# The Impact of the Severe Consequences of a Stroke on Family Members Providing Care

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## ABSTRACT

Background and rationale: Stroke radically changes the life not only of the patient but also of their relatives. Family members experience this event no less, and sometimes even more, than the patient themselves. Suddenly, they bear a huge additional burden: in the first weeks, they balance between household chores, work, and frequent hospital visits. After discharge, a complex process of caring for a bedridden patient begins. If the recovery of lost functions is prolonged, and aspects such as mobility, memory, speech, and self-care skills do not return, relatives accumulate chronic fatigue—both emotional and physical—as well as what is known as "caregiver fatigue." Like the patient themselves, the family member providing care experiences an overwhelming sense of anxiety, and sometimes they too lose hope of returning to the previous life, which now seems distant and carefree.

## Keywords

stroke, relatives of stroke patients, care for stroke patients, quality of life, telerehabilitation, questionnaire.

## INTRODUCTION

As part of this study, an anonymous survey was conducted among the close relatives of stroke patients. The goal was to better understand their quality of life and the challenges they face while caring for their loved ones at home. The survey was available in both Kazakh and Russian and was carried out among the families of patients undergoing rehabilitation at the "Mediker" medical center over the past year. Participants came from various regions of the Turkestan region, including Jetysai, Saryagash, Shardara, Turkestan, Sayram, and others. To ensure the accuracy and relevance of the responses, the questionnaire was carefully validated before being used in the study. The validation process included expert evaluation of

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the questionnaire's content to verify its alignment with the research questions and target audience. The expert group consisted of recognized specialists in neurology, psychiatry, rehabilitation, and neurosurgery, as well as international experts. After making the necessary adjustments, the questionnaire was tested on a small group of caregivers to assess its clarity and ease of completion. The questionnaire asks respondents to rate their quality of life on a scale from 1 to 116, where higher scores indicate better quality of life and lower scores indicate worse quality of life. The expected time required to complete the questionnaire is approximately 15 minutes. The questions are aimed at identifying the main difficulties faced by relatives of patients with severe stroke consequences. The questionnaire includes 10 questions with additional sub-items. The collected data were analyzed using statistical methods to identify key issues faced by caregivers and to assess their impact on quality of life.

## RESULTS

Based on the analysis of responses from the relatives of patients who have suffered a stroke, several conclusions can be drawn, and specific measures can be proposed to improve the situation. Many caregivers experience significant psychological pressure, which adversely affects their emotional well-being. Relatives of patients who received continuous rehabilitation and utilized tele-rehabilitation demonstrated significantly better quality of life outcomes ($\chi^2 = 64.0002$, df=6, $p=0.000000$). The emotional and psychological state of respondents significantly differs ($p<0.005$) from those respondents who do not receive or rarely receive rehabilitation services ($\chi^2 = 51.4600$, df=6, $p=0.000000$). Data analysis from the survey using Kruskal-Wallis ANOVA by Ranks revealed that the total score of responses significantly varies ($p<0.005$) among groups formed by familial relationships ($H(9, N=287) = 110.3189$, $p<0.001$). Respondents noted a lack of highly qualified rehabilitation centers in the Turkestan region, forcing patients to seek care in larger rehabilitation facilities in the city of Shymkent. The study results underscore the need for psychological support and training in stress coping strategies, which has laid the groundwork for developing a program to enhance psychological assistance through tele-rehabilitation, planned for implementation on the website: https://rehabhome.kz.

## MATERIALS AND METHODS

Stroke is one of the leading causes of disability and death worldwide, creating a significant burden not only for patients but also for their families. Family members who provide care often face physical, emotional, and financial challenges, which can adversely affect their quality of life [1].

**The Importance of Social Support:** The study "Social support as a predictor of rehabilitation outcome in stroke patients" emphasizes how emotional and practical support from family and friends can significantly influence rehabilitation outcomes after a stroke. The authors found that patients with high levels of social support demonstrate better results in physical recovery and psychological well-being. However, it is essential to expand training for caregivers while carefully developing new interventions and programs to avoid increasing the burden on those providing care[2]. The role of family in the rehabilitation process. The results of the study "Family involvement in stroke rehabilitation" confirm that active family participation in the rehabilitation process contributes to improved functional outcomes and overall quality of life for patients after a stroke. Researchers emphasize the need to educate families on caring for patients and providing them with appropriate resources and support [3]. Another study addresses the issues of accessibility and quality of rehabilitation services for stroke patients. Survivors of stroke and their caregivers identified the lack of information about stroke as a major barrier to accessing post-stroke rehabilitation services. Caregivers expressed a significant need for support in managing family dynamics [4]. Overcoming social isolation and stigma. The authors of the study "Overcoming social isolation and stigma after stroke" discuss the issues of social isolation and stigma faced by many stroke patients. The study highlights the importance of social initiatives and programs to facilitate the reintegration of patients into society, including public education campaigns and the development of support networks. Researchers argue that reducing stigma and social isolation contributes to improved psychological well-being and eases the recovery process, enhancing patients' confidence in their abilities and promoting their social engagement [5].

