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

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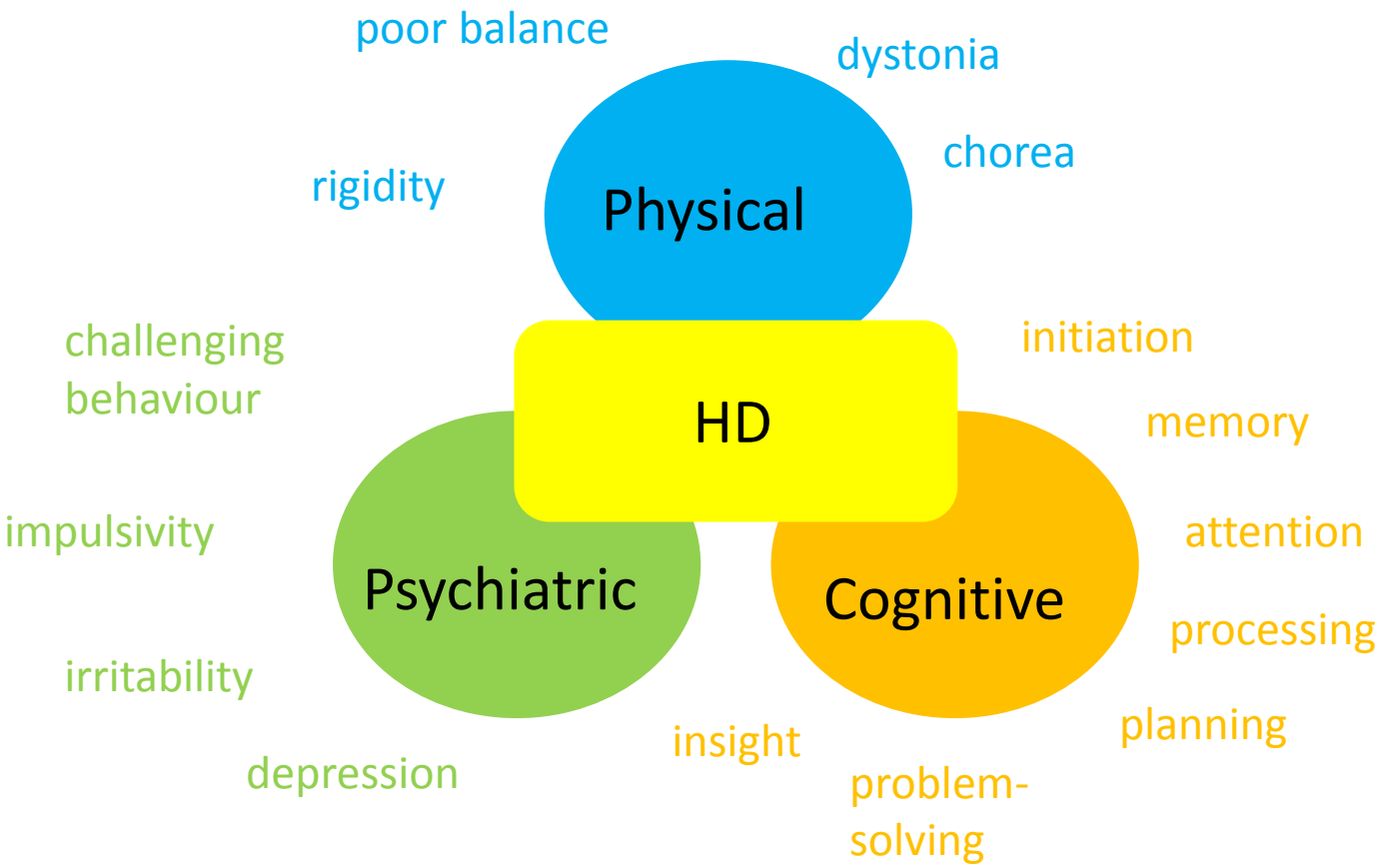
Huntington's Disease (HD) - what is it?

- 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



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

NICE Guidelines

The UK Department of Health NICE guidelines on dementia, 2006, state that:

"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 (4)

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).

