services for stroke survivors. This study result was consistent with a previous study that mentioned the status of chronically ill and disabled as need factors were significant indicators of health service utilization.[32]

In Andersen's original behavioral model, the perceived need was why people use the health service. The care could be increased or decreased based on the health education program or the financial approach.[11] These care needs of stroke survivors with age were related to the level of disability. A gerontological study has shown that age is essential to long-term care use in the United States.[33] This finding is explained by the fact that the participants were selected using criteria of disability, diagnosis, and age. However, existing research has paid relatively rare attention to long-term care use among stroke survivors; this study expands the current understandings and demands from family caregivers' perspectives to examine this issue, especially among Bangladesh's fastest-growing aged population.

An ongoing trend is to move new survivors to post-acute care out of the hospital into less expensive long-term care settings. They are going to skilled nursing homes and other long-term care providers or into home-based settings higher than before to reduce expenses further.[34] However, stroke survivors' daily living activities can predict the need for institutional long-term care in Bangladesh. Data showed many factors in determining the use of institutional long-term care were ADL dependencies. These findings are consistent with an earlier study that stroke survivors have more significant needs of care resulting from the functional disability and cognitive impairments and therefore need more residential care.[32] A recent study conducted in Thailand showed that functional status had direct and indirect effects on caregiver burden with the working hours of care and self-efficacy of the caregivers.[35] In addition, long-term care might be more challenging because stroke survivors and their families are reluctant to make hospital placement until the stroke survivors are seriously impaired, making lives difficult for them and their families.

Long-term care services as an essential support

Even though the participants understood their condition and the importance of long-term care, many admitted that others did not provide any information regarding appropriate decision-making for placing their stroke survivors in the acute stage. The participants often had limited knowledge of the various long-term care facilities. Participants believed that their families actively placed complete trust in the outcome, and sometimes they were frustrated. They shared the consideration of a different care program, but the family was later selected for a government hospital. One reason was that family caregivers used long-term care services from government hospitals related to income as an enabling factor of the behavioral model.

A US study found that low-income families were more likely to assist their elders than high-income families.[30] Other study findings indicated that caregiving families were likelier to have low incomes,[36] since it was possible that those with the lowest income or fewest assets would receive some assistance from welfare programs. However, it was also likely that stroke survivors were more socioeconomically constrained. This impeded their ability in costly options such as private institutional care and other quality nursing care, making them highly dependent on unpaid family care[19] or care that might be of lower quality.

Moreover, researchers pointed to the importance of income that should consider with the stroke survivors' acceptance of long-term care. Stroke survivors with high incomes and positive attitudes towards professional help were more willing to purchase paid care from private healthcare service institutions.[32]

Facilitators and barriers to using the long-term care services

This study presented findings about facilitators and barriers to using long-term care and reflected that family caregivers of stroke survivors were satisfied or dissatisfied with using services. Common facilitators of using long-term care services in a hospital referred to the cost of health services and the behaviors of doctors and nurses to stroke survivors. This finding about the cost of services is similar to another study,[33] where medication costs are high. For barriers to using long-term care at the government hospital, the quality of health services was of most concern and was affected by the availability of doctors and nurses, and the cleanliness of the hospital environment.[37]

Regarding Andersen's behavioral model, consumer satisfaction is an outcome of using health services.[11] In this study, most participants reported dissatisfaction with long-term care services from government hospitals. In addition, participants expressed their opposing views, which were consistent with the previous study. Among them, the main concerns were the difficulty of accessing health services, poor quality of existing facilities, shortage of medical supplies, lack of time from doctors and nurses, short consultation time, and lack of professional behavior. The reasons might be that the caregiver's satisfaction or dissatisfaction with care arrangements showed two issues: the well-being of stroke survivors and the family's well-being.[35] Generally, the primary reasons concerning stroke survivors' well-being encompassed their health condition and the quality of institutional care.

Moreover, some participants expressed negative opinions regarding satisfaction in a face-to-face interview. Most caregivers who used institutional care felt dissatisfied because they felt burdened when stroke survivors were hospitalized. These findings were consistent with a recent Thai study indicating that family caregivers faced some fundamental problems: a lack of caring knowledge, family relationships and conflict, no time to take care of themselves and relax, and no support from others.[38]

At the same time, they could not afford another form of private long-term care other than a government hospital. Instead of getting quality long-term care, stroke survivors received lower-quality care in a healthcare facility. This trend will be challenging as the population grows, and Bangladesh also has a fast-growing number of stroke survivors. To develop an appropriate social policy and care programs for stroke survivors in Bangladesh, studies based on randomly selected samples of this population need to be conducted. Future studies in Bangladesh should include institutional and home care to clarify the differences in long-term care. In addition, future research should explore how changing long-term care is linked with family caregivers' expectations and level of satisfaction.

Limitations

The methods of this study posed limitations, such as cost, time, and few available participants—moreover, purposively selected information-rich family caregivers who were challenging to locate and recruit due to the COVID-19 pandemic. Furthermore, the participants selected in this research contained only those stroke survivors admitted to the study hospitals and discharged from hospitals with moderate to severe functional levels. The content analysis approach might involve informed bias based on the previous knowledge and evidence of the researcher. Thus, the findings of this study were limited to the population of stroke survivors of the Rangpur division but can help to inform long-term care elsewhere in Bangladesh. Similarly, the findings cannot have transferability to other older people who use long-term care for health problems other than stroke.