## Socioeconomic aspects of recovery.

The study "Socioeconomic factors influencing post-stroke recovery" examines the impact of socioeconomic status on recovery outcomes after a stroke. The authors found that low socioeconomic status is associated with poorer recovery outcomes, including reduced access to quality rehabilitation services and medical care. It is recommended to enhance support from the government and community organizations to improve access to rehabilitation for individuals from less affluent backgrounds [6]. Technology and social support. The study "The role of technology in enhancing social support for stroke survivors" focuses on the development of digital technologies that create new opportunities for strengthening social support for stroke patients. The research explores how social networks, mobile applications, and tele-rehabilitation platforms can facilitate the social integration of patients by providing access to information, educational resources, and communication with peers. Such technologies can help overcome physical and geographical barriers, improving quality of life and accelerating the recovery process [7]. Social aspects of recovery after a stroke encompass a wide range of issues, from the accessibility of medical and rehabilitation services to social support and integration into society [8]. Scientific research emphasizes the need for a comprehensive approach to rehabilitation that considers both the medical and social needs of patients. Active family involvement, access to quality rehabilitation services, overcoming social stigma and isolation, as well as utilizing digital technologies to enhance social support are key factors for successful recovery after a stroke [9]. The disability experienced by stroke survivors, along with symptoms of depression, anxiety, and stress in both survivors and their family caregivers, affects their own quality of life and that of their partners. The disability of stroke survivors directly diminishes their overall, physical (PCS), and mental quality of life (MCS). Furthermore, it indirectly reduces both physical (PCS) and mental quality of life (MCS) for stroke survivors and their family caregivers through symptoms of depression, anxiety, and stress [10,11]. Formulating a testable working hypothesis is the first step toward conducting original research. Such studies can confirm or refute the proposed hypothesis. Case reports, case series, online surveys, and other observational studies, clinical trials, and narrative reviews help generate hypotheses. Observational and interventional studies assist in testing hypotheses. A good hypothesis is typically based on previous evidence-based reports. Hypotheses lacking evidence-based justification and a priori ideas are not favorably received by the scientific community. Original research to test a hypothesis must be meticulously planned to ensure appropriate methodology and adequate statistical power [12].

Psychological aspects of recovery after stroke represent a complex field that requires careful investigation. The main psychological challenges include coping with post-stroke depression, anxiety, stress, as well as issues of social isolation and loneliness, which cannot be overlooked. For a deep understanding of these aspects, it is important to refer to current scientific research and reviews. Studies show that depression occurs in 1 in 3 patients after a stroke. The importance of early diagnosis and treatment of depression is emphasized in works analyzing its impact on recovery after a stroke. They indicate that depression not only worsens of life for patients but can also negatively affect physical recovery [13]. Anxiety is also a common consequence of stroke, with research indicating a high comorbidity of anxiety disorders and depression post-stroke. Works such as the study by Campbell Burton et al. discuss the importance of considering anxiety in a comprehensive recovery plan, emphasizing that anxiety can significantly impact a patient's overall rehabilitation capacity [14]. Social isolation and feelings of loneliness can be exacerbated in the context of a pandemic, which in turn worsens psychological well-being and slows the recovery process. A study conducted by Valtorta and Hanratty demonstrates how social isolation affects the physical and mental health of older adults, which is particularly relevant for stroke patients, as age is one of the risk factors for stroke [15]. Research on psychological resilience during crisis situations, such as a pandemic, emphasizes the significance of adaptive coping strategies, such as seeking social support, positive reframing, and developing problem-solving skills. For instance, the work of Connor and Davidson presents a resilience assessment scale that can be useful for evaluating patients' ability to adapt to challenges related to their condition and external circumstances [16]. The role of social support cannot be underestimated. Studies demonstrate that quality social support contributes to improved psychological well-being and accelerates the recovery process. In the context of a pandemic, finding new ways to maintain connections and communication has become even more crucial. Research conducted by Smith and Lim highlights the significant role of virtual social networks and technologies in sustaining social connectivity during the pandemic [17]. Reduced functional independence, immobility, and depression were the primary clinical conditions initially targeted by survey participants during rehabilitation after a stroke. Survey participants believed that collaborative efforts among patients, physiotherapists, rehabilitation specialists, and family members were essential for effective stroke rehabilitation. Reportedly, family- and patient-centered efforts enhance the effectiveness of rehabilitation initiatives [18].

## The use of telemedicine in patient care.

Below are key strategies based on the latest scientific research in this area. Tele-rehabilitation includes video consultations with doctors, the use of mobile applications to track progress and perform exercises, as well as online sessions with therapists. The impact of telemedicine on the rehabilitation of stroke patients. Telemedicine is becoming an increasingly important tool in the rehabilitation of patients who have suffered a stroke. Research shows that tele-rehabilitation can significantly improve the quality of life for both patients and their relatives. Telemedicine provides unique opportunities for post-stroke rehabilitation, allowing patients to receive necessary assistance without leaving their homes. Tele-rehabilitation (TR) is less costly and equally effective as in-clinic rehabilitation in improving functional outcomes for stroke patients. TR ensures similar patient satisfaction. TR can be combined with other types of therapy, including virtual reality (VR), speech therapy, and robotic assistance, or used as an adjunct to direct in-person care [19]. A systematic review confirms that tele-rehabilitation can lead to improved functional outcomes and quality of life for stroke patients only if it is supported by a tele-education program for caregivers and ongoing technical, computer, and medical support to meet the needs of the dyad [20]. This is particularly important for relatives who often face challenges in caring for patients, and telemedicine can alleviate their burden by providing access to professional help and resources. The reverse learning method combined with video training enhances the caregiving skills of family members and can improve the self-care abilities of stroke survivors [21]. This is especially relevant considering that caring for stroke patients can be emotionally and physically exhausting. The authors note that telemedicine interventions have demonstrated significant effectiveness in managing chronic diseases. The implementation of tele-rehabilitation not only improves access to medical care but also promotes the individualization of rehabilitation programs, which, in turn, can lead to more effective treatment outcomes [22]. Additionally, research shows that telemedicine can improve access to specialized care. The use of telemedicine in the care of stroke patients helps overcome geographical barriers and provides broader access to rehabilitation services [23]. This can be particularly beneficial for families living in remote or rural areas. The integration of telemedicine technologies into the rehabilitation process can significantly enhance the quality of life for both patients and their families [24]. The use of remote access and telemedicine services, which played a crucial role during the pandemic, is expected to gain even greater importance in the coming years. Furthermore, artificial intelligence technologies hold significant potential in revolutionizing the delivery and individualization of rehabilitation according to the needs of each patient [25]. Medical professionals and researchers should collaborate with caregivers of stroke patients to identify their valuable activities and implement realistic strategies to maintain these activities [26]. The results of another study indicate that depression affects the quality of life of both stroke survivors and their caregivers, not only emotionally but also physically [27]. A multidisciplinary approach to post-stroke rehabilitation, including the use of modern modalities, plays a crucial role in conducting comprehensive rehabilitation activities [28].

