Supported communication for access and participation

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Supported Communication to Improve Participation in Rehabilitation of people with moderatesevere aphasia after a first stroke: a pilot study (SCIP-R)





The NHS working in partnership with education: Cambridge University Hospitals NHS Foundation Trust NHS Norfolk | Norfolk Community Health & Care NHS Trust

Overview

- Communication / conversation in day-to-day life
- Doing speaking & listening: the speech chain
- Speech, language and communication impairments after stroke
- Supporting communication for people with aphasia
 - Key issues, impact & strategies
 - All about the person
 - The environment
 - Supporting understanding
 - Supporting expression
- Supported communication: resources & skills
- Putting it into practice

Learning outcomes

- After the preparatory session and practical skills training you will have
 - Furthered your understanding of the role of communication/conversation in daily life
 - Updated your knowledge of post stroke communication impairments
 - An understanding of the principles & practice of supported communication
 - Developed insights into your own supported communication skills & implementation in practice

Communication / conversation in dayto-day life

- Central to our lives as social beings
- Making and sustaining relationships
- Expressing and sustaining social identity
 - Language group / dialect / accent
 - Emotional expression, attitude etc
 - Role & identity
 - Status & 'life history'
- Informing others and being informed: messages in / out

The speech chain...or from here to ear...and back

- Messages out
 - Selecting words to express meaning
 - Sentences putting words in order
 - Producing speech respiration, voice, resonance, articulation
- Sound waves travel through the air
- Messages in
 - Hearing
 - Auditory perception
 - Comprehension decoding the speaker's message
 - Interpreting meaning









Conversations are collaborations

- Co-operation in two-party conversations
 - Speaker speaks







Speaker makes sure listener understands

A: "I was there a week ago – I mean a week ago this Wednesday..."

B: "aha"

Listener makes sure s/he has understood

A: "I took the dog out for a walk"

B: "You mean that old collie of yours?"

A: "that's the one"



'Speech' vs 'language'

'Speech'

 Articulating words – co-ordinated efforts of breathing, voice, tongue, lips etc

'Language'

- Symbols representing objects, actions, ideas, emotions, qualities etc
- Includes all modalities: speaking, listening, writing, reading, gesture (i.e. sign languages)

Speech, language and communication impairments after stroke

Impact of nervous system pathology on

- Language
- Motor control (e.g. voice, articulation, breathing)
- Cognition, including attention, memory etc
- Special senses (i.e. vision, hearing)
- Social communication

Speech, language and communication impairments after stroke (cont)

Aphasia

- Many different forms; may affect any modality (i.e. spoken language, writing etc)
- Certain types may co-occur with apraxia of speech

Dysarthria

Different forms according to site of lesion(s) and organs involved

Dyspraxia

Oral dyspraxia; apraxia of speech

Pragmatic or cognitive communication disorders

Use of speech/language in conversation

Aphasia: impairments

Different types according to site/s of lesion

- Expressive e.g. Broca's aphasia
 - Word-finding difficulties, but preserved understanding
 - 'Struggles' with forming words e.g. apraxia of speech
- Receptive e.g. Wernicke's aphasia
 - Fluent but 'empty' speech; comprehension difficulties; self-monitoring may be poor
 - Severe comprehension difficulties and no / reduced speech output
- Mixed aphasia, including difficulties with reading, writing, gesture etc

People with aphasia may "communicate better than they speak" (Holland, 1977)

- Social 'rules' of communication preserved e.g. turn-taking; 'repairing' problems; being informative etc
 - Question-Answer; Offer-Acceptance etc
 - Invites completion (of word; of turn etc)
 - Use of word + gesture + intonation
- Use of non-verbal communication e.g.
 - Facial expression
 - (Symbolic) gesture
 - Intonation
 - Vocal non-verbal expression

Why 'supported communication'?

