

SHARED CLINICAL DECISION-MAKING IN **STROKE** CARE



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SHARED CLINICAL DECISIONS

BACKGROUND:

In clinical practice, patients, families, and healthcare professionals continually face situations in which they must make decisions with varying levels of uncertainty, whether in relation to diagnostic or therapeutic procedures.

Shared decision-making allows both the professional and the patient to participate jointly in health decisions, after considering the range of available options. Joint assessment of the advantages and disadvantages of every alternative takes into account the individual characteristics, values, preferences, circumstances of each person. This model favors a more active role by the patient in the disease process and marks a change in the relationship between the patient and healthcare workers.

The research discussed below attempts to analyze at what stage the *Shared Clinical Decision-Making* model is found within the stroke care process in the community of Navarre, assessing current limitations or tools needed to establish it. It also seeks to provide a space for reflection to identify unmet needs or suggest possible improvements in the different stages of the integrated stroke care process.

This work was carried out jointly between the Neurology Service of the Complejo Hospitalario de Navarre (CHN), Navarrabiomed (Biomedical Research Centre of the Government of Navarre), and the Navarre Brain Damage Association (ADACEN), a non-profit organization that works with patients and family members. This initiative is linked to the ICTUS NET project, whose mission is to create a collaborative network between different southern European regions, made up of patients and professionals from different areas related to stroke care.

1.1 What is shared clinical decision-making?

Shared decision-making is a healthcare professional - patient relationship style, which can be extended to all sorts of interaction or consults, as there can be many different choices to consider, including *doing nothing*. It applies to acute processes (how they are treated), chronic diseases (administering a drug or not, lifestyle habits changes such as diet, exercise, etc., or treatment adherence), or a preventive action (screening tests and/or preventive procedures).

Currently, it is a legal and ethical imperative **to respect patients' decision-making, allowing them to exercise their autonomy**. Law 41/2002 regulating patient autonomy emphasizes “... *the patient is entitled to freely decide, after receiving adequate information between the available clinical options*”, while noting “... *the obligation of every professional to perform the duties of information while respecting the free and voluntary decisions taken by the patient.*”

Several methods have been developed and assessed to engage and promote a more active role from the patient in his/her healthcare. To this end, European health organizations recommend health strategies that focus on three points:

1. Health literacy (patients' schools)
2. Shared decision-making, and
3. Self-care for chronic patients

At present, there are **three decision-making models** that can be considered when selecting a final treatment, and these models differ depending on the various roles that healthcare professionals and the patient assume:

- **Paternalistic model:** The healthcare professional decides for the patient and leaves him out of the decision-making process.
- **Informed decision model:** The healthcare professional informs the patient about all possible options but does not advise, and the patient is responsible for making the decision. The healthcare professional merely transmits the information.

- Shared decision-making model: Decisions are made jointly between the healthcare professional and the patient.

The different models are not set in isolated compartments or are unalterable. The patient may need to move from one model to another according to the circumstances.

Shared decision-making includes three essential elements:

- ⇒ Information exchange (personal and medical) between patient and healthcare professional.
- ⇒ Analysis of each option.
- ⇒ Patient and healthcare professional reach an agreed decision.

In this interactive process, healthcare professionals provide their knowledge, as well as information about the risks and benefits of a diagnostic or therapeutic intervention, while the patient provides his/her values, preferences, concerns, and experience with his/her health issue.

Different procedures have been implemented for shared decision-making according to each different institution and/or country, although essentially they all include the same **actions**:

1. Build a trusting relationship with the patient, offering empathy and warmth. It is important to promote a fluid communication and encourage the patient to talk.
2. Explore and determine the patient's preferences in relation to the information they want to receive (format, quantity, etc.) and their role in decision-making
3. Check and respond to patients' ideas, concerns and expectations
4. Identify options (including ideas and information that the patient may have) and assess each patient's individual background, being mindful that doing nothing is also an option.
5. Present the evidence and help the patient reflect and evaluate the impact of each alternative in connection to their values and preferences. The way in which the information is presented must consider the patient's emotional state, since different reactions may occur depending on how the data is presented.
6. Reach or negotiate the decision jointly with the patient and sort out possible conflicts.

7. Agree on an action plan and prepare a follow-up.





Achieving a shared decision-making model necessarily entails changes in the organization and structure of the medical activity. It demands a **shift from a paternalistic model to a more collaborative relationship** that involves yielding healthcare professionals' control and constant negotiation. It also requires a change in the way that different therapeutic options are presented to the patient, using tools (visual or otherwise) over and above a mere exposition by the professional, to make the choice easier to understand and explaining the expected consequences of each option.

Stages of the stroke process and most frequent decisions

A stroke is a sudden disturbance of cerebral blood flow in an area of the brain, either because a blood vessel (usually an artery) is blocked, causing ischemia, or because it ruptures, causing hemorrhage.

When blood flow is interrupted, brain functions of the affected part of the brain may be temporarily or permanently altered.

In this study, four defined phases or milestones within the stroke process have been established and the key decisions that may develop in each of them have been defined.

-  **PHASE I: Emergency room and admission.**
-  **PHASE II: Admission to the neurology ward and hospital discharge.**
-  **PHASE III: First three months. Beginning neurorehabilitation. Reconnection with neurology.**
-  **PHASE IV: Three months to a year. Stabilization, maintenance, and chronicity.**

PHASE I: Emergency room and admission.

When a stroke occurs, there's a sudden neurological condition that often prevent the patient from expressing themselves normally or from having an adequate self-awareness of what is happening. At this stage, the patient is often confused, restless, bewildered, lacking understanding, or tending to fall asleep. In some cases, they maintain consciousness and understanding of the situation, feeling their limitations and seeing everyone running around them with the resulting anguish this generates. It is a very traumatic and stressful situation.

