A HEARING VOICES GROUP FOR PEOPLE WITH LEARNING DISABILITIES

DR JOHN CHEETHAM
CLINICAL PSYCHOLOGIST, MHLD SOUTHWARK
Aims of today

1) What is a Hearing Voices Group?

2) Summary of the pilot Hearing Voices Group for People with Learning Disabilities.

3) Next steps
What is a Hearing Voices Group?
What is a Hearing Voices group?

- A space for exploration of personal meaning of experiences of hearing voices or seeing visions that others don’t hear/see.
- Space to share and understand what triggers the voices, and what helps.
- Peer support – I am not alone with this.
- Sharing the group’s expertise, not just ideas from ‘the professionals’.
Origins

- Patsy Hage, Marius Romme, & Sandra Escher
- Research continued by Romme & Escher and internationally. Shows consistent validity to the approach
- Which led to the Hearing Voices Movement
  - Hearing Voices Network
  - Intervoice
  - Soteria Network
Hearing Voices Movement Approach

- HVM understands voice-hearing as “a normal reaction to abnormal experiences”.
- Sees voice-hearing as relating to underlying difficulties and/or previous trauma, rather than biochemical illness or maladaptive perceptions/cognitions.
- Voices on a continuum with thoughts
- In the group multiple possible explanations are held – avoiding truth claims.
- Focus within the group is on the experience.
Speaking of ‘focus on the experience’...

What might it be like to hear voices?
Please get into groups of 3/4 and allocate the following roles:

- Person 1: Interviewer
- Person 2: Client who hears voices and has a learning disability
- Person 3/4: Voice(s)
Focus on the experience...

- **Person 1**, please interview the client for 5 minutes. Ask **safe** questions about the client’s current weekly timetable or something equally low-key: work, day services, support workers, where they live, etc etc.

- **Person 2**, try to respond only to the questions Person 1 is asking you.

- **Person 3/4**, embody the voices. Talk to the client about the interviewer, give them answers to questions, talk about completely erroneous things, tell them what to say etc. *Keep it safe* – no derogatory comments about the client or commands to harm etc.
Reflective 5 minutes

- What was that like?
- What might it be like to hear those voices 24/7?
- What might it be like if they didn’t keep to the ‘safe’ boundaries?
- What might it be like if you have a cognitive impairment? ASD? Communication difficulties?
- What might it be like to hear those voices whilst taking anti-psychotic medication?
The Pilot Hearing Voices Group for People with Learning disabilities.
Where did the idea for this group come from?

- Few referrals to Psychology for work with people experiencing psychosis.
- Not an area of expertise within the department.
- My wish to share past experiences from working in Psychosis services.
- Parity - Mainstream HV Group exists, but MHLD clients who tried to attend found it inaccessible.
- 1 published paper outlining experiences of a HVG for people with learning disabilities.
Hearing Voices Group

19th January to 23rd February 2016

Nunhead Community Centre

Tel: 0203 228 1060
# Demographics

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<thead>
<tr>
<th>ID</th>
<th>Gender</th>
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<th>ID</th>
<th>Gender</th>
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<th>Outcome</th>
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Assessments

- CORE-LD & WHO-QOL
  - Used Maastricht Interview (Romme & Escher)
    - Adapted language to increase accessibility
    - Developed visual aids to represent concepts
    - Added 3-point likert questions
      - Do you know or recognise the voices that you hear?
      - Do you know of certain times and/or types of situations that make the voices happen?
      - How well do you cope when you hear voices?
    - Added section on stigma
Themes of the sessions

- Week 1: Introductions, ground rules, hopes & fears. You hear voices too?!?
- Week 2: How do we look after each other here? What do your voices say? Normalisation & myth-busting.
- Week 3: How do we make sense of this? 3-stage model of Voice-Hearing.
Themes of the sessions cont.

- Week 4: What choice do we have – if you fight the voices you just get into trouble. You just have to accept the abuse – don’t you? Can you stand up to the voices?
- Week 5: Triggers & coping with stress.
- Week 6: The end. What do we do now?
- Goodbye celebration, with a visitor from DH.
Outcomes

- At follow-up after the group:
- Re-administered CORE-LD & WHO-QOL
- Re-visited three likert & stigma questions from Maastricht
- Patient Reported Experience Feedback questionnaire
- PEDIC
CORE-LD

The image shows a bar chart with the x-axis labeled as "Pre mean" and "Post mean." The y-axis ranges from 0 to 0.9. The bar chart compares the mean values before and after an intervention or change, with a consistent value for both "Pre mean" and "Post mean."
WHO-QOL

Pre-therapy
Post-therapy

1 2

3 4

5
Maastricht

Recognise triggers coping

Pre Post
What do you think of people who hear voices?