This survey was developed based on relevant reviews and practical recommendations. Relevant survey reports were studied to create the questionnaire. The survey protocol was reviewed and approved by the Local Ethics Committee of the Medical Academy of South Kazakhstan in Shymkent, Kazakhstan (protocol No. 3 dated June 5, 2024). Written informed consent was obtained from all voluntary participants at the beginning of the questionnaire. No compensation for participation in the survey was offered. All questions were mandatory. The survey was completely anonymous, and only completed forms were processed. Convenience sampling was used in this report, adhering to widely published guidelines for survey design and reporting.

## Brief Description of the Structure and Content of the Questionnaire:

1. Identification and Relationship:
2. The survey begins with questions about the relationship of the relatives to the patient and their age.
3. Daily Challenges: Questions address the problems relatives face daily, such as tracheostomy care, diaper changes, and feeding, with response options ranging from “Always” to “Never”.
4. Emotional and Physical Discomfort: This section touches on emotional, physical, and practical difficulties in providing care, with response options from “Definitely true” to “Definitely not true.”
5. Adherence to medical recommendations: Relatives are asked about difficulties with medication dosages, names, and adherence to the diet prescribed by the doctor.
6. Household and Financial Issues: Questions explore logistical and financial difficulties in the home environment, such as lack of space for wheelchair movement and financial problems due to the patient’s illness.
7. Access to Rehabilitation Services: The questionnaire assesses the availability of rehabilitation centers and the presence of medical consultations.
8. Awareness and Participation in Rehabilitation: The knowledge and involvement of the relative in the rehabilitation process are checked.

**Statistical Analysis**: Descriptive statistics are presented in both absolute numbers and percentages. Microsoft Excel was used to create the database of responses and for their coding. The Kruskal-Wallis ANOVA by Ranks test was applied to compare responses between groups. Since the groups did not have a normal distribution, the surveyed relatives were divided into several categories (father, mother, husband, wife, brother, sister, daughter-in-law, son-in-law, son, daughter), and the table of critical values for the $\chi^2$ test was used, as the Kruskal-Wallis test asymptotically approaches the $\chi^2$ distribution. Results were considered statistically significant at a significance level of P less than 0.05. Statistical analysis was conducted using Microsoft Excel and Statistiks. Table 1 presents data on relatives caring for patients after a stroke. A total of 340 relatives were surveyed, of which 52 were excluded from the analysis (for reasons such as poor-quality responses, repeated refusals, etc.). The final analysis included 287 respondents aged 18 to 67 years.

**Table 1.** Distribution of Relatives by Gender and Age

| n | 287 | age | Men/ women |
|---|---|---|---|
| Mother | 20 | 49-67 | 20 |
| Father | 13 | 47-61 | 63 |
| Wife | 38 | 42-66 | 38 |
| Husband | 31 | 43-64 | 31 |
| Son | 63 | 22-53 | 63 |
| Daugther | 57 | 18-42 | 57 |
| Son-in-law | 3 | 29-52 | 3 |
| Daugther-in-law | 11 | 28-44 | 11 |
| Brother | 27 | 28-44 | 27 |
| Sister | 24 | 33-49 | 24 |

To analyze the impact of the type of family relationship on the qualitative indicators of caregiving skills for a sick relative, the non-parametric Kruskal-Wallis test was applied. The test results (H (9, N=287) = 110.3189, p <0.001) indicated statistically significant differences between groups. The most common caregiving difficulties and emotional discomfort were reported by «Wives» (H (9, N=20) = 171.2), « Brothers» (H (9, N=26) = 103.2), and «Sons» (H (9, N=63) = 113.81), as well as «Sisters» (H (9, N=20) = 26.3) and «Daughters-in-law» (H (9, N=43) = 171.2). «Daughters» (H (9, N=57) = 213.4), «Fathers» (H (9, N=23) = 177.2), «Husbands» (H (9, N=31) = 155.2), and «Mothers» (H (9, N=20) = 175.2) reported satisfactory emotional states and noted that they cope better with caregiving challenges. For clarity, the results are presented in Figure 1.

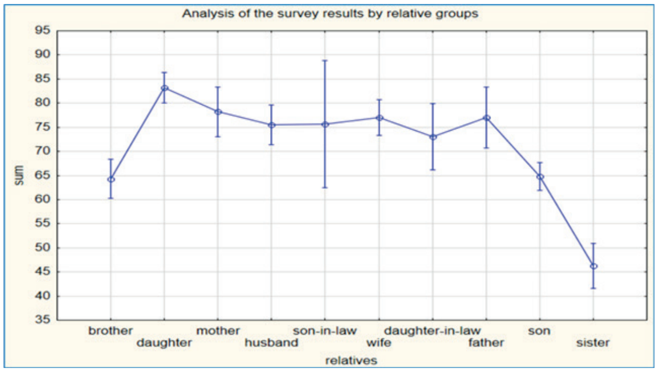

**Fig. 1** This may suggest that many caregivers experience stress and dissatisfaction during the caregiving process. «Difficulties in Feeding Relatives» 33.5% of respondents

noted that they “Sometimes” face difficulties in feeding, while 16.7% reported that this happens “Always”. This may indicate a need for training and support to improve feeding skills. «Psychological Difficulties» 36.9% of respondents reported that they “Sometimes” experience psychological difficulties while caring for the sick and 11.5% stated that this occurs “Always”. This underscores the importance of psychological support for caregivers to help them cope with emotional burdens.