This pathology most be handled very quickly at the start, mainly in the first six hours from the onset. Every passing minute counts in the quest to administer a treatment that can minimize the damage sustained by the brain, making it a “time-dependent urgency.” This implies that quick action is required from the moment it is detected. Decisions must be made in a very short space of time on arrival to the health center, sometimes in less than an hour. These are major and consequential treatment decisions. To achieve this, the main informant and speaker must be the neurologist, and for the patient, the accompanying relative, especially in cases where the patient is not able to understand, discuss, or decide.

In Phase I, there are decisions related to thrombolytic therapy, which often are only partially effective and create a high probability of permanent disability. The more severe the stroke, the higher this probability. Thrombolytic therapy has the potential of a significant adverse effect, which is the hemorrhagic transformation of the infarction.

In some cases, at this stage, intracranial artery catheterization for thrombus extraction must be considered and a decision made quickly. In other cases, it is necessary to decide whether urgent neurosurgery is performed (if the patient is eligible). These interventions entail prolonged intensive care unit admission associated with invasive procedures such as mechanical support, anesthesia, intracranial drains and catheters, invasive monitoring and risk of nosocomial (hospital

acquired) infections. Many of these patients, although they manage to survive, are left with important neurological sequelae.

In this first phase, most patients with ischemic or hemorrhagic stroke require admission to a continuous monitoring and special care unit, and the decision of whether to admit a patient to a stroke unit or intensive care unit arises.

It is important to consider that each patient has different experiences on what it is to live with a potentially serious permanent disability and has diverse family, emotional, and socioeconomic support situations. A significant part of the patient's recovery will depend on the above and whether they have associated diseases and previous functional limitations, their age, and resilience.

Key decisions identified in Phase I:

- 1.- *Decide on intravenous thrombolytic treatment (in ischemic stroke).*
- 2.- *Decide on intracranial artery thrombus extraction via femoral artery catheterization in the groin (endovascular treatment of ischemic stroke or thrombectomy in ischemic stroke).*
- 3.- *Decide on surgery for cerebral hemorrhage evacuation.*
- 4.- *Decide on decompression craniectomy in severe ischemic stroke with a high probability of the patient going into a coma.*
- 5.- *Decide on admission to stroke unit.*
- 6.- *Decide on admission to ICU.*

PHASE II: Admission to the neurology ward and hospital discharge.

After a variable period in the stroke unit (usually 1-2 days), the patient is moved to a more conventional care bed, in a Neurology wardroom. At this stage, patients are more stable. They generally become aware of what is happening to them and are increasingly aware of their deficits.

Scans aimed at diagnosing the cause of stroke and severity of brain damage are started: magnetic resonance imaging or cerebral scans, arterial ultrasound assessment (Doppler ultrasonography), heart assessment (echogram to evaluate its size and function, continuous electrocardiography to evaluate cardiac rhythm), and complete blood tests. Once the most likely cause is diagnosed, treatment is adapted accordingly to reduce the odds of a new stroke. Several treatments are administered to virtually all patients, which may cause some side effects.

The neurorehabilitation team must evaluate the patient in the first 48 hours to begin treatment as soon as possible, ideally physiotherapy and motor rehabilitation sessions, along with language rehabilitation, occupational therapy, and standardized neuropsychological assessment.

There is evidence that patients benefit from early mobilization; however, this may take a few days for a number of reasons. Some do not tolerate immobilization because of pain and anxiousness; others have difficulty moving and do not want to stand up because they are very afraid of falling, etc.

Infectious complications, e.g., respiratory or urinary, may be frequent. Epileptic seizures and confused mental states may also occur.

The condition of some patients are so serious that a relatively common decision must be made: how far to go with the treatment. In some cases the prognosis, although uncertain, leaves no doubt about the serious disabilities the patient will suffer, which can lead to him/her becoming

bedridden or unable to communicate. Decisions such as inserting a nasogastric feeding tube, urinary catheter, and antibiotic treatment in case of infection must be taken. These are difficult decisions in which many subjective factors are involved and getting the patient's opinion should be a priority.

In cases where a narrowing (stenosis) in the carotid artery is the cause, open surgery is proposed to correct it in order to avoid a new stroke. This is a preventive surgery and will not improve patient's current stroke. In certain circumstances, the risk is high, and the decision of whether to operate or just treat with oral medication is debatable.

To reduce the likelihood of a new stroke, physical measures and lifestyle changes are just as or more significant than drug-based treatments, including quitting smoking, dietary changes, losing weight, exercising, monitoring blood pressure, and diabetes follow-ups. These measures are commonly linked to myocardial infarction rather than stroke. Education is essential in preventing vascular pathology, and this is where nurses play an important advisory role during patient's admission.

As the time of hospital discharge approaches, the family has to face an important decision: referral to another hospital to continue convalescence and neurorehabilitation as inpatients or return home to continue rehabilitation as an outpatient. This decision should ideally be shared between the patient and/or family, and healthcare professionals, following defined and measurable objectives.

In this phase, social worker's guidance is also key, as he/she advises and explains to the family the potential aid and support available at home, and starts the procedures or contacts with the health worker of the patient's health area or town.

Key decisions identified in Phase II:

- 1.- *Decide on the amount and nature of scans to perform (and for what purpose).*
- 2.- *Decide which treatments to administer (and their purpose), and their expected effect, considering possible risks.*
- 3.- *Decide to operate the carotid artery in patients with severe carotid stenosis.*
- 4.- *Decide to limit therapeutic measures in patients with severe stroke with poor functional and vital prognosis.*
5. *Decide on lifestyle changes (and which will have the greatest impact on reducing the risk for the patient) and how these changes will be undertaken in relation to the patient's background.*
- 6.- *Decide on the rehabilitation plan, best adapted to the objective expectations of the patient's improvement.*
- 7.- *Decide on the patient's destination at discharge from the acute care hospital: home, residence, Clínica Ubarmin, Clínica San Juan de Dios.*

PHASE III: First three months. Beginning neurorehabilitation. Reconnection with neurology.

