Cognitive stimulation group: An Exploration of a successful Intervention with people with Huntington`s Disease.

Presenters:
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Rizwana Haneef, SLT Technical Instructor
Rosanne Tyas, Music Therapist
Huntington’s Disease (HD) - what is it?

- Genetic neurodegenerative disorder that affects **physical**, **psychiatric** and **cognitive** functioning
- **Prevalence:** Approximately 4-10 per 100,000 (Paulsen, 2011)
- **Typically diagnosed in mid-adulthood** but individuals can become symptomatic at any age (Myers, 2004)
- **Typical disease duration** of 15-20 years (Walker, 2007)
- 50% chance of inheriting the condition
Triad of Impairment

Physical:
- poor balance
- dystonia
- chorea
- rigidity

Psychiatric:
- challenging behaviour
- impulsivity
- irritability
- depression

Cognitive:
- initiation
- memory
- attention
- processing
- planning
- insight
- problem-solving

HD
Cognitive difficulties in HD

- **Cognitive changes** already in the prodromal stage of HD (could be decades before motor diagnosis).
- **Early signs:** emotional recognition difficulties, changes in time perception, speed of processing, and olfaction.
- **Judgment,** attention, executive functions, awareness and perceptual skills (space, emotions, time) typically affected.
- **Progression:** global deterioration and memory deficits, implicit memory in particular.
Communication difficulties in HD

- **SPEECH** – Dysarthria. Impacts on other people understanding what person saying.
  - Difficulty producing sounds with tongue, lips and palate.
  - Reduced coordination of breathing and using voice
  - Harsh/strained voice
  - Volume can vary
  - Lack of rhythm

- **COGNITIVE-COMMUNICATION**
  - Reduced understanding of complex/abstract info
  - Delayed response
  - Word finding difficulties & reduced vocabulary
  - Shorter and simpler sentences
  - Difficulty staying on topic
  - Repeating self/getting ‘stuck’ on a topic

- **SOCIAL INTERACTION**
  - Reduced body language, gesture, facial expression, eye-contact
  - Reduced initiation & attention
  - Agitation, frustration, irritability, impulsivity, behaviour
HD Service at RHN

• In-patient care
• Specialist assessment
• Therapeutic input from therapists specialising in HD
  • SLT, MT, Psychology, OT, PT, DT
• Management of challenging behaviours
• Management of complex physical, cognitive and communication difficulties
• Complex capacity assessments and supporting decision making/future planning
• Specialist clinics: e.g. respiratory, wheelchair, mealtime, tone and splinting
• Support for families
• Seamless discharge home/to alternative placement with a comprehensive management plan
• Long term residential placements
• Palliative care
What is cognitive stimulation?

Cognitive Stimulation Therapy (CST) is an intervention that offers a range of enjoyable activities providing general stimulation for thinking, concentration, and memory, usually in a social setting such as a small group.

Group CST is an evidence-based treatment designed through a systematic literature review of the non-pharmacological therapies for dementia. (2) This was followed by a pilot study conducted in 2003 by Aimee Specter et al. (1)
The Evidence Base

*Pilot Study

- Randomised Control Trial in 23 centres
- 201 participants with a diagnoses of dementia, randomly allocated to either CST group or a ‘treatment as usual’ control group

- Results: CST led to significant benefits in peoples’ cognitive functioning
  → As measured by the MMSE and the ADAS-COG
"People with mild / moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme. This should be commissioned and provided by a range of health and social care workers with training and supervision. This should be delivered irrespective of any anti-dementia drug received by the person with dementia".
Key Principles of CST

• Orientating people sensitively / when appropriate
• Information processing and opinion rather than factual knowledge -> implicit learning
• Multi-sensory stimulation
• Flexible activities to cater for group’s needs and abilities
• Using reminiscence (as an aid to here-and-now)
• Building / strengthening relationships
Rationale for CSG with HD

The Cognitive Stimulation Group (CSG) trialled on a specialist HD ward at the Royal Hospital for Neuro-disability (RHN) is based on the CST group programme (Spector et al., 2006 & Aguirre et al., 2012).

Even though the original programme was developed for people with dementia, CSG was hypothesised to be a suitable intervention for the HD patients at RHN due to the nature of the cognitive, psychological, and social difficulties they experience.
Aims

• Facilitate verbal expression and choice making.
• Encourage social communication.
• Encourage use of total communication approach.
• Facilitate naturalistic assessment of communication, cognition and functional ability.
• Assess for appropriateness of activities on discharge from hospital/during RHN placement.
• Improve mood and manage anxiety
• Increase wellbeing and quality of life through social inclusion.
Structure

The group runs once a week for 45 minutes in blocks of 8 weeks. The structure is loosely based on the manuals: ‘Making a Difference: An Evidence-based Group Programme to Offer CST to People with Dementia’ volumes 1 and 2 (Spector et al., 2006 & Aguirre et al., 2012).
Structure