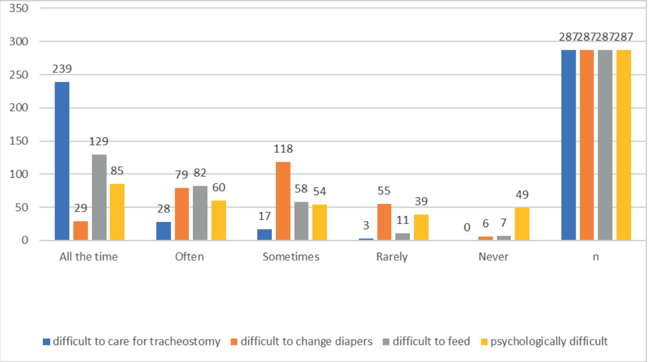

**Figure 2** – Difficulties Faced by Caregivers of Sick Relatives

Figure 3 illustrates the distribution of the “Quality of Life” indicator, depending on the frequency of rehabilitation methods used and rehabilitation skills. As seen from Figure 1, the median “Quality of Life” varies based on the skills in using rehabilitation methods. The lowest level of “Quality of Life” is observed among relatives who rarely use rehabilitation methods (I know, but don’t use = n-32 = 55). Relatives who regularly use rehabilitation methods («I use regularly» n-89=82) demonstrate the highest level of “Quality of Life.” The median stress level in the groups («Rarely used» = n-76 = 58) and («We use it sometimes»= n-90 = 76) lies between these two extremes. There are also relatives of patients who hardly visit rehabilitation centers but utilize tele-rehabilitation, resulting in good quality of life (see [description]) (Pearson Chi-square: $\chi^2 = 64.0002$, df = 6, p = 0.000000).

Table 2. Respondents Agreement Levels on Various Aspects Related to Accessibility of Rehabilitation Centers and Physician Oversight. The table presents information on the level of agreement among respondents regarding various aspects related to the accessibility of rehabilitation centers and oversight by treating physicians. Respondents rated how often they utilize the specified resources, with possible response options: - “I do not use this” n-93 (32.4%), “I rarely use this” n-76 (26.5%), “I use this sometimes” n-96 (33.5%), “I use this regularly” n-22 (7.7%). The data indicate that most respondents have some level of utilization of rehabilitation resources. However, a significant number of respondents also do not use them or do so rarely. This may suggest a need to raise awareness about the available rehabilitation services and their importance.

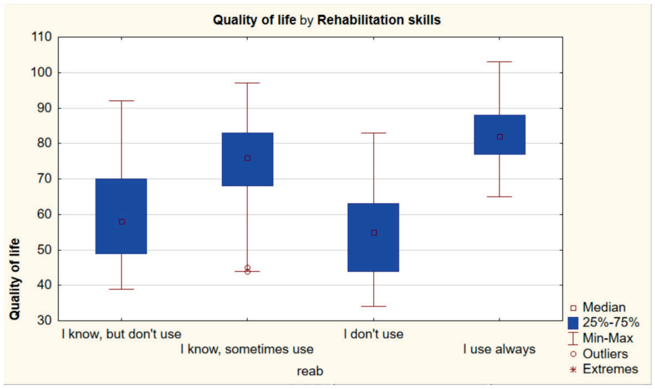

**Figure 3.** Distribution of Quality of Life Indicators Based on Rehabilitation Skills

**Table 2**. Knowledge and application of rehabilitation among relatives of respondents

| Level of agreement | I don’t use it (n) | I rarely use it (n) | I use sometime (n) | I use it regularly (n) |
|---|---|---|---|---|
| Availability of a rehab center in our region | 93 (32,4%) | 76 (26,5%) | 96 (33,5%) | 22 (7,7%) |
| Observation by the attending physician | 57(19,9%) | 70 (24,4%) | 101 (35,2%) | 59 (20,6% |
| Knowledge about rehabilitation activities, us of TR | 32 (11,1%) | 76 (26,5%) | 90 (31,4%) | 89(31,0% |

To assess the housing and living difficulties faced by caregivers of sick relatives, an analytical visualization was created based on the proposed categories. Each column displays the number of responses across four categories – from “Definitely true” to “Definitely not true.” This allows for an understanding of which living conditions are most problematic for caregivers. For instance, most caregivers indicated that their relatives often stay home alone while everyone is at work, which poses a significant challenge. Figure 4 illustrates various aspects of discomfort experienced by caregivers of sick relatives. Different colors of the columns reflect the degree of agreement among caregivers with each statement – from “Definitely true” to “Definitely not true.” This visually highlights which aspects of caregiving cause the greatest difficulties and discomfort.

**Table 4**

| Level of agreement | Definitely true (n) | Mostly true (n) | Mostly not true (n) | Definitely not true (n) |
|---|---|---|---|---|
| Psychologically discomfort | 189(66%) | 52(18%) | 35(12%) | 11(4%) |
| Physical discomfort | 36(13%) | 85(30%) | 115(40%) | 51(18%) |
| Uncertainty about help | 35(12%) | 90(31%) | 93(32%) | 69(24%) |
| Discomfort due to gender | 35(12%) | 90(31%) | 122(42%) | 42(15%) |

The responses from the participants indicate that the most significant issue for them is psychological discomfort, with 66% responding “Definitely true.” In contrast, physical discomfort is distributed more evenly. Uncertainty regarding assistance and discomfort related to gender show a more varied distribution of responses, suggesting less consensus on these issues. The results highlight the need for further investigation into the causes and consequences of each type of discomfort.

