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Beyond survival: An exploration of quality of life after stroke

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Abstract

Beyond its biological effects, stroke is a serious public health concern that has a substantial impact on survivors’ quality of life (QoL). This study looks at stroke from a sociological angle, highlighting how social factors influence how well people recover. In order to examine how stroke is not just a medical disease but also a socially constructed experience, it examines important theoretical frameworks such as medical sociology, disability studies, and social determinants of health. Post-stroke quality of life is greatly influenced by socioeconomic variables, including work difficulties, healthcare accessibility, and financial instability. Furthermore, the contribution of policy initiatives, community rehabilitation, and social support networks to reintegration into society is evaluated. Disability rights, mobility, and accessibility all influence survivors’ experiences. This chapter promotes a multifaceted strategy that combines social, medical, and policy viewpoints to improve the general wellbeing of stroke survivors.

Keywords: Stroke, quality of life, social determinants of health, disability, rehabilitation

Introduction

Stroke is a serious public health issue that affects millions of individuals globally and has a substantial impact on quality of life (QoL) in addition to its medical consequences. According to estimates from the World Health Organization (WHO), more than 15 million people have a stroke each year, and around 5 million of those individuals sustain long-term disability (WHO, 2022) [27]. Although prevention, diagnosis, and treatment are the main goals of the biomedical approach, it frequently ignores the larger social, economic, and psychological difficulties that survivors encounter, including marginalization, loss of social positions, and unstable finances (Feigin *et al*., 2021) [7]. A sociological approach to stroke emphasizes the ways in which institutional support, healthcare accessibility, and social determinants of health (SDH) affect recovery and reintegration into society.

After a stroke, quality of life encompasses more than just physical recuperation; it also includes social relationships, financial security, and community involvement. Conventional medical evaluations frequently overlook long-term social effects in favor of survival and functional rehabilitation (Cieza *et al*., 2021) [5]. Numerous survivors encounter prejudice in both their personal and professional lives, financial hardship, and job loss (Mukherjee & Patil, 2019) [17]. A comprehensive strategy encompassing social support networks, disability rights, and inclusive policy is needed to address these problems.

Sociology provides useful theoretical frameworks for comprehending chronic disease and stroke. According to the social model of disability, participation is restricted by social obstacles as well as physical disabilities (Oliver, 1990) [19]. Recovery is a social and medical process since stroke survivors frequently experience limited mobility, discrimination at work, and insufficient access to healthcare (Shakespeare, 2018) [24]. Due to differences in healthcare, education, and income, the SDH framework shows that those with lower incomes have worse rehabilitation results (Marmot, 2020) [15]. Additionally, symbolic interactionism explains how stroke-related deficits alter self-identity and social roles (Charmaz, 1983) [4]. According to Talcott Parsons’ (1951) [20] ‘sick role’ hypothesis, people with long-term illnesses, like stroke survivors, find it difficult to fully heal from their illnesses, which frequently results in stigma and marginalization.

By demonstrating that those with lower incomes have less access to high-quality healthcare and rehabilitation, the SDH method emphasizes the influence of socioeconomic variables on stroke recovery and exacerbates inequities (Marmot, 2020) [15]. Survivors are forced to rely on family care in many low- and middle-income nations due to the lack of affordable or accessible rehabilitation programs, which may not be enough for the best possible recovery (Cieza *et al*., 2021) [5]. Furthermore, prejudice at work and a lack of accommodations prevent survivors from returning to the workforce, exacerbating already-existing disparities (Hansen *et al*., 2017) [10]. Improving post-stroke quality of life requires addressing these discrepancies through social policies, universal healthcare, and community-based assistance.

A sociological viewpoint offers a comprehensive understanding of stroke as a disease that impacts social integration and personal well-being by transcending the biological model. In addition to physical healing, rehabilitation should include social support networks, accessible settings, and economic stability. The quality of life for stroke survivors may be greatly improved by policies that support universal healthcare, community-based rehabilitation, and inclusive workplaces (Wade, 2020) [26]. Addressing systemic injustices and guaranteeing survivors' meaningful reintegration require acknowledging stroke as a social phenomenon.