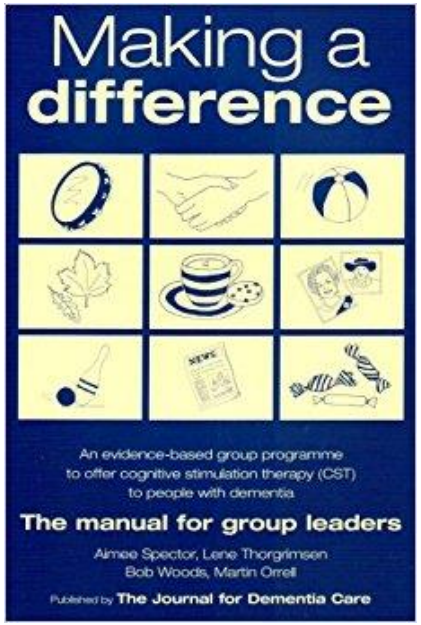
Even though the original programme was developed for people with dementia, CSG was hypothesised to be a suitable intervention for the HD patients at RHN due to the nature of the cognitive, psychological, and social difficulties they experience.

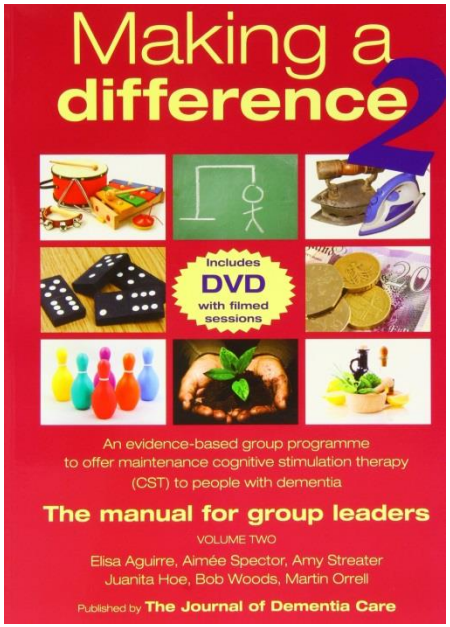
Aims

- 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.

Activity	Content	Ideas for facilitative techniques
Topic: 'Current Affairs: past and present'		
Famous British political figures throughout history	Recognizing and naming famous faces -Ordering from most current to oldest -Who do you prefer? Prompt for justification of opinions	- 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
Notable quotes from political campaigns and speeches	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	- 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?
Landmark political events- past and present	Do you remember what event this is? Where were you when it happened- did you watch it on the TV?	- Print out visual images of events e.g. Profumo scandal, 'Brexit' vote, coal miners' strike, 7/7 bombings, Channel Tunnel completion
Closing Sequence		
Rating scale	Patients self-rate enjoyment using a visual scale	- Use visual rating scale

Record Form

Version 3 – February 2017

TOPIC:

Wolfson Cognitive Stimulation Group – Participation and Activity Analysis

Name: **D.O.B:** **NHS Number:** **Date:**

Communication skills					
Scale: 1 = Extreme difficulty/unable; 2= Moderate difficulty; 3 = Minimal difficulty; 4 = Independent with no difficulty					
	1	2	3	4	Comment
Initiates comments/topics					
Appropriate social interaction (e.g. turn taking, appropriate language and topics)					
Uses non-verbal communication (e.g. eye contact, gestures, facial expression, AAC)					
Use of verbal communication (e.g. speech intelligibility, sentence length etc)					
Comprehension (e.g. following instructions, responding appropriately to conversation)					
Cognition					
	1	2	3	4	Comment
Maintaining arousal (e.g. alertness)					
Speed of information processing (e.g. length of time before responds)					
Maintaining attention (e.g. shifting attention between speakers/topics, distractibility)					
Reasoning (e.g. justification of opinions)					
Remembering information (e.g. recent events, past knowledge)					

Record Form

Patient Name: NHS:

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

Behaviour & Mood					
Scale: 1 = Extreme; 2= Moderate; 3 = Minimal; 4 = Not at all					
Level of....	1	2	3	4	Comments
Impulsivity					
Agitation					
Distress					
Withdrawal					

Patient self-rating				
1 = Didn't enjoy 2 = Neutral 3 = Enjoyed session				
	1	2	3	Comment
Level of patient enjoyment				

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.

Video

References

1. Spector A, Thorgrimsen L, Woods B, Royan L, Davies S, Butterworth M and Orrell M (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: Randomised Controlled Trial. British Journal of Psychiatry, 183: 248-254.
2. Spector A, Orrell M, Davies S and Woods B (2000). "Reality Orientation for dementia: A review of the evidence of effectiveness from randomised controlled trails." The Gerontologist, 40 (2), 206-212.
3. National Institute for Health and Clinical Excellence (2006). Dementia: supporting people with dementia and their carers in health and social care. NICE clinical guideline 42, November 2006. www.nice.org.uk/guidance/cg42
4. Aguirre E, Spector A, Streater A, Hoe J, Woods B and Orrell M (2011). Making a Difference 2. Hawker Publications: UK.