Pre
• They’re OK
• It’s terrible that they hear voices. It’s really sad.
• I’d worried about them because they [voice-hearer] might hurt me.
• They’re probably the same as me.

Post
• They’re alright. They still have friends.
• They’re alright
• It makes me sad that other people hear voices.
Stigma

What do you think other people might say about someone who hears voices?

Pre:
• They look at me as if I’m mad
• [Others] would probably take the micky because they’re nasty
• They’d be interested in what the voices say
• They’d say “why is he like that?!?” and then they’d laugh.

Post:
• They’re alright.
• [Others] might get angry at them if they talk about the voices too much
• They’d be worried about them. [Others] might think people are saying things about them, but they’re not [i.e. be just as confused as the voice-hearer]
If someone told you that they heard voices, what would you think of them?

Pre:
• I’d tell them to keep quiet about it
• I’d try to help them
• I’d still be their friend, I’d help them. I’d not think any less of them.
• I’d be worried – they might have a gun.
• I’d want to help them.

Post:
• They’re my friend. I’d be worried about them – they’re probably frightened.
• I’d think they were OK.
• I’d say Oh, I hear voices too. I’d feel sorry for them.
Can you finish this sentence for me:

“Someone who hears voices is ______”

Pre:
- Not mad
- A friend
- Mental illness
- ill

Post:
- Scared
- Sometimes men, sometimes women [implication in conversation was that they can be anybody]
- Scared
Patient Experience Feedback

- How would you rate the group overall?
  - Good: 3

- Have you learned anything new from the group?
  - Yes: 3
    - Talking works.
    - Other people can hear voices too – it’s not just me.
    - It can be OK to listen to other people talk about voices.

- If you needed help again, would you come to another group?
  - Yes: 3
Patient Experience Feedback

- If a friend needed similar help, would you tell them to come to this group?
  - Yes: 3

- How would you rate the venue the group was in?
  - Good: 3 – It felt safe; It looked nice.

- How did you find getting to the venue every week?
  - Difficult: 1       Easy: 2
Patient Experience Feedback

- What were the two most helpful things about the group:
  - Having chats about the voices
  - Talking about my voices – that made me happy
  - Listening to other people’s stories
  - Making new friends
  - Listening to others talk about their voices – I was frightened at the start but then it was OK in the end.
  - Meeting new friends.
Patient Experience Feedback

- What changes would you make to the group? What were your least favourite bits?
  - Keep it going every week forever!
  - The venue was too far away
  - It would be better if it was every week.
Patient Experience Feedback

- Anything else you’d like to tell us about the group?
  - The voices liked it too. They liked me talking about them.
  - It was sad to hear what other people’s voices tell them.
  - It helped me with my mood.
  - (informal carer feedback) – the workbook was just right. Accessible for [client] and helped us understand more too.
Non-measurable Outcomes

- Adaptations seemed successful
- Facilitators found combination of unstructured approach with use of accessible resources & some structure helpful.
- Disclosures of trauma.
- Impact on personal relationships
- Normalisation
What didn’t we get to talk about?

- Understanding or exploring functions of voices
- Exploring beliefs about the power of the voices (although we started this)
- Loss of the group — who can you talk to now?
- Voices as an extension of thoughts
- Touched on trauma and abuse and their role in relationship to voice-hearing, but more could be done.
Next steps
Ideas I’ve been left with

- Running the group again – longer next time? Mirror of mainstream group?
- Building links with Psychosis CAG.
- Building links with Recovery College.
- Working towards maximum possible SU involvement - maybe peer co-facilitation?
- Publication with service-users involved as much as possible in the process and as named co-authors. Already have ROSE approval.
Areas of need

- How many people are there on our caseloads with psychosis who haven’t been offered psychological input of some kind?
- Access to mainstream specialist Psychosis services
- Family carers
- Support teams
- 1:1 therapy
- Family Interventions
Discussion


Hearing Voices Network Website: [http://www.hearing-voices.org](http://www.hearing-voices.org)