After the patient is discharged from hospital, he/she has to adapt to his/her environment with the accompanying consequences of the stroke. In this phase, sequelae become especially evident, including those that did not seem too relevant at admission. Besides speech and motor impairment, other types of cognitive, behavioral, or emotional disorders may emerge, which might not seem obvious at first.

Ambulatory specific neurorehabilitation treatment should continue after discharge, pursuing the treatment started at admission. Interruptions in this phase may have negative consequences and setbacks in progress. In many cases, the patient has to travel by ambulance, sometimes long distances depending on their place of residence, to achieve continued therapy.

In this phase of outpatient neurorehabilitation, the patient is assessed and a treatment plan is recommended. In addition to physiotherapy and occupational therapy and, based on the observed non-motor sequelae, the patient is scheduled for neuropsychological evaluation, psychiatry, and speech therapy. There are many appointments and many days to attend to, and this can be overwhelming for the patient and his/her family, potentially losing the desired benefits.

At this stage, the patient receives new treatments, established before his/her discharge. Their purpose is often unclear, and in some cases may cause side effects. Frequently, the patient does not go to the health center for help, either because of ignorance or lack of confidence.

This phase is also critical regarding the introduction of the recommended lifestyle changes. Many patients do not have the resources to know how to make changes in their dietary habits, or how to quit smoking, drugs, and/or alcohol. Furthermore, in many cases follow-up is not performed by the Health Center.

The first contact with neurology is usually established three months after the stroke. This is a momentous consultation for the patient to understand the purpose of the medication they are taking and to allow them to explain how they have adapted to it, talk about the risk of stroke recurrence and the importance of preventive measures, clear up any doubts that they may have about the disease, discuss sequelae, and identify any needs. In some cases, specific therapeutic decisions are proposed, such as closure of the patent *foramen ovale* or intracranial vascular malformation treatment, and requires further discussion with the patient.

Most patients attend this appointment in significant need of medical contact and explanations.

Key decisions identified in Phase III:

- 1.- *Decide on the neurorehabilitation treatment plan: objectives, timing, effort required, alternatives.*
- 2.- *Decide on treatment adherence or change of preventive medication (mainly anticoagulants, hypocholesterolemic agents).*
- 3.- *Decide on accomplishing a healthy lifestyle.*
- 4.- *Decide on the mode and regularity necessary to monitor hypertension, diabetes, atrial fibrillation.*
- 5.- *Decide on the psychological/behavioral sequelae treatment*
- 6.- *Decide on patent foramen oval closure.*
- 7.- *Decide on vascular malformation treatment (aneurysms, arteriovenous malformations).*

PHASE IV: Three months to a year. Stabilization, maintenance and chronicity.

The patient usually continues with neurorehabilitation treatment but, at this point, makes less progress. He/she is now familiar with his/her disabilities, as he/she has suffered them for a while. Accepting reality and learning to live with them is a necessity at this stage, while continuing to fight for improvement.

Fatigue in the patient's environment becomes more evident, particularly in the primary caregiver. The needs of the primary caregiver begin to emerge and are an important thing to consider. This may involve changes in patients' care organization: hiring help, day centers, involving others, etc.

During neurorehabilitation the following aspects are emphasized:

- Adjustment and acceptance of the disabilities
- New training to perform tasks and get around
- The importance of personal autonomy and avoid overprotection
- The importance of a positive, proactive, and collaborative attitude. Resilience
- Treatment to mitigate symptoms that will not disappear: spasticity, pain

A key moment is the decision of when to end neurorehabilitation treatment. The objectives agreed upon in the first evaluations need to be revisited, and it is important that the patient perceives that this is not a doctor's one-sided decision, but rather that the decision was taken with the support of a team, and based on something previously discussed with the patient. All the same, all patients benefit from maintenance therapies (in groups, on less demanding gyms, online...), which ideally should be closer to their place of residence to create a patients' community.

In patients of working age, this phase is particularly difficult. If possible, they have to face the return to work, and if work is not possible, they must begin the disability procedures, relocation, etc.

At this stage, many patients are discharged from neurology. After 2-3 evaluations, preventive treatment should be taken regularly (chronic medication) (doses may vary) and medical care is transferred 100% to the patient's health center.

More than in any other phase, it is essential for the patient to understand that he/she should continue treatment as well as pursue healthy lifestyles to prevent a recurrence of stroke. At this phase, the patient tends to perceive risk less than before and may abandon the treatment and new habits. Ideally, education for stroke prevention should have periodic reminders in their health centers in the form of lectures and other education methods.

Monitoring drugs' side effects is necessary, as well as periodic checks of analytical parameters, weight, BP, blood glucose, etc.

Key decisions identified in Phase IV:

- 1.- *Decide to end neurorehabilitation treatment and discharge from the neurology service*
- 2.- *Decide to search for patients' communities and support groups*
- 3.- *Decide on changes in patient care organization*
- 4.- *Decide on reinsertion/relocation/job disability*
- 5.- *Decide on adherence to treatment or change of preventive medication*
- 6.- *Decide on adherence to healthy lifestyles*
- 7.- *Decide on the mode and regularity necessary to control hypertension, diabetes, atrial fibrillation.*

OBJECTIVES

- ❖ Understand how and in what way are shared clinical decisions are being made in our community in the different stages of the stroke care process.
- ❖ Assess positive aspects provided by this healthcare model, as well as existing constraints and necessary tools to carry it out.
- ❖ Encourage the participation of patients, family members, and healthcare professionals to achieve consensus and draw conclusions from a joint perspective that includes all parties involved in this process.
- ❖ Carry out actions to help increase the humanization of healthcare.
- ❖ Reflect about the stroke care process and identify areas of improvement to promote integration and focus on the patient.

METHODOLOGY

The review process on the *Shared Clinical Decision-Making* model application was carried out with the **joint methodological participation perspective of all the actors involved**. To do this, we sought the collaboration of patients, family members, and professionals, and tried to establish general agreements to draw conclusions on this issue.