- Many barriers to access and participation
- Aphasia may mask 'competence'
 - May be hard to see 'the person' / the active mind / the capacity
 - Importance of "I know that you know"
 - A person's decision-making capacity may be questioned / person may be 'excluded' from discussions or decisions
 - A person may be treated as a child
- Competence can be revealed by
 - Awareness of barriers
 - Skilled communication partners

Communication in context: rehabilitation activities

- Therapy / care activities
 - Case history; assessment; doing therapy etc
- Understanding instructions / explanations
 - What has happened; what this means etc
- Day-to-day choices
 - Menus; comfort (e.g. bed / chair); pain relief etc
- Keeping in touch with people: reducing social isolation
 - Family; friends; staff; other patients
- Key decisions
 - Discharge destination; medication etc
- Family meetings: being meaningfully involved

All about the person

Key issues	Impact
The lived experience not acknowledged: lack of awareness and focus on the person	Feels isolated Validity of experience not acknowledged May not feel valued
Having to re-learn many things Abilities not known Not known as a person	Low confidence & self-esteem May feel 'useless': own competence in doubt / unacknowledged May feel disorientated & uncertain May feel unsupported / left out
Feels anxious / frightened Depression / emotional reactions Low mood	Withdraws / does not want to engage or try things Barrier to participation & progress

All about the person (cont.)

Key issues	Impact
Feels embarrassed / shy about communication	Doesn't want to communicate / participate in activities Gives up Becomes withdrawn
Cannot communicate feelings, needs, wishes, decisions	Frustration and emotional upset
Not ready to take things 'on board'	Barrier to participation & fulfilling potential May restrict rehabilitation progress
Individual personal factors e.g. variability in health / well-being; effects of time of day etc	Time and effort for staff to accommodate individual needs

The lived experience not acknowledged: lack of awareness and focus on the person



Acknowledging the person's lived experience



All about the person: strategies for staff

- "imagine being..."
- Treat the person as trustworthy, interesting and sincere
- Acknowledge the person's lived experience
 - Empathise: be open to the person's point of view & show you understand; help people feel included
 - "I understand it must be very confusing / frightening / frustrating etc"
- Take an interest in the person ('This is me')
 - Get to know them (bit-by-bit) & build a relationship
 - Find out about their abilities / difficulties
 - Learn from the person, colleagues, family etc

All about the person: strategies for staff (cont.)

- Accommodate individual needs
 - Give people a sense of importance and a feeling of being looked after
 - Attend to the person's environment be flexible (e.g. 1:1 rather than group; take time out etc)
- Help lift their mood
 - Encourage appropriately: help people to know how to try
 - Help them cope with the present
- Hard for staff "but ten times harder for the person with aphasia"
 - Share the work of communication

The environment

Key issues	Impact
Noise	Trouble concentrating
 People talking (too loud) Noise of TV, radio, music, Hoovers etc 	Trouble understanding / making oneself understood
	Feeling disorientated
	Feeling disrespected
	Feeling angry
Being in a 4 – 6 bedded bay	Staff / patient / relatives chatter
	Talking about others within earshot
	Companionship, mutual support, 'modelling'
Being in a side room	Isolation

Noise, interruption & the mobile



The environment: strategies for staff

- Be aware; be respectful
- Think about confidentiality
- Turn down the volume / turn it off
- Ask people to be quiet(er)
- Create quiet conditions e.g. 2-3 people in a group
- Go elsewhere e.g. side room; outside etc
- Mutually supportive (group) vs privacy

Supporting understanding

Key issues	Impact
Staff do not know person's level of understanding Trouble understanding • Activity / questions / statements etc not contextualised	 Disempowerment Not able to take an active role Not included in decision-making Does not benefit; progress slowed Frustration, disorientation, anxiety Staff unable to help / support – feel frustrated and helpless
Lack of focus on the person	Person feels excluded / not valued
Talking to others & not the personOther staffFamily members	Important issues / information may be missed
Environmental barriersNoise, lighting etc	Distraction for person and staff
Personal barriers • Pain, discomfort etc	Person cannot concentrate / engage

Supporting understanding: strategies for staff

- Get to know the person's strengths and difficulties
 - Ask colleagues; listen / observe; find out what works best
- Use environmental / contextual clues
 - Who are you?
 - Name and role
 - Objects; familiar photos etc
 - Demonstrate / model activity / gesture etc
 - Put into context: "You remember the other day..."