Conclusions and Implications for Nursing Practice

This study on stroke survivors' long-term care use has focused chiefly on the exclusive use of hospitalized care. Overall, stroke survivors likely to use hospitalized care were men with the highest income and assets and higher levels of ADL disability. Universally, affordable and equitable access to institutional care is needed for stroke survivors to achieve the institution's expected outcomes because most participants expressed negative opinions regarding their satisfaction. This study added new information by contributing to a deep understanding of the real-life caregiving experience of Bangladeshi family caregivers of stroke survivors. Despite many challenges during caregiving, participants were prone to getting long-term care from traditional Bangladesh healthcare settings. With substantial changes and government investment, stroke survivors' safety and quality of care in institutions and residential care settings can be improved.

Furthermore, healthcare providers should train family caregivers to meet stroke survivors' needs after discharge from the hospital. Policymakers should develop strategies to ensure optimal long-term institutional and family care services for chronically ill stroke survivors. Considering the socio-cultural context of Bangladesh, stakeholders and policymakers should address the needs of long-term care services for stroke survivors for appropriate planning and policies to deliver this in a more structured and formal way. The findings of this study provide valuable information for nurses, clinical administrators, and social workers to identify the needs of stroke survivors. In this sense, hospital workers have the most significant responsibility to contact the family caregivers before stroke survivors' are discharged from the hospital. Long-term care may begin with the home, involve hospitalization, and possibly move back and forth in the continuum of care. Studies based on randomly selected samples of the stroke survivor population in Bangladesh need to be done to develop an appropriate social policy and care program for stroke survivors in Bangladesh, These studies could complement a small but growing body of knowledge on stroke survivors in Bangladesh.

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การรับรู้ของผู้ดูแลเกี่ยวกับบริการการดูแลระยะยาวในประเทศบังคลาเทศ: การวิจัยพรรณนาเชิงคุณภาพ

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บทคัดย่อ: ความต้องการในการดูแลระยะยาวสำหรับผู้ป่วยโรคหลอดเลือดสมองในประเทศบังคลาเทศและในพื้นที่อื่นทั่วโลกเพิ่มขึ้น ญาติผู้ดูแลมีบทบาทสำคัญในการดูแลบุคคลที่รอดชีวิตจากโรคหลอดเลือดสมองอย่างต่อเนื่อง อย่างไรก็ตาม ความรู้เกี่ยวกับประสบการณ์การใช้บริการการดูแลระยะยาวจากญาติผู้ดูแลที่ได้ดูแลผู้ป่วยโรคหลอดเลือดสมองยังพบน้อย การศึกษานี้มีวัตถุประสงค์เพื่อบรรยายการรับรู้เกี่ยวกับการใช้บริการการดูแลระยะยาวสำหรับผู้ป่วยโรคหลอดเลือดสมองของญาติผู้ดูแลชาวบังคลาเทศ เป็นการศึกษาเชิงคุณภาพแบบบรรยายในพื้นที่เขตรังเปอร์ ประเทศบังคลาเทศระหว่างเดือนกุมภาพันธ์ถึงเดือนมิถุนายน 2563 ผู้ให้ข้อมูลเป็นญาติผู้ดูแลจำนวน 15 คนที่ได้รับการคัดเลือกอย่างเจาะจงตามเกณฑ์การคัดเข้า ผู้ให้ข้อมูลได้รับการสัมภาษณ์แบบเผชิญหน้าโดยใช้คำถามแบบกึ่งมีโครงสร้างร่วมกับการบันทึกเทปแบบดิจิทัล ใช้ระยะเวลาในการสัมภาษณ์ 60-90 นาที การวิเคราะห์ข้อมูลโดยการวิเคราะห์เชิงเนื้อหา

ผลการศึกษาพบ 4 ประเด็น ได้แก่ 1) ความเข้าใจในการดูแลระยะยาว 2) ความท้าทายในการดูแล 3) บริการในการดูแลระยะยาวเป็นการช่วยเหลือที่สำคัญและ 4) การสนับสนุนและอุปสรรคของการใช้บริการการดูแลระยะยาว ข้อค้นพบนี้แสดงให้เห็นว่าบริการการดูแลระยะยาวในการพยาบาลและการดูแลโดยสหวิชาชีพสำหรับผู้ป่วยโรคหลอดเลือดสมองเป็นความต้องการทั้งในสถานบริการการดูแลและการดูแลที่บ้าน การนำผลการศึกษานี้ไปใช้มีความสำคัญต่อบุคลากรสุขภาพ โดยเฉพาะพยาบาล ผู้ปฏิบัติงานทางคลินิก นักการศึกษาทางการพยาบาลและผู้กำหนดนโยบายในการพัฒนาหน่วยการดูแลผู้ป่วยโรคหลอดเลือดสมองโดยเฉพาะ และการฝึกอบรมสำหรับญาติผู้ดูแลในการให้การดูแลระยะยาวอย่างมีคุณภาพ

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