Can neuroscience help families adjust to the psychological impact of stroke and aphasia?

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Issues for Families
‘Lost at Sea’

- Shock
- Grief (complex as grief for losses related to a living person)
- Blaming Self (especially if not there when stroke happened)
- Aphasia/ communication issues
- Practical issues (child care, employment, housing issues, financial implications, care packages)
- Issues for children of the survivor especially when dependent
- Relationship and sexual issues
- Power dynamics within family life
- Mobility issues – hoist/ wheelchair use
- Separation due to need for SLS/ nursing care
- Relationship breakdown
Finding a Way Together…
Through the Experience of Hospital

- Strong collaboration in multi-disciplinary team
- Speech and Language and Psychotherapy sessions combined
- Physiotherapy and Psychotherapy together
- Psychology and Psychotherapy work alongside each other
- Time off ward – restoring a sense of normality/ connection
- Counselling group – breaking the isolation and shame
- Collaboration with Spiritual services
- Psychotherapy with family members
- Preparing the person practically, physically, emotionally, psychologically and spiritually for discharge
- Features of a Therapeutic Community Approach
Finding a Way Together….
Therapy at Home

- Reduce length of hospital stay and readmission
- Aim to visit at home within 48 hours discharge
- Intervention lasts 6 – 12 weeks
- Physiotherapist/ Occupational Therapist/ Speech and Language Therapist/ Therapy Assistant/ Psychotherapist
- Patient -centred approach to goal setting
- Community visits
- Confidence Building
- Adaptations to the home
- Psychotherapy with the survivor and/ or family
- Linking with other services
Uncertainty
Being lost at sea

• Uncertainty is psychologically one of the most difficult things for human beings to endure
• Stroke and recovery are highly individual experiences
• Family circumstances, pre-morbid health are factors
• Physical impairment (i.e. incontinence, loss of ability to speak and mobilise) can bring up early attachment issues
• Previously no clear markers around how recovery will progress
• PLORAS research could act as a ‘bouy in the water’ by providing a clear predictive pathway around recovery from aphasia
Impact of aphasia on families

• Around 150,000 people have a stroke every year
• 50,000 survive with aphasia

(Stroke Association, 2013)

• Caregivers of aphasic stroke patients are more stressed, with symptoms of depression, loneliness and other emotional problems than caregivers of non-aphasic stroke patients.

• Their overall adjustment to the stroke is poorer and they experience greater role changes.

(Draper at al. 2007)
Predicting Language Outcome and Recovery After Stroke (PLORAS)
Who are we?

Neuroscientists, Neurologists and Speech and Language Therapists.
Where are we?

Wellcome Trust Centre for Neuroimaging

Queen Square

London
Our experience as clinicians

Stroke survivors and their families want to know about aphasia:

Will it get better?

How long will it take?

How much better?
Our goal for the future

To give future people with aphasia, their families and healthcare professionals a prediction about:

- How much language the person is likely to re-gain.
- How long this is likely to take.
- Each prediction shows the level of confidence.

E.g. 80% of people with the same stroke site as you recovered their language within 5 years.
How do we do this?

We use MRI scanners to see how the brain looks after a stroke and find the area(s) of damage.
We assess areas of language: speaking, understanding, reading and writing.
For **hundreds of patients** we find the **link** between:

- Exact stroke site
- Language score
- Time post stroke
We look for **patterns in recovery** by **grouping** together people with **matching areas** of damage.

Speech production scores for 53 patients with **extensive damage** to **critical sites** for speech production:
Speech production scores for patients with **minimal damage** to **critical sites** for speech production:
Speech production scores for patients with partial damage to critical sites for speech production are falling within the normal range in around 5 years.
Where next?

So far we have included nearly 600 volunteers who have had a stroke.

We are always looking for more people to take part.

This is because there is a lot of variety in:

- **Combinations** of brain areas damaged.
- **Time** since stroke.

The more people included, the more patterns we can find.
What does it mean for stroke survivors and their families?

- Answers
- Hope
- Plan for the future
- Inform therapy
- Goal setting

Plan for the future
Contact details

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Website: www.ucl.ac.uk/ploras

‘Like’ our Facebook page: Predicting Language Outcome and Recovery After Stroke

Follow us on Twitter: @PLORASResearch
Support networks

Stroke and aphasia

• Different Strokes: http://www.differentstrokes.co.uk/
• The Stroke Association: http://www.stroke.org.uk/
• Connect: http://www.ukconnect.org/
• Speakability: http://www.speakability.org.uk/

Counselling and wellbeing

• Mind: http://www.mind.org.uk/
• Relate: http://www.relate.org.uk/
References


Thank You!
Any Questions?
Additional slides
Ingredients for predictions

Precisely matched stroke areas

+ Similar scores on language tests

+ Clear effect of time post stroke

= can predict scores in new patients
Individual patient prognosis

Black band = The width of the band predicts the precision of the prediction.

Red circles = measured score in one new patient

Person A

Speech production score

Time since stroke (0 -10 years)

Precise prediction

Person B

Speech production score

Time since stroke (0 -10 years)

Imprecise prediction
Where is therapy in all this?

The key is that everyone is improving: we don’t know what the contribution of therapy is (yet!)

There is a huge range in the amount of therapy people included in the study have had and we are collecting data on this

The fact that our predictions are not perfect i.e. 100% means that other factors (not just lesion) are contributing – therapy may well be one of these
Relevance for intervention studies

Does intervention accelerate the expected time course of recovery?

Precise prediction

Imprecise prediction

Speech production score

Time since stroke (0 -10 years)

Time since stroke (0 -10 years)