Communicating with patients who can´t speak

People with complex communication needs

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Content of my lesson today, 2 hours

- Patients with severe communication disorders who use Augmentative and Alternative Communication methods (AAC)

- The important role of the communication partner when communicating with people with severe communication disorders
The goal of your work as medical doctors is

A satisfied patient who got help and feels that you have listened to him/her

The goal is not:

A dissatisfied and unhappy patient who feels that he/she couldn´t communicate with you
What is the first thing a doctor does after shaking hands with the patient and asking him/her to sit down?

- Takes an anamnesis
- Asking questions
What if the patient has severe communication problem, does not understand you fully or is not able to speak?

Now I do not mean deaf people.
We have to look a little bit what communication is
What is communication?

- We have a **sender** and a **receiver**
- They need a **common channel** (usually auditory) and **communication method** (usually speech)
- The **receiver reacts** to the message and either expresses his/her own message or asks for more clarifications
- The **sender has to check** if his/her message has been **understood** and change the message or give more information if it has not been understood
Communication chain when we use speech

**The sender:**
Formulating the thought in to language

**The receiver:**
Interpreting the meaning of the message we have heard

Picture from Anders Nygård, revision and free translation to English Pirkko Rautakoski
In the brain we plan

- What we want to say
- How we want to say it
- With which words and grammatical constructions we want to say it

We plan also
- The motoric movements we need to be able to speak out the message
- We use hundred muscles when we produce voice and articulate the words in our expression
In the brain we also interpret the meaning of the message we have heard.
What makes it possible to change our ideas/thoughts into speech and to understand other’s speech?

- The answer is:
  The development of the language as a child
Typical language and speech development has 3 prerequisites

A. Biological prerequisites
B. Cognitive prerequisites
C. The social ground of the language (interaction)
Biological prerequisites

= The development of the brain

- The nervous system develops and matures
- The information perceived through different senses, the child’s experiences and his/her actions generate connections between neurons (synapses)
- Auditory stimuli are important for the development of speech and visual stimuli for the development of visual language (e.g. sign language)
- The auditory perceptions mature with age in children
The relationship between language and speech

**Pragmatics:**
How the language is used in interaction in different situations.

**Speech, signed message, a message expressed with pictures or symbols:**
The linguistic expression in a mode that can be heard or seen.

**Language ability:** Internalized ability in the neuronal network
- The knowledge of the sound system (phonology)
- The knowledge of the meanings of the words (semantics)
- The knowledge of the grammatical rules (syntax)

When this knowledge has developed we can express our thoughts linguistically and understand other’s expressions.

**In addition:**
- Our inner speech directs our actions
- We use language to structure/discern our world
Patients with severe communication disorders

- There are **children** with whom language and speech development does not proceed typically and they need other communication methods.
- There are **children and adults** who have motoric coordination difficulties (e.g. CP) which make it impossible to speak.
- There are **adults** who lose their ability to speak because of some neurological diseases and they need other communication methods.
Who are they?

For example some children with:
- Motoric disabilities (like cerebral palsy)
- Specific language impairment (SLI)
- Autism spectrum disorders
- Intellectual disabilities
- Certain syndromes
- And multiply disabled people

Some adults with acquired disorders like:
- MS, ALS (SLA), Anarthria after stroke
- Aphasia
- Dementia
- Other neurological diseases…
They need Augmentative and Alternative Communication methods (AAC)

AND

certain support from the communication partner
Three different groups of AAC users (von Tetzchner & Hygum Jensen, 1996)

**Group A:**
They can hear and understand speech well but they need AAC to be able to express themselves
(e.g. patients with ALS, MS, severe CP)

**Group B:**
They can understand and produce some speech but need also another communication method to support their speech
(e.g. children with SLI or intellectual disabilities,
e.g. adults with aphasia)

**Group C:**
They need AAC both to be able to understand others and to be able to express themselves
(e.g. some persons with autism spectrum disorders)
Definition of Augmentative and Alternative Communication (AAC)

- ASHA 2002:

  AAC is, foremost, a set of procedures and processes by which an individual's communication skills can be maximized for functional and effective communication (both production as well as comprehension).

If the acoustic level is not working well it helps if we add the visual level (make the speech “visible”)

We can also modify the acoustic level, how we speak, to be more understandable
Total communication: The use of different communication methods

- Speech as much as possible
- Writing if possible. Maybe beginnings of words
- Drawing if possible
- Gestures, signs
- Individual communication books
- Extra material
Two kind of AAC methods

A. **Unaided communication methods**
   - Require only the body to produce:
     Manual signs, fingerspelling, gestures

B. **Aided communication methods**
   - Require some type of transmission device:
     Tangible objects, picture communication symbols,
     line drawings, Blissymbolics, symbol boards,
     symbol books, technical devices
Acquired communication disorders

= Communication disorders after language development
It is important to distinguish if the person has

A. Only expressive difficulties, difficulties in speech production (can understand speech well)

OR

B. Difficulties on language level (both receptive and expressive difficulties, difficulties both in comprehension and speech production)
Difficulties only in speech production, dysarthria/anarthria *(now we are talking about adults)*

- Usually no difficulties in understanding speech
- The cause is neurological:
  - stroke (for example Locked in syndrome)
  - brain injury
  - brain tumour
  - Parkinson's disease
  - Amyotrophic lateral sclerosis (ALS)
  - Huntington's disease
  - Multiple sclerosis (MS)
  - …
Because people with dysarthria/anarthria often have only expressive problems but not problems in the use of language, they can use communication methods, which are based on writing.
Without technical devices

Paper and pencil

Alphabet boards:
The letters can be pointed out for example with a finger or a gaze
Technical aids for writing

- LightWriter (different models)
- Computer (different techniques to use the keyboard: with fingers, gaze, switches)
- Mobile phones SMS
- Tablets and smartphones