The following actions were taken:

- ❖ **MEETINGS.** Joint meetings were held with the participation of the Neurology Service of the *Complejo Hospitalario de Navarra (CHN)*, *Navarrabiomed*, and the Navarre Brain Damage

Association (*ADACEN*) at the outset of the process and subsequently to settle on and detail the objectives and methodology of the study.

- ❖ **INTERVIEWS.** Five in-depth interviews were conducted with relevant people in stroke care of Navarre's health service. Each one of them works in one of the phases defined in the project.
 - Neurologist in *CHN*
 - Social Worker in the Social healthcare division. Healthcare integration.
 - Neurologist in the *CHN-A* stroke unit
 - Nurse in the *CHN-A* stroke unit
 - Rehabilitation physician at *Clinica Ubarmin (CHN-D)*

- ❖ **FOCUS GROUP.** Organization of workshops/dynamic groups. Four workshops were held, one for each healthcare phase in which the possible clinical decisions to be made in each phase were analyzed. The workshops were overseen by professionals with experience in focus group development (*inPactos* consultancy) and were held at the Navarre Brain Damage Association (*ADACEN*) office.

The groups were diverse with the following participants:

- Patients
- Family members
- Neurologists of the *CHN* and *San Juan de Dios* Hospital
- Neurorehabilitation doctor
- Neuropsychology therapist
- Primary care physicians
- Healthcare professionals from Navarre's Efficiency Service and Healthcare Safety department
- Neurology and stroke unit nurses of the *CHN*
- Social Workers of the Navarre Brain Damage Association (*ADACEN*)
- Observers

The main decisions to be assessed in each phase and workshop were established

previously along with the elaboration of an outline/script aimed at focusing the group's debate and achieving a greater precision.

- ❖ **MINUTES AND FINAL DOCUMENT.** Minute preparation with the workshops' main conclusions. In this process the neurology service, *ADACEN*, the *inPactos* consultancy moderators, and people who acted as observers in each participating group. A final document was written containing the actions taken, the main conclusions, and recommendations or guidelines to be followed.

CONCLUSIONS BY PHASE AND WORK GROUP

Phase I Conclusions: Emergency room and Admission.

Swiftness of events characterizes the emergency phase and first hours of care: symptoms appear abruptly, attention is a race against the clock, and decisions must be made promptly. Frequently at this stage, the patient is not fully aware of what is happening and members of the family are in shock. **The medical professional bears the weight of making treatment decisions**, and has to explain them in the shortest possible time.

Time and haste in this phase are an important constraint to shared decision-making.

Later, after admission to the stroke unit, the urgency decreases, but the scenario changes and the patient and his/her family find themselves dealing with a bedridden patient, constant monitoring, new diet, and visiting restrictions following a protocol and often without tailoring based on the severity or characteristics of the patient.

Protocols are rigid in the stroke unit. This means that the patient is bedridden and cannot get up to use the toilet, is on an NPO diet, hydrating intravenously, and with constant monitoring and nursing assessments that prevent night rest.

Information in this process is **solely verbal**, and therefore depends on the communicative skills of the professional and the patient's or family member's ability to understand. **The terminology used is too technical or scientific**, which poses an important impediment.

Tools and best practices:

- **Give information effectively. Provide visual information** (fixed screens, slides, flyers...), available anywhere, about what is happening and what is going to be done in the emergency room, and what are the care processes in the stroke unit. Providing information

in a more effective way would be beneficial and may help reduce anxiety and stress reduction in these early stages.

- **Improve communication**

From the professional to the patient: emotional communication, connect through gestures, engage patients in a way they can understand, call them by their names. Patients expressed they felt forgotten in this regard, even though they may not be in a position to make decisions they need to feel implicated, they are not merely objects. **The professional team involved needs training** on experiential education aspects, and to think about how and who in the stroke unit healthcare team can assume this role. The doctor bears most of the weight. **Promote a more trusting environment**, where questions can be asked, and doubts cleared. Facilitate the expression of patient's fears, and allow them to say what is important for the him/her.

From family/patient to the professional: Promote a trusting environment, where questions can be asked and doubts cleared. Take on a **more accountable and less passive role** (acceptance of the event does not necessarily mean to be compliant of everything that is said), particularly in the stroke unit where things are quieter, be the patient's voice. The role of the family member at this stage is essential, so **their presence** is very important **from the start**. To date, family members are not allowed to travel with the patient in the ambulance, and that should change.

- **Tailored care** in the stroke unit. The presence of a suitable trained team is essential to **provide individualized solutions for each patient**, without losing healthcare quality. **Stroke training and teamwork** are fundamental prerequisites for people taking care of patients. Greater humanization in the stroke unit remains a pending task.
- **Promote greater knowledge about stroke among the population.** People should learn to recognize not only symptoms but other related aspects: what is a stroke, the consequences, what does brain damage entail, to be aware of the existence of a stroke unit

and its characteristics. This information may help the patient and family members to be more prepared in the moment of crisis. Many people (patients and relatives) expressed how they experienced a lot of stress and suffering due to the poor knowledge on what was happening and what could be expect afterwards.

- **Handling bad news.** It is important to address the taboo of **talking about death and our thoughts about living with disabilities**. During these hard conversations, what should prevail is whatever the patient has been able to express about it or how they envision their life, rather than healthcare professional and family's subjectivity.

Phase II Conclusions: Admission to the neurology ward and hospital discharge.

In this phase **there is a lot of uncertainty** about the patient's progression, which consequently generates fear and anxiety. In many cases, the patient is still unable to collaborate and the **family member remains a fundamental figure** being the one who bears the weight of the situation. This condition of emotional shock and confusion, along with the patient's disability due to the stroke, are a major obstacle when it comes to taking a more active role in the decision-making.

Hospital discharge is considered even on the first few days when family and patients are still in shock. The decision to discharge early comes from the need to have available beds in acute phase treatment hospitals.