Socio-economic factors influencing post-stroke quality of life

Socio-economic variables, such as access to healthcare, rehabilitation, and social support, have a substantial impact on the quality of life for stroke survivors. Stroke-related permanent disabilities might affect social activities, employment, and financial stability. Economic instability, loss of livelihood, and significant rehabilitation expenditures are obstacles to recovery, especially for people from lower socioeconomic backgrounds. Disparities in social security benefits, access to healthcare, and the availability of assistive devices all contribute to the gap between affluent and underprivileged groups in post-stroke recovery. Support systems and caregiver availability are also impacted by socioeconomic level. Understanding these socioeconomic aspects is essential to creating inclusive policies that enhance the quality of life for stroke survivors.

A stroke can have a catastrophic effect on a person's financial security, frequently resulting in job loss, diminished earning potential and unstable finances. Many stroke survivors have cognitive and physical disabilities that make it difficult for them to go back to work, especially in occupations that require a lot of manual labor or mental processing (Feigin *et al*., 2021) [7]. Workplace prejudice, inadequate accommodations, and a lack of accessible infrastructure frequently keep survivors from returning to the employment, even in cases where recovery is feasible. Losing a job not only impacts the person but also puts a strain on families' finances, particularly in low- and middle-income nations where social security and health insurance may not be sufficient (Marmot, 2020) [15]. Beyond lost income, medical bills, rehabilitation expenditures, and long-term care requirements are all part of the financial burden of stroke. According to studies, stroke survivors and their families frequently spend all of their money, take on debt, or liquidate assets in order to pay for necessary rehabilitation and medical care (Cieza *et al*., 2021) [5]. For those from lower socio-economic situations, who may already have difficulty accessing high-quality healthcare and rehabilitation services, this financial hardship is especially acute. Furthermore, social assistance programs and disability payments are often insufficient or impossible to access in many nations, depriving survivors of the money they need.

The financial instability brought on by losing a job can cause psychological suffering, social alienation, and dependence on family members for those who were the major breadwinners before to the stroke. Survivors may experience decreased social mobility and a higher risk of poverty and homelessness if they are unable to return to employment. Furthermore, because they frequently lack job stability, disability insurance, or employer-sponsored healthcare, women and those working in informal employment sectors are disproportionately impacted (Mukherjee & Patil, 2019) [17]. Governments and legislators must put in place comprehensive financial assistance programs, workplace reintegration efforts, and inclusive employment regulations that help stroke survivors regain their financial independence in order to solve these issues. The long-term financial effects of stroke can be lessened and survivors' general quality of life can be enhanced by ensuring access to vocational training, remote employment options, and disability-inclusive hiring practices.

The high expense of long-term care and rehabilitation, such as physical therapy, occupational therapy, speech rehabilitation, and ongoing medical treatment, presents major obstacles for stroke survivors and their families. Because of the constant need for prescription medications, assistive technology, and home modifications, these expenses put a burden on household budgets, especially in low- and middle-income nations. Many stroke survivors need professional caregivers or institutionalized care, both of which are costly. Particularly when family members have to reduce their working hours or quit their employment to give full-time care, home-based care can be costly. Families may not be able to afford institutionalized care, which might result in worse care and slower rates of recovery. Inadequate health insurance coverage also forces survivors to pay for rehabilitation programs out of pocket, which leads to debt accumulation and unstable finances.