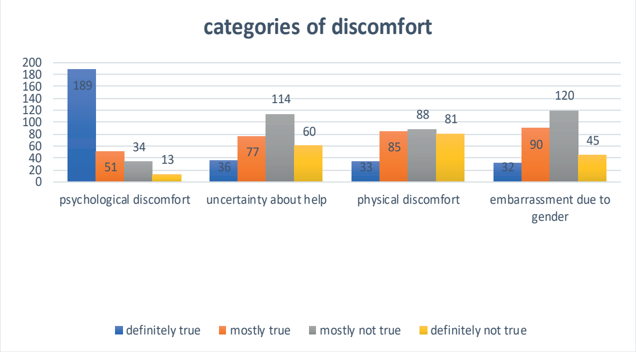

**Figure 4 –** Discomfort of Caregivers for Sick Relatives

To evaluate the living conditions and challenges faced by caregivers of sick relatives, an analytical visualization was created based on the proposed categories. Table 4 presents the living difficulties encountered by caregivers. Each column displays the number of responses across four categories – from “Definitely true” to “Definitely not true”. This allows for the identification of the most problematic living conditions for caregivers. For instance, the majority of caregivers indicated that their relatives often stay home alone while everyone is at work, which poses a significant challenge. Table 5 presents the survey results in which respondents assessed their level of agreement with various statements regarding living conditions and support for sick relatives. Each respondent selected one of four options: “Definitely true,” “Mostly true,” “Mostly not true,” and “Definitely not true”. The data indicates that respondents largely agree with statements regarding the challenging living conditions and support for sick relatives. The most pronounced agreement is observed for the statement “there is no one to care for the sick relative,” with 54% of respondents agreeing with this assertion. A significant number of respondents also point to financial constraints and limited space for wheelchair access. These findings underscore the importance of improving living conditions and support for families caring for the sick.

**Table 5.** Housing difficulties among respondents

| Level of agreement | Definitely true (n) | Mostly true (n) | Mostly not true (n) | Definitely not true (n) |
|---|---|---|---|---|
| The toilet is located outside | 39(18.5%) | 79(37.5%) | 98(46.7%) | 70(33.3%) |
| The sick relative was the only breadwinner in the family | 27(12.8%) | 88(42.0%) | 102(48.8%) | 69(32.5%) |
| Cramped accommodation for wheelchair | 36(17.0%) | 78(36.5%) | 101(47.0%) | 72(33.3%) |
| Financial limitation | 26(12.3%) | 85(40.7%) | 107(51.2%) | 69(32.5%) |
| No one to care for a sick relative | 27(12.8%) | 87(42.0%) | 113(54.0%) | 60(28.3%) |

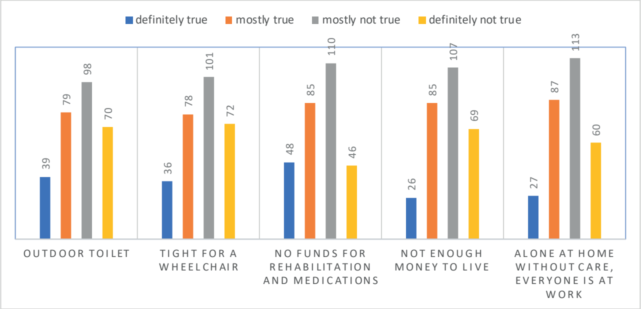

**Figure 5** – Housing and living difficulties faced by caregivers of relatives.

The data indicates that the majority of respondents experience various conditions such as apathy, neurotic changes, and feelings of malaise with noticeable frequency. The most pronounced symptoms, such as fatigue and frustration, show high rates of "Always" and "Often." Meanwhile, feelings of loneliness and sleep disturbances also raise significant concern, with a notable number of respondents reporting that they "never" experience these states.This data may be useful for further analysis of the mental and physical health of respondents and the development of appropriate interventions.

**Table 6.** Emotional and mental state of respondents

| Level of agreement | All the time (n) | Ofthen (n) | Sometimes (n) | Rarely (n) | Never (n) |
|---|---|---|---|---|---|
| Apathy | 24(8,0%) | 61(20,3%) | 102(34,3%) | 92(30,7%) | 8(2,7%) |
| Neurotic change | 26(8,7%) | 65(21,7%) | 89(29,7%) | 98(32,7%) | 9(3,0%) |
| Feeling unwell | 59(19,7%) | 61(20,3%) | 93(31,0%) | 57(19,0%) | 17(5,7%) |
| Fatigue | 72(24,0%) | 71(23,7%) | 73(24,3%) | 56(18,7%) | 15(5,0%) |
| Disouraged | 79(26,3%) | 54(18,0%) | 86(28,7%) | 52(17,3%) | 16(5,3%) |
| Loneliness | 26(8,7%) | 59(19,7%) | 64(21,3%) | 49(16,3%) | 89(29,7%) |
| Sleep disorder | 41(13,7%) | 89(29,7%) | 97(32,3%) | 51(17,0%) | 9(3,0%) |
| Deterioration of health | 64(21,3%) | 62(20,7%) | 88(29,3%) | 49(16,3%) | 24(8,0%) |

Each respondent indicated how often they experience the specified conditions by selecting one of five options: "Always", "Often", "Sometimes", "Rarely" and "Never". The main categories and their values are as follows: Apathy: n-24 (8.0%) reported feeling apathetic "Always" n-61 (20.3%) "Often" n-102 (34.3%) "Sometimes" n-92 (30.7%) "Rarely" and n-8 (2.7%) "Never" Neurotic changes: n-26 (8.7%) "Always," n-65 (21.7%) "Often," n-89 (29.7%) "Sometimes" n-98 (32.7%) "Rarely" and n-9 (3.0%) "Never". Sleep disturbances: n-41 (13.7%) "Always," n-89 (29.7%) "Often" n-97 (32.3%) "Sometimes" n-51 (17.0%) "Rarely" and n-9 (3.0%) "Never". Health deterioration: n-64 (21.3%) "Always" n-62 (20.7%) "Often" n-88 (29.3%) "Sometimes" n-49 (16.3%) "Rarely" and n-24 (8.0%) "Never" (Table 6).