Decisions to be made at this stage are not only clinical or medical, **but also include social and family aspects**. Where will patients go when discharged? How are patient's needs going to be taken care of? What are the possible obstacles at the patient's home.

Life has taken a drastic turn and these decisions create a lot of stress due to the many changes they entail.

Diagnostic tests and procedures performed on the patient are **highly standardized** and relatives and patients feel this as another constraint. Many times, they are unaware of the doctor's name or of those responsible for the tests. Patients say that they feel like objects on an assembly line and that they are treated with coldness. To achieve shared decision-making, **communication and information** should be adjusted to the patient's emotional state with the patient being the main focus.

Tools and Best Practices:

- **Improve communication.** To achieve shared decision-making, communication and information should be adjusted to the patient's emotional state and be the main focus. To accomplish this the following are required:

- **Promote spaces that encourage intimacy**
 - **Time dedicated to sharing information.** Duration of this interaction can be short; the important thing its quality.
 - **Staff communications training,** to prevent relying solely on their personal skills. Avoid excessive use of technical language.
 - **Teamwork** is essential. Although patients, family and healthcare professionals **have different missions** in terms of information and support, training the family in care is part of the whole.
- **Designing content or materials that complement and facilitate sharing of information.** Content should cover information about all stages of the process. It should explain the main causes of stroke, the importance of changing habits, and the capacity of the treatment to reduce the chance of a new event.

Look into the feasibility of using **new technologies**, for example, a Navarre health application explaining stroke issues that patients and relatives can check, with links to videos, content from other communities, etc.

- In Phase II, people other than the doctor can assume **patient and family information** sharing and training: nurses, social workers, auxiliary nurses, etc. There is a possibility of creating a space in the ward for a **stroke patients association**, with the collaboration of volunteers, patients who have had the same experience, etc., as long as the participation of the patient and family members is voluntary.
- Consider the possibility of implementing **satisfaction surveys** at discharge or a suggestion box to understand the needs of patients and relatives and assess whether these needs are being met.

- **Maintain coherence and continuity in the decision-making process in each new area of patient care**, whether in a convalescence and/or rehabilitation hospital, in the health center, or home care. Two key figures emerge in this context: **the figure of the case manager and/or liaison nurse, and the figure of the social worker**, as well as novel **technological tools**, such as **electronic medical records** that alert the new person in charge about the patient's status in regards to hospital discharge and transfer, and of the agreed-upon management. Patient adherence to the recommended treatment depends largely on the above-mentioned points.

- **Carrying out actions aimed at decreasing stress levels and creating a positive environment**. To achieve this, it would be necessary to acquire resources and make changes to the neurology ward:
 - With **spaces that provide intimacy** for the patient and family or **gathering spaces** for groups of patients and/or relatives. With **pleasant and humanizing decoration**.

 - With the **possibility of stimulating or relaxing guided therapies**.

 - With the inclusion of **other professional profiles**; occupational therapist, psychotherapist, or speech therapist. This may encourage a variety of other therapies, such as music therapy, physical stimulation activities (walks, gait stimulation), occupational relaxation, etc.

 - **With visual material that complements neurorehabilitation**, to help the patient communicate and perform the exercises indicated by the physiotherapist: fixed or individual screens with informative videos or links (QR) to access on any device.

 - **With adapted schedules and protocols** with enough flexibility so that the patient's and companion's needs for nocturnal rest are considered while promoting their

autonomy. The idea of weekends ensues as a favorable moment for certain activities because there is more time available.

- A **fully accessible** floor without architectural or furniture barriers.
- With **access to information about the stroke process** designed for patients and families. Through flyers or simple posters that prioritize visual information, computer graphics, video links, screens, etc.
- With **properly identified, stable, and trained personnel with a positive attitude**.

✚ Phase III Conclusions: First three months. Beginning neurorehabilitation. Reconnection with neurology.

At this point, there is a **strong emotional impact, and an adaptation process begins that requires time and attention.**

About the **neurology consultation after three months**: It is an important patient-neurologist reunification. There are many unasked questions or aspects that remain unclear. The **specialists' lack of time** is an important constraint. During this encounter, there are many topics to discuss and too little time. Furthermore, professionals are excessively dependent on the computer.

It is necessary for the patient to listen to the information several times in order to understand it and for the professional to use a less technical, more familiar and understandable language. Family and patients feel very lonely and with many doubts at this stage.

There may be other consultations with diverse specialists. Sometimes there is a lack of coordination or consensus among them and the patient is used as the channel to convey information. It is important to build trust by having the patient and family members perceive that a team is supporting them.

Tools and Best Practices:

Each patient experiences a different situation and it is important to view it through the premise of **“My stroke, in my life, in my environment”**. This should be taken into account throughout all communications and interventions with the patient.

- **Adherence to medical treatment and lifestyle changes.** It is important that recommendations for lifestyle changes and treatments be presented **positively**:

emphasizing the good aspects that are being pursued, rather than the restrictions and harmful effects of unfavorable elements. Establish steps, differentiating what is key and what is merely convenient.

- Improve **continuity of care and coordination between hospital and new environments** (health center, new hospital), making them part of a team, of a whole, and including the presence of a remittal professional and a protocol at discharge. The figure of the liaison nurse arises to link both areas.
- **Improve communication. Design and improve information contents. ICT opportunities:** create an app with frequently asked questions and actions to take, with potential drug-related side effects, etc. Have access to baseline data from the Navarre Health System specifically focused on people with stroke. Study the possibility of doing it in the patient's health record.

Communicate through images to explain what has happened, which is often more effective than verbal communication.

A **pre-consultation questionnaire** may be useful in the **three-month consultation**, laying out a foundation and allowing a more effective use of the consultation time.