These financial difficulties are made worse by socioeconomic inequalities. Low-income people may have limited access to rehabilitation services and receive subpar post-stroke care, whereas wealthier people have access to top-notch private rehabilitation facilities, cutting-edge treatment alternatives, and assistive technology. Stroke survivors have limited reasonably priced choices for long-term care since public healthcare systems in many developing nations are underfunded and lack specialist rehabilitation facilities (Oliver, 1990) [19]. Financial issues are further exacerbated for rural communities, who have a harder time receiving rehabilitation treatments because of geographic distance and transportation expenses (Cieza *et al*., 2021) [54]. Policy measures, such as government-subsidized rehabilitation programs, extended health insurance coverage for long-term care, and financial help for caregivers, are necessary to address these financial pressures. In order to accommodate stroke survivors, employers should be urged to adopt flexible work schedules and return-to-work initiatives. Many stroke survivors and their families still face financial difficulties in the absence of such institutional assistance, which has a detrimental effect on their general quality of life and recovery results.

Social status has a big impact on stroke survivors' access to rehabilitation programs and medical care. Government laws, healthcare infrastructure, geographic location, and economic inequality are some of the systemic barriers that keep people from lower socioeconomic backgrounds from getting timely and effective post-stroke care. Rich people may afford private rehabilitation centers, specialist stroke units, and cutting-edge therapies, whereas low-income people must rely on overburdened public health systems. One of the main reasons for this disparity is the expense of healthcare services; in many nations, stroke survivors are required to pay for their hospital stays, medications, physical therapy, and home-based treatment. A reduced level of life, persistent disability, and worse recovery outcomes can arise from this. Even in nations with universal healthcare, socioeconomic disparities in access to rehabilitation centers, availability of experts, and quality of care still exist, favoring wealthy and urban residents over those in rural areas and those with lower incomes.

Geographical differences compound healthcare inequities; metropolitan regions have greater access to specialist stroke facilities, whereas rural towns sometimes face high transportation expenses and long commutes to hospitals. This leads to shortages of qualified healthcare workers in impoverished areas and inadequate or nonexistent rehabilitation services for rural people. These disparities are also influenced by social and cultural factors; underprivileged groups frequently face discrimination, distrust, communication difficulties, and a lack of awareness regarding the signs of stroke. Stroke survivors are deterred from seeking treatment by social shame, especially in traditional or patriarchal settings. To guarantee equitable treatment for stroke survivors from all socioeconomic backgrounds, governments and lawmakers must put in place focused initiatives such financial help programs, rural healthcare growth, mobile rehabilitation units, and telemedicine services. Improving stroke outcomes, lowering long-term disability, and making sure recovery is unaffected by social or economic position all depend on addressing healthcare disparities.

Social support networks and rehabilitation

Social support affects both physical and emotional well-being and is essential to stroke healing and rehabilitation. A stroke survivor's capacity to reintegrate into society is greatly influenced by family, caregivers, and community-based networks in addition to medical therapies. The efficiency of rehabilitation can be influenced by the quantity and caliber of social support, which can have an effect on long-term results like mental health, functional independence, and quality of life (Cohen & Syme, 1985) [6]. For many stroke survivors, the reintegration process is still complicated by institutional impediments, societal stigma, and unequal access to support networks. This section discusses social stigma and isolation as significant barriers in the post-stroke experience, looks at the benefits and drawbacks of community-based rehabilitation, and investigates the role of family, caregivers, and social capital in stroke recovery.

For stroke survivors, family members and caregivers frequently provide the majority of their emotional and physical assistance. They are crucial to the healing process because they help with everyday tasks, medicine administration, mobility support, and emotional health (Visser-Meily *et al*., 2006) [25]. However, providing care can be financially, emotionally, and physically taxing, which can contribute to caregiver strain, particularly when professional help is scarce or prohibitively expensive (Rigby, Gubitz, & Phillips, 2009) [22]. Better recovery results for stroke survivors have been associated with the idea of social capital, which refers to the resources accessible through social networks. In addition to offering emotional support, a robust social network—which includes friends, family, and peer support groups—also offers useful help in the form of financial aid, transportation, and access to medical information (Nicholson *et al*., 2013) [18]. According to research, stroke patients who have more social capital recover more quickly and have better lives, whereas those who are socially isolated have worse rehabilitation results (Berkman *et al*., 2000) [1].