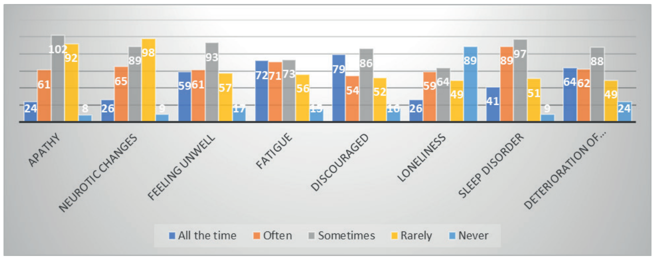

**Figure 6** – Emotional State of Respondents

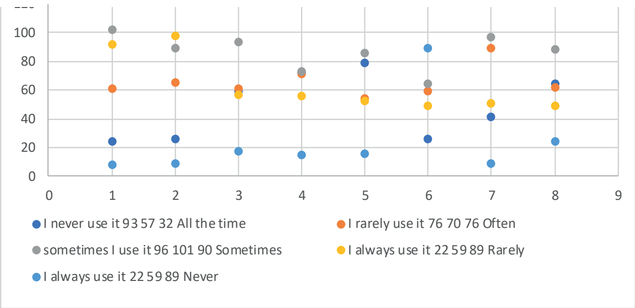

**Fig.7 –** Dependence of 2 variables -Emotional state of respondents and application of regular rehabilitation

The graph illustrates the relationship between various emotional states (such as apathy, neurotic changes, feelings of malaise, fatigue, despondency, loneliness, sleep disturbances, and health deterioration) and the frequency of rehabilitation visits. The horizontal axis represents different emotional states, while the vertical axis indicates the number of respondents. «Feeling unwell»: n-59 (19.7%) - "Always", n-61 (20.3%) "Often", n-93 (31.0%) "Sometimes", n-57 (19.0%) -"Rarely", n-17 (5.7%) "Never". «Fatigue»: n-72 (24.0%) - "Always", n-71 (23.7%) - "Often", n-73 (24.3%) - "Sometimes", n-56 (18.7%) - "Rarely", n-15 (5.0%) - "Never". «Discouraged»: n-79 (26.3%)

- “Always”, n-54 (18.0%) - “Often”, n-86 (28.7%) - “Sometimes”, n-52 (17.3%) - “Rarely”, n-16 (5.3%) - “Never”. «Loneliness»: n-26 (8.7%) - “Always”, n-59 (19.7%) - “Often”, n-64 (21.3%) - “Sometimes”, n-49 (16.3%) - “Rarely”, n-89 (29.7%) - “Never”. Each column for each emotional state is divided into four colored sections representing the frequency of experiencing that state. Although the graph itself does not show a direct correlation between emotional state and attendance at rehabilitation, it provides a basis for such analysis (Figure 7). It can be suggested that more frequent negative emotional states may be associated with more frequent attendance at rehabilitation activities. An analysis was conducted between two variables: those who regularly attended rehabilitation centers and those who did not. It was found that the quality of life for relatives of patients who regularly attend rehabilitation centers is better than for those who have little contact with medical personnel and who receive rehabilitation

less frequently or never. Pearson Chi-square -$\chi^2$=51.4600, df=6, p=0.000000 (see description ).

## RESULTS

The study involved relatives of patients who had suffered a stroke, with a total of n=287 respondents and an average age of 38 years (ranging from 18 to 67 years), including 145 women and 142 men. Many relatives experience significant psychological pressure related to caregiving, which negatively impacts their emotional well-being. Based on the analysis of responses from relatives of stroke patients, several key conclusions can be drawn, along with specific recommendations for improving the situation. Many caregivers face considerable psychological stress, which negatively impacts their emotional well-being. Relatives of patients who engaged in continuous rehabilitation and utilized tele-rehabilitation reported significantly better quality of life outcomes ($\chi^2$= 64.0002, df=6, p=0.000000). The emotional and psychological states of respondents were found to differ significantly ($p<0.005$) from those who do not receive or infrequently access rehabilitation services ($\chi^2$= 51.4600, df=6, p=0.000000). Analysis of survey data using Kruskal-Wallis ANOVA by Ranks indicated that the overall response scores varied significantly ($p<0.005$) among groups categorized by familial relationships (H (9, N=287) = 110.3189, $p<0.001$). Respondents highlighted a shortage of highly qualified rehabilitation centers in the Turkestan region, compelling patients to seek care in larger rehabilitation facilities located in the city of Shymkent.

Psychological support and training in stress coping strategies are necessary. A lack of knowledge about proper caregiving, including medication management and dietary adherence, often leads to mistakes and increases the stress of relatives. This issue highlights the need for more accessible and effective educational programs. Access to rehabilitation and medical services is limited, especially in underprivileged or remote areas. The situation requires improvements in infrastructure and the implementation of innovative solutions, such as telemedicine. Continuous caregiving exceeds the physical and emotional capacities of many relatives, emphasizing the need for additional support and home care services.

## DISCUSSION

To support families caring for stroke patients, it is essential to implement targeted psychological support programs and self-help groups, helping relatives navigate both the emotional and practical challenges of caregiving. Providing accessible educational resources on medical care, medication management, and dietary adherence can empower caregivers with the knowledge they need. Regular training sessions and seminars led by medical professionals can further enhance their skills and confidence. Expanding rehabilitation services by increasing mobile clinics and integrating telemedicine for remote consultations can make care more accessible. Additionally, offering home care services—including professional caregiving and assistance with daily tasks—can help ease the burden on families. These recommendations can contribute to the development of policies and programs that improve the quality of life for both stroke patients and their caregivers, ensuring a well-rounded and effective approach to post-stroke care.

### Authors Contributions

Conceptualization: KBF, AMI, YM. Data acquisition and literature review: KBF, AMI, YM. Interpretation: KBF, AMI, YM. Writing — review and editing: KBF, AMI, YM. Final approval: KBF, AMI, YM.