- **Schools for the patient and family members.** Some participants felt that it was too soon to join these schools but others envisioned the possibilities of learning if they met with people who had undergone a similar situation and of having Q&A forums. Family members also need their own space as caregivers, and these groups can be supportive. Professionals noted that it is important to ensure that the information is accurate and that adapted to each patient.
- Trained personnel to manage **speech rehabilitation** is needed from the first days, as this generates a lot of frustration and constraint. In neurorehabilitation there are significant

delays in some areas such as speech therapy. **Alternatively**, exercises, possible material to use, etc. **can be offered**.

- A **more open attitude from the professional**, who often perceive questions as annoying or with mistrust. Both parties have things to learn. Therefore a **positive attitude on the part of the patient/family is also necessary**, to propose and to express needs rather than to claim, demand, or complain.

The need for a fair **attitude on the patient and family's part regarding neurological rehabilitation** was discussed, with the potential to understand that resources are limited, that rehabilitation must be carried out by objectives, with commitment. Complaints may be a symptom of passivity, if not dealt with.

Phase IV Conclusions: Three months up to one year. Stabilization, maintenance, and chronicity.

In this phase, the fact of accepting reality and learning to live with the disabilities prevails, without giving up on improvement efforts.

The topic of the main caregiver's overload immediately surfaces in the discussion, where it is not uncommon to see emotional exhaustion situations, stress, tiredness, and sometimes self-care abandonment.

A critical moment is the decision to **end neurorehabilitation treatment and the discharge from the neurology service**. Patients fear not getting better or going backwards in functional recovery, and there is a feeling of abandonment. **Lack of resources** is a problem, as well as the **lack of information** about the available resources. This prevents patients from finding alternatives, so they hold on to what is familiar and often are not willing to be discharged. It becomes clear that **communication** is essential, as well as discharge criteria that the patient should know from the start. Professionals restrict themselves to giving information, when they should provide tailored communication, including asking the family what is happening with the patient.

Tools and Best Practices:

- **Design the Osasunbidea web space** to gather all the information on stroke and show the resources available in Navarre. It would be very useful as a tool for the professionals to inform and at the same time give access to any person who might be interested. Provide a **specialized information line** to address any questions that may arise.
- **Care integration**. Have a specific **health center for this phase** where the patient feels supported and teamwork is promoted in coordination/integration with specialized care. Encourage and promote the **social aspect of health** and include the **family and community dimension** in **primary care** (not in vain this medical specialty is called **Family and Community Medicine**).

Promote possible **joint efforts** between **patients' associations and the municipalities' social services** for lectures, resources for physical therapy maintenance, support, social workers, etc. Sometimes they already exist but are not well known. This information is usually available only through an interview with the social worker.

Strokes are frequent and have a significant socio-economic impact. This issue should be a **priority for public health.**

- **Carry out post-stroke lectures in the health center**, in which social workers talk about the available alternatives, economic aids, etc., besides general information. It can also be a meeting point where families share and generate mutual support relationships.

Other aspects should also be addressed, such as those related to work (disability processes) or the acquisition of a driver's license. This responsibility often falls on health professionals, and there is a lack of attainable information.

Information group initiatives, e.g., in Ubarmin, have had a tepid reception. This is attributed above all to the burden of the family caregiver who has to find balance and does not have the time. Furthermore, the talks given by professionals are typically a flow of one-way information with no communication or connection. The health environment turns unfriendly and unapproachable.

- **Keep up with the treatment and healthy lifestyles.** More than at any other phase, it is essential for patients to understand that **treatment and healthy lifestyles should persist** to prevent stroke recurrence. To do this, communication must be **positive**. Highlight the expected benefits from adhering to the treatment and new daily habits, and identify the essential changes for a favorable evolution (emphasize on that). Involve the caregiver.
- **Have knowledge of what the patient understands by quality of life and agree on "health status"**. In patients with severe sequelae, it is important to know what to do if a new stroke occurs. To be able to respect the will of the patient, the issue must have been dealt with

and know their desires. Advanced directives are included in the patients' medical record; however, the main thing is to talk about it. It is a hard step, particularly for family members, but in the professionals' experience, the patient appreciates it. The health system seems to be changing its view on this aspect, but society prefers the previous model and avoids making decisions.

Be aware of the difference between information and communication. Communication requires previous information, but communication occurs in both directions, and for this, listening is required. **If there is no communication there cannot be a shared decision.** Both sides need communication skills, but at least professionals should undertake **communicational training.**

IDENTIFICATION OPPORTUNITIES AND RECOMMENDATIONS FOR PRIORITY STRATEGIES.


In this research, we have explored and analyzed the stroke care process by phases, from admission to the completion of rehabilitation. From approach, the current *SHARED CLINICAL DECISION-MAKING* model has been applied in these phases in our community.

The different research techniques used, interviews and focus groups, have allowed the identification of constraints and possible facilitating tools for the further development of this model. The methodology used has encouraged the joint participation of patients, family members, and professionals in order to reach agreements, thus obtaining more objective information from a pluralistic perspective.

The research has also helped identifying unmet needs or possible improvements to be dealt with to achieve a more comprehensive and continuous care during the different phases of the stroke process.

The general conclusion is that this model is gaining importance in the clinical stroke care practice in Navarre and that substantial changes are necessary to reach a greater deployment.

The following strategies have been identified as priorities:

-  CHANGE THE ATTENTION FOCUS TOWARDS THE PATIENT AS AN INDIVIDUAL
 - ✓ Provide individualized solutions to each patient, without losing quality in care. Work on the premise *“My stroke, in my life, in my environment”*.
 - ✓ Provide training to professionals in stroke care, teamwork, and patient-centered care.
 - ✓ To the extent possible, adapt care protocols minimizing their rigidity and standardization.

- ✓ Target individual situations to favor lifestyles changes and greater adherence to treatments.
- ✓ Have knowledge of what the patient understands by quality of life and reach agreements on health status. Respect the will of the patient.

