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The Importance of a Holistic Intervention in Stroke: Guiar en DCA Project

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ABSTRACT

When a patient is discharged from the hospital after suffering a stroke, they often face a significant lack of information about the next steps and the available resources that can improve their quality of life. This situation leads to a host of social, economic, familial, occupational, and even healthcare-related problems that must be addressed. For this reason, the Freno al Ictus Foundation created a project in 2023 to provide direct support to patients and their families, offering comprehensive assistance in the phases following the stroke.

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Introduction

Stroke is a cerebrovascular disease that is the leading cause of acquired brain injury and is currently highly prevalent in Spanish society. Each year, 120,000 people suffer a stroke in Spain, making it the leading cause of death in women and the leading cause of acquired disability in adults. Furthermore, it is estimated that 1 in 4 people will suffer a stroke in their lifetime, with 50% of cases occurring in people of working age. Stroke is a largely invisible disease that is increasingly prevalent and requires greater attention due to its prevalence.

Most people who suffer a stroke, upon leaving the hospital, face a series of aftereffects that cause a severe disruption to their lives and routines. This disease has a profound impact on the lives of those who suffer from it and their loved ones, generating a series of health, social, family, and work-related consequences that require comprehensive, continuous, and person-centered social and healthcare intervention so that those affected can achieve a higher quality of life and greater well-being, adapted to the new circumstances resulting from the disease.

Generally, stroke is approached from a clinical perspective, addressing issues such as diagnosis, the urgency of appropriate action, rehabilitation treatment, etc., and it is essential to discuss these matters. However, we must also focus on what families feel once they are discharged from the hospital, because feelings and emotions such as uncertainty, anger, frustration, misinformation, confusion, etc., often surface. These feelings, which they experience in the initial phase, continue throughout the entire course of the illness, in many cases increasing in intensity due to the various barriers and challenges that families face. Presented below are several aspects of daily life in individuals with acquired brain injury that have a significantly impact in their lives.

Lack of Information After Hospital Discharge

Often, there is significant misinformation surrounding hospital discharge regarding the various resources and procedures available that can improve patients' quality of life and well-being, and which can have a very positive impact on their functional recovery. This highlights the importance of ongoing support, as families are often in a state of shock while in the hospital, which can lead to them being unable to retain all the information provided due to their emotional state. Furthermore, the aftereffects of the illness evolve, along with the needs and concerns of patients. Therefore, it is essential to implement a long-term support program that addresses the new needs and challenges that arise for both patients and their families.

On the other hand, accessing resources is complex due to the existing bureaucratic burden, which causes delays in obtaining essential resources for the patient's daily support.

Economic Impact

As a result of the illness, families face a series of significant expenses, primarily related to private rehabilitation, which they must undertake to achieve as normal a life as possible. These are not the only expenses they must face, as they also include those related to home modifications, transportation, medication, etc. Added to these are the costs of daily life for a patient, which leaves many families in a precarious situation, unable to afford many of these expenses, directly impacting the patient's functional recovery.

Workplace Issues

The workplace is another problem faced by people affected by an acquired brain injury, as they often encounter significant difficulties reintegrating into their working lives or accessing adapted employment. They must manage disability claims, which represent a bureaucratic burden for their families. In many cases, individuals have to face new realities that involve a new job search or a completely new life routine due to the inability to return to a profession.

This situation affects not only the patient's mental health but also their financial situation, exacerbating the problem of covering the various expenses they have to face.

Family Changes

At the family level, the impact of the illness is significant, and various aspects can arise. On the one hand, many families experience a loss of both social and familial roles, leading to a shift in the roles of each family member. This can cause identity crises, mental health problems, and direct consequences for each family member, who must adopt new routines and ways of life. In these situations, the figure of the caregiver often emerges. This person takes on the role of caring for the patient and must be considered when working with families due to the potential for overload and exhaustion. It is important to recognize that the burden of caregiving can lead to mental health problems for the caregiver, and therefore, we must not lose sight of this when working with families.

Lack of Support Networks

At a social level, due to the consequences and aftereffects of the illness, many people find themselves in situations of social isolation and loneliness because their limitations prevent them from resuming the activities they previously enjoyed with friends and family, leading them to believe they are excluded from active participation in society. However, this lack of support networks is not only evident at the social level, but also at the institutional level. Many people face difficulties due to the lack of resources provided by government agencies that could significantly improve their lives, creating a sense of vulnerability in the face of the process they are experiencing.

Importance of Social and Healthcare Intervention

People affected by brain injury face a range of challenges in different areas of their lives, hindering their functional recovery and profoundly impacting their quality of life and the dignity of those who survive acquired brain injury. It is precisely here, at the social level, that intervention must continue, because the various social factors surrounding families are having a significant and real impact on their lives.

Therefore the importance of considering acquired brain injury intervention from a holistic and socio-health perspective, where the clinical aspect coexists with the integration of specialized, personalized, and coordinated social intervention. At this point, the professional role of Social Work becomes essential, given its professional nature, which informs, guides, and supports families through the various procedures and resources they must access at each stage of the process. Only in this way can a truly comprehensive intervention be achieved.

Guiar en DCA Project-Freno al Ictus Foundation

After analyzing all these issues and understanding the real problems faced by stroke survivors upon hospital discharge, the Freno al Ictus Foundation created a project called "Guiar en DCA", within the Foundation's inclusion program.

The "Guiar en DCA" project was created to address the lack of information and ongoing support that patients and their families receive after hospital discharge regarding the various procedures and social resources available. This is achieved by incorporating social workers and volunteers who have experienced brain injury themselves, who meet the needs expressed by families and offer guidance and support services after hospital discharge.

The project aims to provide patients with acquired brain injury with personalized care, including information and advice on dependency, disability, support measures, and work incapacity procedures; to offer specialized guidance on available resources; to provide free administrative and management support to expedite the processing of procedures and reduce waiting times; to establish continuous support for affected individuals and their relatives who, due to their socioeconomic situation, need assistance in carrying out procedures; and to offer emotional support to families facing the multidimensional consequences of stroke.

The project offers personalized care that adapts intervention to the needs of each patient with acquired brain injury, reducing the stress and uncertainty associated with managing paperwork and facilitating access to social, healthcare, and community resources. Comprehensive support is provided by social work professionals and volunteers affected by brain injury who work together to improve the quality of life for families, favoring patient autonomy, preventing additional problems, and providing social, emotional, and administrative support.

Furthermore, the project promotes the social inclusion of patients with stroke, encouraging the creation of support networks through coordination with different organizations.

By implementing this project, continuity of care for patients is enhanced, along with socio-health intervention, focusing on the various aspects of people's lives in a specialized and personalized way over time.

Conclusion

In Spain, the need to integrate social intervention with healthcare has been recognized, in order to create comprehensive interventions that offer holistic care to patients and improve their well-being and recovery.

The Guiar en DCA project promotes this holistic care. It is a well-established project with a clearly defined structure and an ever-expanding reach, demonstrating an effective, accessible, and sustainable intervention model centered on the individual and geared towards inclusion, autonomy, and the overall well-being of those affected [1, 2].

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