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Data Availability: Appendix on questionnaire validation

**Conflict of Interest:** The authors declare no conflicts of interest.

## DESCRIPTION

### Interview Methodology

To gain a deeper understanding of the personal experiences of patients and healthcare providers, the study employed both individual and focus group interviews. These qualitative research methods are particularly valuable for exploring complex issues, such as the impact of the pandemic on daily life and well-being. Individual interviews were conducted in a quiet, confidential setting, allowing participants to freely express their thoughts and feelings. The interviewer utilized a semi-structured approach, posing open-ended questions that enabled participants to share their experiences, emotions, and opinions without strict limitations. Focus group interviews gathered several participants (typically 4-8 individuals) to discuss specific topics. This method facilitated interaction among participants, which could lead to the emergence of new ideas and insights that may not always be attainable in individual interviews. Focus groups were organized to promote open and honest dialogue, taking into account group dynamics and ensuring that each participant had the opportunity to voice their perspectives.

### Adaptation to Pandemic Conditions:

In light of social distancing measures, many interviews were conducted via video conferencing. This ensured the safety of both participants and interviewers while also allowing the inclusion of individuals who might not have been able to attend in-person meetings due to geographical or health-related constraints.

### Data Assessment Methods for Interviews

The data collected through interviews necessitates careful analysis and interpretation:

1. **Transcription:** All audio and video recordings of the interviews were transcribed for subsequent textual analysis.
2. **Coding:** The interview texts were coded to identify key themes and categories. This process could be inductive (data-driven) or deductive (based on pre-defined categories).
3. **Thematic Analysis:** Thematic analysis was employed to identify recurring themes and patterns within the data. This approach allowed for the summarization of data and the identification of both explicit and implicit aspects of the pandemic's impact.
4. **Validity Checks:** The credibility and reliability of the findings were assessed through processes such as triangulation (utilizing different methods or data sources) and participant feedback.

This comprehensive approach to data collection and analysis from interviews aids in deeply understanding the personal experiences of participants, enriching quantitative survey data with qualitative details and in-depth insights.

## REFERENCES

1. Bourbonnais, A., et al. (2018). "Family caregivers of stroke survivors: A systematic review of the literature." *Journal of Stroke and Cerebrovascular Diseases*, 27(5), 1234-1242
2. Erler KS, Sullivan V, Mckinnon S, Inzana R. Social Support as a Predictor of Community Participation After Stroke. Front Neurol. 2019 Sep 20;10:1013. doi: 10.3389/fneur.2019.01013. PMID: 31616364; PMCID: PMC6763952.
3. Creasy KR, Lutz BJ, Young ME, Stacciarini JM. Clinical Implications of Family-Centered Care in Stroke Rehabilitation. Rehabil Nurs. 2015 Nov-Dec;40(6):349-59. doi: 10.1002/rnj.188. Epub 2015 Feb 3. PMID: 25648522; PMCID: PMC4544639.
4. Kamalakannan S, Gudlavalleti Venkata M, Prost A, Natarajan S, Pant H, Chitalurri N, Goenka S, Kuper H. Rehabilitation Needs of Stroke Survivors After Discharge From Hospital in India. Arch Phys Med Rehabil. 2016 Sep;97(9):1526-1532.e9. doi: 10.1016/j.apmr.2016.02.008. Epub 2016 Mar 2. PMID: 26944710; PMCID: PMC5813710.
5. Fan W, Ma KK, Yang CX, Guo YL. The mediating effect of stigma between self-perceived burden and loneliness in stroke patients. Front Psychiatry. 2023 Jul 27;14:1219805. doi: 10.3389/fpsyt.2023.1219805. PMID: 37575575; PMCID: PMC10412817.
6. Putman K, De Wit L, Schoonacker M, Baert I, Beyens H, Brinkmann N, Dejaeger E, De Meyer AM, De Weerdt W, Feys H, Jenni W, Kaske C, Leys M, Lincoln N, Schuback B, Schupp W, Smith B, Louckx F. Effect of socioeconomic status on functional and motor recovery after stroke: a European multicentre study. J Neurol Neurosurg Psychiatry. 2007 Jun;78(6):593-9. doi: 10.1136/jnnp.2006.094607. Epub 2006 Dec 8. PMID: 17158561; PMCID: PMC2077960.
7. Ortiz-Fernandez L, Magnusson C, Ruiz AG, Indart LM, Zabala JS, Menica JAA, Arri EA. Exploring attitudes towards use of technology to support stroke survivors living at home: A quantitative and qualitative content analysis study in Spain. J Rehabil Assist Technol Eng. 2021 Aug 20;8:20556683211019690. doi: 10.1177/20556683211019690. PMID: 34434561; PMCID: PMC8381459.
8. McHorney C.A., Ware J.E., Lu J.F.R., Sherbourne C.D. The MOS 36-Item Short-Form Health Survey (SF-36®): III. tests of data quality, scaling assumptions and reliability across diverse patient groups. Med Care1994; 32(4):40-66.
9. Ware J.E., Snow K.K., Kosinski M., Gandek B. SF-36® Health Survey Manual and Interpretation Guide. Boston, MA: New England Medical Center, The Health Institute, 1993.
10. Ware J.E., Sherbourne C.D. The MOS 36-Item Short-Form Health Survey (SF-36®): I. conceptual framework and item selection. Med Care 1992; 30(6):473-83.
11. Yuliana S, Yu E, Rias YA, Atikah N, Chang HJ, Tsai HT. Associations among disability, depression, anxiety, stress, and quality of life between stroke survivors and their family caregivers: An Actor-Partner Interdependence Model. J Adv Nurs. 2023 Jan;79(1):135-148. doi: 10.1111/jan.15465. Epub 2022 Oct 18. PMID: 36257927.
12. Misra DP, Gasparyan AY, Zimba O, Yessirkepov M, Agarwal V, Kitas GD. Formulating Hypotheses for Different Study Designs. J Korean Med Sci. 2021 Dec 27;36(50):e338. doi: 10.3346/jkms.2021.36.e338. PMID: 34962112; PMCID: PMC8728594.
13. Hackett ML, Anderson CS, House A, Halteh C. Interventions for preventing depression after stroke. Cochrane Database Syst Rev. 2008 Jul 16;(3):CD003689. doi: 10.1002/14651858.CD003689.pub3. Update in: Cochrane Database Syst Rev. 2020 May 11;5:CD003689. doi: 10.1002/14651858.CD003689.pub4. PMID: 18646094.
14. Campbell Burton, C. A., Murray, J., Holmes, J., Astin, F., Greenwood, D., & Knapp, P. (2013). Frequency of anxiety after stroke: A systematic review and meta-analysis of observational studies. International Journal of Stroke, 8, 545–559. doi:10.1111/j.1747-4949.2012.00906.x
15. Valtorta N, Hanratty B. Loneliness, isolation and the health of older adults: do we need a new research agenda? J R Soc Med. 2012 Dec;105(12):518-22. doi: 10.1258/jrsm.2012.120128. PMID: 23288086; PMCID: PMC3536512.
16. Connor KM, Davidson JR. Development of a new resilience scale: the Connor-Davidson Resilience Scale (CD-RISC). Depress Anxiety. 2003;18(2):76-82. doi: 10.1002/da.10113. PMID: 12964174.
17. Smith WPW, Seah KTM, Lim SK, Khan WS. Cryopreservation of Human Adipose Tissues and Adipose-Derived Stem Cells with DMSO and/or Trehalose: A Systematic Review. Cells. 2021 Jul 20;10(7):1837. doi: 10.3390/cells10071837. PMID: 34360005; PMCID: PMC8307030.
18. Assylbek MI, Zimba O, Yessirkepov M, Kocyigit BF. Healthcare professionals' knowledge and perceptions of post-stroke rehabilitation in the peripandemic period: an online cross-sectional survey. Rheumatol Int. 2024 Oct 26. doi: 10.1007/s00296-024-05746-7. Epub ahead of print. PMID: 39460762.
19. Knepley KD, Mao JZ, Wieczorek P, Okoye FO, Jain AP, Harel NY. Impact of Telerehabilitation for Stroke-Related Deficits. Telemed J E Health. 2021 Mar;27(3):239-246. doi: 10.1089/tmj.2020.0019. Epub 2020 Apr 23. PMID: 32326849.
20. Bartoli D, Petrizzo A, Vellone E, Alvaro R, Pucciarelli G. Impact of telehealth on stroke survivor-caregiver dyad in at-home rehabilitation: A systematic review. J Adv Nurs. 2024