 **IMPROVE COMMUNICATION.**

- ✓ Carry out training sessions aimed at professionals to allow them to improve their communication skills with patients and families.
- ✓ Use of a less technical and more comprehensible language.
- ✓ Use spaces that promote intimacy and adequate communication, always according to the emotional state of the patient and family members.
- ✓ Foster environments that encourage patients and family members to gain in confidence and to have a more proactive role.
- ✓ Go from a “command or assume” scheme to reaching agreements.

 **INFORM MORE EFFECTIVELY.**

- ✓ Informing more effectively may help reduce anxiety and stress in the early stages.
- ✓ Use visual media, fixed screens, slides, flyers, etc., which allows providing information in any space.
- ✓ Design supporting material that complements and provides information: main causes of stroke, phases of the care process, importance of prevention by means of habit changes and treatment adherence to reduce the likelihood of a new event.
- ✓ Designate a space on the floor for the stroke patients association, with the collaboration of patients who had undergone through the same situation and families on a voluntary basis.
- ✓ Conduct lectures in the health center, focused on post-stroke, in which social workers report on alternatives, resources, economic aid available, etc.

- ✓ Launch a Patients and Families School that encourages mutual aid.

 CARE INTEGRATION.

- ✓ Improve hospital - health center continuity of care.
- ✓ Improve hospital - neurorehabilitation centers continuity of care.
- ✓ Design a discharge protocol and be able to count on a reference professional. Figure of nursing liaison staff between different areas.
- ✓ Promote a stronger coordination and integration between primary care and specialized care where the patient feels supported.
- ✓ Foster and promote social health and family/community medicine in health centers, establishing joint efforts with social initiatives and social health resources in the patient's environment.
- ✓ Promote continuity of care, differentiating phases with diverse and specific needs.

 UNDERSCORE THE IMPORTANCE OF PREVENTION.

- ✓ Differentiated primary stroke prevention (not within the common branch of vascular diseases). Strategies for stroke knowledge, how to detect it, what causes it.
- ✓ Encourage treatment compliance and the development of healthy lifestyles at all stages to avoid stroke recurrence.
- ✓ Promote the importance of positive communication on lifestyle changes recommendations or treatment proposals.
- ✓ Individualize, know the patient, reach agreements and establish the essentials
- ✓ Promote the figure of the expert patient.

 USE OF ICTs AS TOOLS FOR CARE IMPROVEMENT.

- ✓ Design an Osasunbidea web space where all the information about stroke and resources available present in Navarre is collected.
- ✓ Design of an application about stroke that patients and relatives can consult, with video links, content from other communities, frequently asked questions, possible drug-related side effects, etc.
- ✓ Create a pre-consultation questionnaire for the three months neurology consultation, to layout a foundation and promote the effective use of time during the encounter.
- ✓ Launch a specialized information line to solve any questions that may arise.

ANNEX

Preguntas base de cada una de las decisiones que se valoran en cada grupo:

- En tu experiencia como paciente/familiar/profesional ¿Crees que estas decisiones que se toman/tomaron son/fueron compartidas?
- ¿Quién crees que tiene que tener el papel principal en esta decisión en concreto?
- ¿Crees que hay/hubo alguna barrera que impide/impidió que esto se pudiera realizar...?
- ¿Qué herramientas crees que podrían ayudar para que estas decisiones sean compartidas?
- ¿Qué aspectos positivos podría suponer que esta decisión sea compartida desde tu punto de vista (paciente, profesional, familiar)?

Fase I "Urgencias e ingreso"

Fecha: 25 de febrero

Horario: 16.00h a 18.30h

Lugar: Sede ADACEN, Camino Zolina, s/n Mutilva

+ info: www.ictusnet-sudoe.eu



DECISIONES CLÍNICAS COMPARTIDAS

En la práctica clínica, pacientes, familias y profesionales sanitarios se enfrentan continuamente a situaciones en las que deben tomar decisiones con diferentes grados de incertidumbre, ya sea en relación con procesos diagnósticos o terapéuticos.

La **toma de decisiones compartida** permite que el profesional y el paciente participen conjuntamente en los acuerdos sobre una decisión de salud, habiendo discutido las opciones, sus beneficios y sus perjuicios (daños), y tras considerar los valores, las preferencias y las circunstancias del paciente. Este y/o su familiar y su médico/a pactan el tratamiento o estilo de vida más conveniente de acuerdo con el conocimiento científico existente, pero también con las preferencias y los valores personales del individuo, valorando desde su perspectiva las ventajas e inconvenientes de cada opción. El resultado final permite que los pacientes tomen un papel más activo en su enfermedad. No es solo un paso para ser agregado a una consulta, sino un proceso, un cambio cultural y la forma de relacionarse que puede usarse en todas las decisiones sanitarias incluyendo exploraciones, tratamientos y opciones de ingreso.

    
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TALLER - GRUPO DE DISCUSIÓN

Decisiones clínicas compartidas en el proceso del ictus



OBJETIVOS:

- Conocer qué y cómo se están trabajando en nuestra comunidad las decisiones clínicas en las diferentes fases del proceso de ictus.
- Reflexionar sobre aspectos positivos que aportaría este modelo de atención, así como las barreras existentes y las herramientas necesarias para llevarlo a cabo.

Se van a realizar cuatro talleres, uno por cada una de las cuatro fases en que se ha englobado el proceso:

- Fase I Urgencias e ingreso**
- Fase II Ingreso en planta de neurología y alta hospitalaria**
- Fase III Tres primeros meses, inicio neurorrehabilitación y re contacto con neurología**
- Fase IV 3 meses hasta 1 año. Estabilización, mantenimiento y cronicidad**

En cada taller van a participar pacientes, familiares y profesionales, intentando llegar a un consenso para establecer unas conclusiones sobre las decisiones clínicas compartidas.

Lo acordado se trasladará al Congreso de Neurología que se va a celebrar en Pamplona el 30 de abril.