Since there are few specialist stroke clinics in low- and middle-income nations, community-based rehabilitation (CBR) has been widely marketed as an affordable and easily accessible method of post-stroke care (World Health Organization, 2010) [30]. CBR programs focus on home-based rehabilitation, peer support groups, and vocational training to assist social and economic reintegration (Hartley *et al*., 2009) [11]. These initiatives lessen reliance on institutionalized care by empowering local communities to assist stroke survivors. Notwithstanding its benefits, CBR has a number of drawbacks. Inadequate financing, a shortage of qualified personnel, and uneven service quality plague many programs (Khan *et al*., 2016) [13]. Rural communities are also less able to attend community rehabilitation programs due to geographic differences, which forces them to rely on family-based care, which isn't always sufficient. Furthermore, traditional beliefs and cultural attitudes in some communities may prevent people from seeking rehabilitation, thus reducing its impact (Brunner-La Rocca *et al*., 2017) [2]. Reforming policies, funding rehabilitation education, and raising community understanding of stroke recovery needs are all necessary to address these problems.

According to Kang *et al*. (2017), stroke survivors frequently experience social stigma and marginalization, which can have a serious negative influence on their mental health, sense of self, and ability to reintegrate into society. Some survivors may be viewed as less competent or reliant due to negative preconceptions brought on by physical disabilities, communication issues, and cognitive problems. This may lead to diminished social connections, discrimination at work, and even neglect in the family. Instead of being seen as a matter of rights and social inclusion, disability is still frequently seen via a medical or altruistic lens in many cultures (Oliver, 1990) [19]. According to Hansen *et al*. (2017) [10], this viewpoint perpetuates stroke survivors' marginalization by making it harder for them to find work, participate in community events, or uphold their pre-stroke social positions. Because they are frequently expected to provide care rather than receive it, women may be more stigmatized and socially isolated than males (Mukherjee & Patil, 2019) [17]. Awareness campaigns, employment adjustments for disabilities, and legislative measures that encourage equitable opportunities for stroke survivors are necessary to fight stigma and advance inclusive rehabilitation. Their quality of life can be greatly enhanced by promoting social reintegration through assistive technologies, peer networks, and accessible public areas.

For stroke survivors to recover and reintegrate into society, social support networks—whether they come from family, caregivers, or community-based initiatives—are essential. However, social shame, regional constraints, and economic inequality frequently reduce the efficacy of these support networks. To guarantee that stroke survivors receive comprehensive and equitable post-stroke treatment, it is imperative to support social inclusion policies, strengthen community-based rehabilitation, and offer caregiver help.

Accessibility, mobility, and social inclusion

It can be extremely difficult for stroke survivors to navigate public areas, reintegrate into the employment, and exercise their rights under legislative frameworks. Accessibility is a key factor in determining post-stroke quality of life since physical and cognitive deficits following a stroke can restrict movement, communication, and day-to-day functioning (WHO, 2011) [29]. However, the social reintegration of stroke survivors is frequently hampered by structural impediments such poor disability legislation, discriminatory job practices, and inadequate infrastructure (Shakespeare, 2018) [24]. This part examines the differences in accessibility between urban and rural areas, the difficulties that stroke survivors have finding jobs, and how disability rights and policy frameworks promote social inclusion.

The mobility and independence of stroke survivors are significantly influenced by public infrastructure. While urban environments often have better healthcare facilities, public transport systems, and accessibility features, these benefits are not always evenly distributed. The mobility of stroke survivors is restricted by the absence of wheelchairaccessible infrastructure in many places, including badly constructed walkways, insufficient ramps, and inaccessible public transportation (Imrie & Hall, 2001) [12]. Even when there are accessible facilities, issues with upkeep and usage persist because ramps may be excessively steep, elevators may not be operational, and there may not be enough accessible bathrooms (Lang, 2014) [14]. On the other hand, mobility issues are considerably more severe in rural locations. For stroke survivors, everyday activities and medical visits are challenging due to poor road conditions, a dearth of specialist rehabilitation facilities, and a lack of transportation choices (Gibson *et al*., 2015) [9]. Stroke survivors must rely on family members or the community for mobility help because public transportation in rural locations is either nonexistent or inadequately designed for those with mobility limitations (Rimmer, 2005) [23]. Furthermore, stroke patients must travel great distances for rehabilitation due to the frequently insufficient healthcare infrastructure in rural areas, which slows recovery and causes social isolation (Wolfe, 2012) [29].