Oct;80(10):4003-4033. doi: 10.1111/jan.16177. Epub 2024 Apr 2. PMID: 38563582.

21. Cott, C., et al. (2020). "The role of telehealth in stroke rehabilitation: A systematic review." *Archives of Physical Medicine and Rehabilitation*, 101(5), 1001-1010.
22. Bashshur RL, Shannon GW, Smith BR, Alverson DC, Antoniotti N, Barsan WG, Bashshur N, Brown EM, Coye MJ, Doarn CR, Ferguson S, Grigsby J, Krupinski EA, Kvedar JC, Linkous J, Merrell RC, Nesbitt T, Poropatich R, Rheuban KS, Sanders JH, Watson AR, Weinstein RS, Yellowlees P. The empirical foundations of telemedicine interventions for chronic disease management. Telemed J E Health. 2014 Sep;20(9):769-800. doi: 10.1089/tmj.2014.9981. Epub 2014 Jun 26. PMID: 24968105; PMCID: PMC4148063.
23. Haleem A, Javaid M, Singh RP, Suman R. Telemedicine for healthcare: Capabilities, features, barriers, and applications. Sens Int. 2021;2:100117. doi: 10.1016/j.sintl.2021.100117. Epub 2021 Jul 24. PMID: 34806053; PMCID: PMC8590973.
24. Johansson T, Wild C. Telemedicine in acute stroke management: systematic review. Int J Technol Assess Health Care. 2010 Apr;26(2):149-55. doi: 10.1017/S0266462310000139. PMID: 20392317.
25. Kocyigit BF, Assylbek MI, Yessirkepov M. Telerehabilitation: lessons from the COVID-19 pandemic and future perspectives. Rheumatol Int. 2024 Apr;44(4):577-582. doi: 10.1007/s00296-024-05537-0. Epub 2024 Feb 6. PMID: 38321330.
26. Lynch EB, Butt Z, Heinemann A, Victorson D, Nowinski CJ, Perez L, Cella D. A qualitative study of quality of life after stroke: the importance of social relationships. J Rehabil Med. 2008 Jul;40(7):518–23. doi: 10.2340/16501977-0203. PMID: 18758667; PMCID: PMC3869390.
27. Dsouza, J. M. ., Veigas, J. ., Dsouza, N. D. ., & Bhat, S. U. . (2022). Effectiveness of Interaction with Children on Happiness among the Elderly: A Pilot Study. *Bangladesh Journal of Medical Science*, *21*(2), 318–322. https://doi.org/10.3329/bjms.v21i2.58064
28. Aung, S., Musa, R., A, J. R., M, A. S., & Abdullah, A. (2018). Relationship between Coping Mechanisms to Psychosocial Stress with Blood Pressure in Young Adults: A Pilot Study. *Bangladesh Journal of Medical Science*, *17*(3), 439–445. https://doi.org/10.3329/bjms.v17i3.37000
29. Assylbek, M.I., Zimba, O., Yessirkepov, M. *et al.* Healthcare professionals' knowledge and perceptions of post-stroke rehabilitation in the peripandemic period: an online cross-sectional survey. *Rheumatol Int* **44**, 3063–3071 (2024). https://doi.org/10.1007/s00296-024-05746-7