Aids that scan the alphabets:
- Different kind of switches to stop the scanner when the right letter has been found
- First the right row and then the right letter on that row
The ”auditory scanning” of alphabets

- The communication partner lists alphabets aloud and the client gives his/her answer when he/she hears the right alphabet
  - The alphabets are not in the order of A, B, C… but according to the frequency in the language in question (the most frequent letter first, second, third…)
Le scaphandre et le papillon
The Diving Bell and the Butterfly

- Jean-Dominique Bauby, chief editor of Elle magazine, got a Locked-in syndrome 1995
- The only part in his body he could move was his left eye
- His speech therapist developed a communication system for him, Alphabetical scanning (a sort of writing):
  - The partner lists alphabets aloud and he blinks his eye when he hears the right alphabet
  - The partner starts to list the alphabets again from the beginning etc. . .
- 1997 his experiences were published as a book
- https://www.youtube.com/watch?v=sQuMsz480xk
- https://www.youtube.com/watch?v=Obwa8DVCSY8
In addition we can use

- Ready made word lists
  - in books, boards, folders, computers
  - often there is lack of space > only the most important words have space

- Ready made sentences
If the disorder is on the language level

- The person has difficulties to express him/herself with speech
- The person may have difficulties in understanding other’s speech
- It can be difficult to write and read
This is the case for example if the person has severe aphasia caused by stroke.
Aphasia

- A damage in the brain tissue in adults can cause aphasia (after the language has been learned)
  - Difficulties to express oneself with speech
  - Difficulties to understand speech
  - Difficulties to read and write
  - Possibly also difficulties in mathematical abilities

  - Intellectual abilities are in general normal although the person can not express his/her thoughts with speech

  - Makes it difficult to be in interaction with others and to participate the social life
Different types of aphasia according to where the damage (usually) in the left hemisphere is (rough division)

In addition: Damages in the tissues under the cortex can cause different kinds of aphasia symptoms
We can change the environment for people with physical disabilities

- We can build ramps and have lifts
What is the ramp or a lift for a person with communication difficulties?
1. **Functional communication** and the use of Augmentative and Alternative Communication methods (total communication)
   (Davis, 2005; Davis & Wilcox, 1985; Holland, 1991; Hopper, Holland, & Rewega, 2002)

2. **Training of communication partners to be able to support communication**
   (Simmons-Mackie, Raymer, Amstrong, Holland, & Cherney, 2010; Simmons-Mackie, Savage, & Worrall, 2014)

3. **Building aphasia-friendly environments**
   (Howe, Worrall, & Hickson, 2004, 2008; Worrall et al., 2005)
Factors in the environment people with aphasia experience to **hinder** their participation

- Negative attitudes of other people
- People do not know what aphasia is
- If the communication partner’s speech is difficult to understand

(Howe, T., Worrall, L., & Hickson, L., 2008)
Factors in the environment people with aphasia experience to facilitate their participation

- If the conversation partner understands the situation the person with aphasia has
- If the conversation partner gives enough time for the person with aphasia to express himself/herself
- If the conversation partner can support the communication of the person with aphasia
  
  (Howe, T., Worrall, L., & Hickson, L., 2008)
Total communication: The use of different communication methods

- Speech as much as possible
- Writing if possible. Maybe beginnings of words
- Drawing if possible
- Gestures, signs
- Individual communication books
- Extra material
The communication partner can write alternatives

- The communication partner writes alternatives on a paper (words, numbers, years etc.)
- There should always be an alternative “Something else”
- The communication partner reads the alternatives aloud while pointing them (it is possible that the patient can not read because of aphasia)
- The patient points his/her answer
- Circle the pointed answer to verify that you have understood right (Kagan, 1998)
Simon without and with help from the communication partner:

https://www.youtube.com/watch?v=KWVoqM9jmEM
The main principle with people with aphasia is to make the speech visible.
Severe aphasia can mask competencies normally revealed through conversation

(Aura Kagan)

These competencies can be revealed by supporting the communication of people with aphasia!

One example of partner training is Supported Conversation for Adults with Aphasia™ (SCA) (Kagan, 1998)
When communicating with a person with aphasia the partner should... (Aura Kagan)

A. Acknowledge the competence of person with aphasia
   • “I know you know.”
   • Use of humour, adult like conversation

B. Reveal his/her competence
   • Ensure that he/she understands (speak slower, use gestures, use no complex language)
   • Ensure that she/he has a means of responding (write words and numbers, draw pictures, use extra material the person with aphasia can point his/her answer)

C. Verify that both have understood
   • To do summaries now and then what we have understood
Training the communication partners has shown positive results

- A systematic review of published studies indicate that training the partner improves communication activities and/or participation of people with aphasia (Simmons-Mackie et al., 2010)
WHO (2001)
International Classification of Functionality, Disability and Health (ICF)

Health Condition
(disorder/disease)

Body function & structure (Impairment)

Activities (Limitation)

Participation (Restriction)

Environmental Factors
Barriers/Facilitators

Personal Factors
Barriers/Facilitators

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The social model concentrates especially on Participation and Environmental aspects of the ICF

Health Condition
(disorder/disease)

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(Impairment)

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Biopsychosocial model of ICF

- ICF is a combination of the medical and the social model

- ICF offers a perspective that refers to health condition from biological, individual and social perspective

- Important part of ICF is Participation / Partecipazione

- If people with severe aphasia are included in or excluded from conversation depends on the attitudes, behaviour and communication abilities of the other persons.
Aphasia is very often chronic. 
Like people with diabetes have to get their daily insulin the people with aphasia need continuous support in their communication.
You can use same techniques also

- With people who do not speak Italian so well
Thank you for your interest 😊