The use of Talking Mats by people with Huntington’s disease, their support persons and a dental hygienist

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Huntington’s disease (HD)

- Rare inherited progressive neurodegenerative disease with significant duration
- All skills and abilities necessary for communication are affected
  - motor and cognitive problems as well as problems with speech production and body communication, comprehension and conversation (finding words, staying on track, latency, repetition), reading and writing, depression, anxiety

Social isolation and apathy is a huge problem!
• Care is demanding
• Team of up to 14 specialists – communication important in all consultations.
• The dental hygienist plays an important role
  – dental and oral health is important to stop teeth loss, for chewing, swallowing and speech, and for social reasons
  – movement of oro-facial musculature, reduced hand function, memory problems, unwillingness and incapability to carry out daily routines are barriers

To summarize
• Communication is difficult at home, with friends and in relation to care
• The needs for communication support are large but people with HD and their partners are under-served
• Few reports but some, including our studies of Talking Mats, show that AAC can function well

Purpose of study
• To examine if Talking Mats can support people with HD and their interaction partners during dental hygienist consultations
• More specifically, to examine how disagreement about the placement of a picture on the mat is handled by the dental hygienist, the individual with HD and the support person
Talking Mats

- A communication method which enables people with cognitive and communicative disabilities to express their views by placing pictures on a mat according to a visual evaluation scale

www.talkingmats.com

Data

- 11 video recorded dental hygienist consultations
- The dental hygienist asked the person with HD and the support person ten questions
  - How does teeth brushing work?
  - How does it work brushing the inside of your teeth?
  - How does it work using a regular toothbrush?
- Very well, well, neither good nor bad, badly, very badly

Data driven analysis

- Looked at interaction partner behaviours such as helping, questioning, adapting
- Concentrated on six instances in data (from six consultations) where an opinion expressed by the person with HD was called into question and the picture on the mat was re-placed
Three questions examined

- We need to look at phenomena such as participation, involvement, independence and control in relation to interaction in real life!
  1. What are the reasons for disagreement in these conversations?
  2. How is disagreement displayed and solved?
  3. To what degree are the individuals with HD involved in the revision, decision and final replacement of pictures?

Reasons – a problem...

- Contradiction between different kinds of information causes lack of understanding and need for clarification
  - oral statement and placement of picture
  - placement of different pictures
- Uncertainty about the meaning of a picture
- Conflicting opinions between participants

- Cognitive problems and restrictions in language comprehension affect participation and trust in the individual’s capability
  - individual with HD must understand both procedure and language used
  - dental hygienist is sensitive, small signs enough to become unsure
Who disagrees and when?

- The dental hygienist or the support person
- When questions and answers are asked
- When mat is looked over
- Individual with HD is guided in reformulating his or her opinion – new expressed opinion may be far from the original placement of the picture on the mat – further disagreement

How?

- Statement concerning the information provided
  - but you still think it works very well
- More or less direct questions
  - it is not in the right place there is it
- Reference to own opinion
  - e I almost think we should put it there eh

Reflect degree of understanding and request response so that the problem can be solved and the activity continue

Final decision - revision

- Sharper oral suggestion complemented with eye gaze or hand gesture
  - are you putting it there or there
  - yes let us put it there
- Metaphors used and understood
  - shall we do some kind of rearrangement (omnöblering)
  - shall we

Final re-placement done by the individual with HD, the dental hygienist or the support person
Involvement

- Overall, skilled interactions; collaborate to understand and reach activity related goals and projects
- Considering the complexity of the interactions
  - difficulties of the people with HD involved
  - data collected during real consultation
  - Talking Mats new to many of the participants
  - no right and wrong ways to perform these consultations

Still

- There are different ways of taking the individual with HD into consideration
  - different approaches (e.g., language, personal pronouns)
  - encourage or discourage involvement in solving the problem
- Mostly try to involve person with HD
  - cognitive restrictions hinder involvement
  - several people and active assistant complicate interaction
- Moving the picture is not equivalent to true involvement
- In the end, not always clear whose opinion is expressed

Implications

- Talking Mats supports independent expression and is appreciated – analysis also point at dangers
- Need for a shared and explicit understanding and agreement among the participants of the goal of the activity
- Instructions and training in using TM important
- Looking through the mat important
  - opportunity to re-establish control and dependence
• Consider the role of the support person – may contradict rights and obligations in other activities
• Defining and agreeing on the visual evaluation scale is an important but delicate issue
  – the concrete scale on the mat seems to bring about an ambition of getting the picture in “the right position”, overshadowing the aim of helping people with disability to express themselves
• Present findings valuable in relation to other interventions as well?

References


References

http://www.futuremedicine.com/doi/10.2217 ndm.11

Ongoing: Disagreements in TM conversations at the dental hygienist’s that don’t lead to a replacement of pictures on the mat.