- **Orientation**: discussion of the day, date, location, providing contextual cues and choices as appropriate.
- **Theme Song**: chosen by group members, providing a link between sessions.
- **Newspaper Article**: supported conversation of current affairs using article with simplified language, large text, and highlighted key words.
- **Main Activity**: see Figure 1 for sample topic.
- **Self-Rating Scale**: patients self-rate enjoyment using a visual analogue scale.
<table>
<thead>
<tr>
<th>Activity</th>
<th>Content</th>
<th>Ideas for facilitative techniques</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Topic: ‘Current Affairs: past and present’</strong></td>
<td>Recognizing and naming famous faces -Ordering from most current to oldest -Who do you prefer? Prompt for justification of opinions</td>
<td>- Show video clip of prime ministers through the decades - Use pictures of prime ministers/politicians - Pointing to choice of two - Phonemic cues for naming - Closed yes/no questions</td>
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<tr>
<td>Famous British political figures throughout history</td>
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<tr>
<td>Notable quotes from political campaigns and speeches</td>
<td>Match the distinctive quote to the figure who said it Who do you think said it? What do you think it means? Prompt for justification of opinions</td>
<td>- Print out large text of each quote - Pictures of campaign slogans - Ask patients who are able, to read aloud text - Offer visual/verbal/written choices of two; did x or y say this?</td>
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<td></td>
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<tr>
<td>Landmark political events- past and present</td>
<td>Do you remember what event this is? Where were you when it happened- did you watch it on the TV?</td>
<td>- Print out visual images of events e.g. Profumo scandal, ‘Brexit’ vote, coal miners’ strike, 7/7 bombings, Channel Tunnel completion</td>
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<tr>
<td><strong>Closing Sequence</strong></td>
<td>Patients self-rate enjoyment using a visual scale</td>
<td>- Use visual rating scale</td>
</tr>
<tr>
<td>Rating scale</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
# Record Form

**Wolfson Cognitive Stimulation Group – Participation and Activity Analysis**

<table>
<thead>
<tr>
<th>Name:</th>
<th>D.O.B:</th>
<th>NHS Number:</th>
<th>Date:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Communication skills</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initiates comments/topics</td>
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<tr>
<td>Appropriate social interaction (e.g. turn taking, appropriate language and topics)</td>
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<tr>
<td>Uses non-verbal communication (e.g. eye contact, gestures, facial expression, AAC)</td>
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<tr>
<td>Use of verbal communication (e.g. speech intelligibility, sentence length etc)</td>
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<td>Comprehension (e.g. following instructions, responding appropriately to conversation)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Cognition</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintaining arousal (e.g. alertness)</td>
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<tr>
<td>Speed of information processing (e.g. length of time before responds)</td>
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<tr>
<td>Maintaining attention (e.g. shifting attention between speakers/topics, distractibility)</td>
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<tr>
<td>Reasoning (e.g. justification of opinions)</td>
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<tr>
<td>Remembering information (e.g. recent events, past knowledge)</td>
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</tbody>
</table>
## Record Form

### Patient Name: ___________________________  NHS: ____________

**Orientated to person (e.g. name, family members etc.), place, time**

### Behaviour & Mood

<table>
<thead>
<tr>
<th>Level of...</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impulsivity</td>
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<tr>
<td>Agitation</td>
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<tr>
<td>Distress</td>
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<tr>
<td>Withdrawal</td>
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</tbody>
</table>

### Patient self-rating

<table>
<thead>
<tr>
<th>1 = Didn’t enjoy</th>
<th>2 = Neutral</th>
<th>3 = Enjoyed session</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of patient enjoyment</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

### Comments

Signed: ___________________________  Print: ___________________________  Designation: ___________________________  Date: ___________________________
Case Study

Patient: Older person with HD, female

Presentation:
- **Executive dysfunction** including impulsivity, reduced problem solving, reduced reasoning, disinhibition.
- **Cognitive rigidity.**
- **Perseveration** and **fixation** on ideas.
- Mild-moderate **dysarthria.** Communicating verbally.
- **Cognitive-communication** impairment
- **Challenging behaviour** including verbal & physical agitation,
Case Study cont. ...

Initially in the group...
- Difficulties with inhibition, talking over others, not considerate of other people.
- Jumping in to respond when comments/questions directed at another group member.
- Hostile towards other patients at times – e.g. hurtful verbal comments.

After 8 weeks of group sessions...
✓ Participated well in sessions, self-reporting enjoyment.
✓ Increase in ability to inhibit responses to allow others to participate with minimal prompts from staff.
✓ Actively supporting others in group.
✓ No further negative comments about/irritation towards other patients.
Benefits

Key areas of benefit to patients as observed by clinicians running the group:

• **Increased quality of life** through provided additional stimulation and opportunities for social engagement with others. 95% of ratings of enjoyment at the end of group sessions are 3/3.

• **Increase in spontaneous interactions** between group members, observed both in the group and on the ward setting.

• Some patients showed **functional gains** in behaviour/interaction.
What worked well...

• Patients engaged positively in the group.

• Skilled professional facilitation by staff - specific needs considered.

• Careful choice of topics and materials aided engagement.

• Consistent structure each week.

• Analysis sheets assisted in monitoring changes.
Challenges...

• Timetabling difficulties, irregularity of attendance.

• Would have been more beneficial to have the same cohort of patients each session.

• Varying needs and abilities of the patients.

• Initial preparation and documentation time consuming.

• Analysis sheet although useful needs adjustment.
Future directions

• Beneficial to use the same format in other wards in the hospital.
• An official pack of resources could be created for easier future facilitation.
• Can be recommended for use in other inpatient settings to aid maintenance of cognitive and social skills and provide pleasurable activity.
• Could the trial the CSG with other patient populations and collect data to establish effectiveness.
References