Supporting understanding: strategies for staff (cont.)

- Concentrate on / address the person
 - Remove / avoid distractions; check source of distraction (e.g. pain, discomfort etc)
 - Eye contact: focus and watch the signs
- Quiet
 - Cut out noise
 - Go to side room; leave the group; 1:1 etc
 - Reduce 'overload'
- Information in manageable chunks
- Always check understanding

Supporting explanations



Supporting expression

Key issues	Impact
Cannot find words / ways to express self Message is not understood / not clear	Person is disempowered / excluded Frustration Staff are anxious / uncertain
 Not supported Unable to finish the message Unable to make use of resources (e.g. pictures; symbols; ABC s etc) 	Frustration Lack of participation Distressing for staff and person with aphasia; pictures etc can seem childish
Variability / uncertaintyYes / no confusionAbilities change from time-to-time	Staff uncertainty Person is unable to convey needs, feelings, decisions etc

Disempowered and excluded



Supporting expression: strategies for staff

- Acknowledge the difficulty
 - Take / share responsibility "sorry I'm being so thick..."
 - Take time to keep trying
 - Stay calm / relaxed
 - Persevere: be prepared for trial & error; be prepared to 'park' the issue and come back later
 - Importance of arriving at an understanding (rather than 'correct' talk)
 - Use humour appropriately
- Don't make assumptions
 - Establish clear Yes / No
 - Check (but don't bombard with questions ask one question at a time)

Supporting expression: strategies for staff (cont.)

- Create time & space
 - Check for environmental / personal barriers
- Get to know the person's strengths and difficulties
 - Ask colleagues; listen / observe; find out what works best
 - Be responsive to the person's skills
- Provide resources and encourage to use alternative means
 - Always have pen / paper to hand

Attending, exploring, supporting



Resources for supported communication

Issue	Resources
People with aphasia cannot be rushed	Take time – reassure him / her you will take time to listen
	Come back later
	Build a trusting relationship: the person feels valued
Words are fleeting / inaccessible	Pen & paper – make a record; share use of resources if you can
Aphasia is unseen / unacknowledged	Stroke & aphasia card
Not knowing the person or their abilities / difficulties	 Family members / colleagues ('champions') • Information on biography • Communicative approaches – learn from each other's expertise Interpret/reassure but not talking for

Resources for supported communication (cont.)

Issue	Resources
Barriers to verbal communication	Objects / photos etc in the immediate environment Pen / paper – writing / drawing Alphabets Pictures; symbols Newspapers, magazines etc Calendars Maps; diagrams Personal items; 'This is me' – meaningful resources Gesture
Environmental barriers	Plan for interactions / meetings Attend to physical spaces

Skills for supported communication

Issue	Skills
 Gaining and focussing attention Ensure you fully capitalise on the person's abilities 	Remove distractions (noise etc) Be well positioned Use focussing talk ("OK, now we were going to talk about") Signals (facial expression; gesture etc)
 Quality of your talk Speed of your talk / delivery: too fast for the person to follow Inappropriately loud voice Talks too quickly / mumbles Chatters (distracting) 	Slow down your talk Introduce gaps (chunking) One question / statement at a time Give time Focus on the most important thing Don't distract with 'asides'

Skills for supported communication (cont.)