Decisiones clínicas compartidas

GUIÓN ENTREVISTA PROFESIONALES RELEVANTES ATENCIÓN ICTUS

DECISIONES CLÍNICAS COMPARTIDAS

- Hablemos de decisiones clínicas compartidas, ¿cómo definirías este concepto?
- ¿Qué cambiaría (aspectos positivos) si se tomaran de forma conjunta médico/
a- paciente/familiar?
- ¿Qué información es imprescindible para poder participar en esa decisión?
- ¿Qué barreras experimentas actualmente para una decisión compartida en esa
decisión?
- ¿Qué herramientas / metodología podrían ayudar a que la decisión fuera
compartida?
- En la fase de atención al ictus en la que tú desarrollas tu actividad, ¿crees que
es necesario cambiar el procedimiento pudiendo ser viable tener más en
cuenta la opinión del paciente, o de la de la familia?
- ¿Cómo describirías el estado emocional del paciente/familia en este momento?
- ¿Valoras que hay una demanda de paciente/familia de ser parte más activa del
proceso?
- ¿Qué información se da a los pacientes y/ o familias sobre los tratamientos?
- Recomendaciones para los grupos focales. ¿Qué aspectos te parecen más
relevantes para trabajar en los talleres sobre las decisiones clínicas
compartidas?



AUTORIZACIÓN IMÁGENES

NAVARRABIOMED-FUNDACIÓN MIGUEL SERVET, dentro de sus fines de investigación biomédica ha planificado la grabación de un vídeo de testimonios (profesionales, pacientes, familiares, entre otros) para dar a conocer el trabajo realizado dentro de la red europea ICTUSNET.

Estas imágenes se utilizarán en varios vídeos con finalidad formativa (material de trabajo en jornadas) y promocional, ya que tendrá como objetivo difundir los avances realizados en la red ICTUSNET. El material editado se dará a conocer tanto online como offline y las imágenes se conservarán en el archivo gráfico histórico de la Fundación. No está permitido el uso de estas imágenes fuera de este contexto.

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Sí autorizo

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Nombre y Apellidos _____ Con DNI. _____

Fecha: _____ y firma _____

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Begin page 37:

*[Image 1 translation:
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Key questions of each of the decisions valued by each group:

- In your experience as a patient/family member/professional, do you think that the decisions taken were shared?
 - Who do you think should have the main role in this particular decision?
 - Do you think there are/were any barriers that impede/are impeding the making of?
 - Which tools do you think may help to share the decision making?
 - What positive aspects do you think it could have to share the decision making from your perspective as a patient/family member/professional?
-
-

Phase I "Emergency room and Admission"

Date: February 25

Timetable: 4:00 PM to 6:30 PM

Location: ADACEN offices, Camino Zolina, s/n Mutilva

+ info: www.ictusnet-sudoe.eu

End]

*[Image 2 translation:
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WORKSHOP – DISCUSSION GROUP
SHARED CLINICAL DECISION-MAKING IN STROKE CARE

End]

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SHARED CLINICAL DECISION-MAKING

In clinical practice patients, family members, and healthcare professionals are continuously confronted with situations where they need to make a decision with different degrees of uncertainty related to either the diagnosis or therapeutic procedures.

The **shared decision-making process** allows the healthcare professional and the patient to participate jointly in agreements related to a health decision after discussing the options, risks and benefits, value considerations, and preferences and circumstances surrounding the patient. The patient and/or their family member make an agreement with the doctor about the treatment choice or lifestyle modifications that will benefit the patient the most, in accordance to the scientific knowledge available as well as the preferences and personal values of the individual, viewing each option's risk and benefit from their own personal perspective. This allows the patient to take a more active role in their disease management. It is not only an extra step to be added to the doctor's visit, but it is a process, a cultural change and the most effective way to establish relationships that can be used in every healthcare related decision, including exploration procedures, treatment, and hospitalization options.

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OBJECTIVES

- To know how the clinical decisions are being made during the different phases of strokes in our community.
- To reflect about the positive aspects that this care model may bring, as well as the existing barriers and needed tools to overcome them.

There are going to be four workshops, one for each of the phases framed by this process:

Phase I Emergency room and Admission

Phase II Admission to the neurology ward and hospital discharge

**Phase III First three months, beginning neurorehabilitation and
reconnection with neurology**

Phase IV Three months up to one year. Stabilization, maintenance and chronicity

Patients, family members, and healthcare professionals will participate in the workshops to try to reach consensus about shared clinical decision-making.

The agreements and conclusions will be presented at the Neurology Congress to be held in Pamplona (Spain) on April 30.

End]

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Begin page 38:

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Shared clinical decision-making

GUIDE FOR INTERVIEWING PROFESSIONALS

STROKE CARE

SHARED CLINICAL DECISION-MAKING

- Let us talk about shared clinical decisions. How would you define this concept?
- What would change (positive aspects) if the decision was being made jointly between the doctor and the patient/family member?
- What information is key to participate in this decision?
- What obstacles are in the way of making this decision a shared one?
- What tools/methodology may help make this a shared decision?
- In the stroke phase that you are responsible for, do you think that is necessary to change the procedure so that the opinion of the patient/family member's is taken into consideration?
- How would you describe the emotional state of the patient or family member at this moment?
- Do you value that patients and/or family members want to take a more active role in the process?
- What information on treatments is given to patients and/or family members?
- Recommendations for focus groups. What do you think is an important topic to discuss during the workshops about shared decision-making?

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IMAGE RELEASE FORM

The NAVARRABIOMED- MIGUEL SERVET FOUNDATION, has planned as part of its biomedical research goals, the recording of testimonial video(s) (of professionals, patients, family members, among others) to share the work done within the European ICTUSNET network.

These images will be used in various videos for training (used as conference material) and promotional purposes as it aims to broadcast the progress made in ICTUSNET. The edited content will be shared both on and offline and the images will be preserved in the Historical Graphic Archives of the foundation. Use of these images outside of this setting is not authorized.

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Full names and surnames _____ with ID nº _____

Date: _____ and signature _____

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End]

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