Furthermore, memory problems, slowed processing speed, and concentration problems are common among stroke survivors, and these can impair confidence and work performance. Reintegration is made more difficult by workplace prejudice, as employers may view stroke survivors as less competent, which might result in job loss, lower pay, or career stagnation (Buijck *et al*., 2012) [3]. Since they might not be able to carry out their prior responsibilities and might not have the necessary skills or support to move into another work, stroke survivors who have had physically demanding professions in the past frequently encounter more difficulties (Martinsen *et al*., 2019) [16]. Stroke survivors can increase their career chances and restore social integration and financial independence by promoting inclusive hiring practices, workplace mentorship programs, and increased use of assistive technology.

The dearth of funding and rehabilitation initiatives for stroke survivors is one of the main policy issues. Stroke survivors must rely on costly private treatment or family assistance because public healthcare systems in many countries do not provide stroke rehabilitation services (Cieza *et al*., 2021) [5]. To guarantee that recovery is not influenced by financial situation, policies must place a high priority on financial assistance for stroke survivors, universal healthcare access, and subsidies for rehabilitation services. Additionally, advancing accessible public transportation, inclusive infrastructure, and workplace safeguards requires public awareness campaigns and policy advocacy initiatives (Oliver, 1990) [19].

Conclusion

It is impossible to comprehend stroke survivors' quality of life (QoL) just from a medical perspective. Instead, it has to be viewed as a multifaceted social construct that includes the social, economic, and environmental elements that affect post-stroke rehabilitation and reintegration in addition to the psychological and physical impacts of stroke. Beyond medical care, stroke survivors deal with a variety of ongoing issues that have a substantial negative influence on their quality of life, such as physical inaccessibility, social isolation, and unstable finances. Therefore, to ensure a thorough healing process, a post-stroke holistic strategy that incorporates medical treatment and social determinants of health is crucial. In order to promote long-term rehabilitation and inclusion, this knowledge urges a change from a purely biological paradigm of stroke recovery to one that takes social, economic, and policy factors into account. In addition to physical recovery, stroke survivors' social engagement, financial security, and mental health should be given top priority. This will guarantee that their experiences are not only characterized by their disability and medical care, but also by their ability to return to society as contributing members of society.

To address the complex nature of stroke recovery, the rehabilitation process must take an interdisciplinary approach that incorporates medical care, psychological assistance, social support, and policy advocacy. In order to restore physical functions, medical treatments and rehabilitation are essential, but they must be supported by initiatives to increase accessibility, lessen financial burdens, and fight social isolation. For example, by encouraging social reintegration, family caregiver support and community-based rehabilitation programs can greatly improve recovery. Campaigns for public awareness can also aid in lowering stigma, dispelling myths about disabilities in society, and encouraging acceptance of stroke survivors as contributing members of society (Priestley, 2003) [21]. Therefore, combining medical, social, and policy methods is not only desirable but also essential for a long-lasting, comprehensive rehabilitation.

In conclusion, a change to a more comprehensive strategy that incorporates the medical, social and policy aspects of stroke rehabilitation is necessary to comprehend quality of life after a stroke. Rethinking quality of life as a multifaceted social construct helps us to understand that rehabilitation encompasses more than just medical care; it also involves social reintegration, economic stability, and the removal of structural impediments. Only by combining these diverse strategies can stroke survivors be helped to lead fulfilling, self-sufficient, and socially integrated lives after their stroke.

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