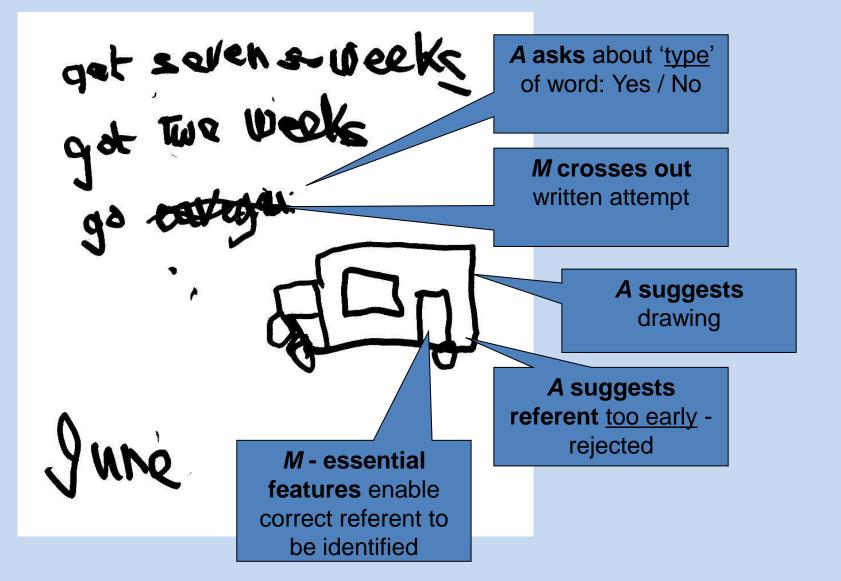
Issue	Skills
Quantity of your talk: giving information • Too much at a time • Too involved / complex / technical	Chunk talk / information – break up with pauses or 'markers' Check understanding – repeat & rephrase as necessary Be aware of word choice (technical terms; acronyms etc) Show; demonstrate; model Give as many clues as possible Support verbal communication • Write down (as appropriate); read out / refer back • Use diagrams / pictures / communication book etc • Use 'visual punctuation'

Skills for supported communication (cont.)

Issue	Skills
 Quality of your listening Not paying attention or listening carefully – distracted Not attending to the message Not supporting adequately 	 Give time and (create) opportunity Environment Eye contact Observation (non-verbal behaviour – intonation; facial expression etc) Show you are listening Offer a range / combination of strategies – share modes Summary & suggestions (checks)
 Respectful communication Acknowledge difficulties and competence Interpret messages as communicative 	Use empathy / person-centeredness Feed back your understanding / interpretation (where there is doubt) Avoid a 'teacherly' manner – accept, don't evaluate Humour as appropriate

Resourceful communication





Practical exercise 1: role play

- In pairs threes, find out / convey biographical information about e.g. yourselves, family, place of birth etc etc
- RULES
 - No speech
 - No writing of words
 - DRAWING
 - NUMBERS
 - GESTURE, NVC only

Practical exercise 2: face-to-face training

- Each person in 1:1 conversation with communication partner trainers e.g.
 - A is with 1st trainer (20 mins) including feedback
 - A is with 2nd trainer (20 mins) including feedback etc etc
- Find out about the person e.g. background, history, family, occupation, interests etc
- Tell them about yourself and your role e.g. provide an explanation about something to do with your job; stroke care etc

Face-to-face training feedback

At the end of the 15 minute session you will be asked to

- Consider what went well
 - Use the feedback sheet to discuss Skills and Resources
 - Trainer discusses these points and emphasises positive aspects
- Consider areas to work on
 - Use the feedback sheet to discuss Skills and Resources.
 - Trainer discusses these points and indicates two key aspects to improve for skills and resources
- Trainer gives overall score
- Trainee puts 'aspects to work on' into practice in second conversation session

Resources for day-to-day practice

- On the ward
 - Handy pack: key pointers / reminders / basic symbols etc
 - Learning logs
 - A monthly reflective record of your experiences using supported communication e.g.
 - Responding to the person
 - Supporting understanding and expression
 - Supporting participation etc
 - Indentifying the need for additional support or training

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