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Research Report

Using Talking Mats to support communication in persons with Huntington's Disease

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Abstract

Background: Many individuals with Huntington's disease experience reduced functioning in cognition, language and communication. Talking Mats is a visually based low technological augmentative communication framework that supports communication in people with different cognitive and communicative disabilities.
Aims: To evaluate Talking Mats as a communication tool for people in the later stages of Huntington's disease.
Methods & Procedures: Five individuals with Huntington's disease participated in the study. Three conditions were compared: unstructured communication, verbally structured communication, and communication using Talking Mats. The conversations were videotaped and analysed quantitatively and qualitatively.
Outcomes & Results: Talking Mats increased communicative effectiveness for all participants. Verbally structured conversation resulted in higher effectiveness than the unstructured counterpart and effectiveness differed depending on the type of conversational topic.
Conclusions & Implications: Talking Mats could be a valuable resource for people with Huntington's disease and their conversation partners. It could be used for social purposes, for understanding a person's opinions and for making decisions. Additional research is necessary in order to generalize the results to the population of individuals with Huntington's disease and to understand better the mechanisms behind the positive effects observed.

Keywords: Huntington's disease, augmentative and alternative communication (AAC), interaction, intervention, Talking Mats.

What this paper adds

What is already known on this subject

People in the later stages of Huntington's disease may experience reduced physical functioning and restrictions in the cognitive and linguistic skills needed for communication, which may affect possibilities for social interaction. The situation is problematic for both the person and his or her conversational partners. Limited attention has been given to the different methods that could support communication for individuals with Huntington's disease.

What this study adds

This study shows that communication in people with Huntington's disease can become more effective when a visually based low technological framework such as Talking Mats is used.

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Introduction

All skills and abilities necessary for communication are influenced by Huntington's disease (HD). Cognitive function, language skills, speech, facial expressions and body language are examples of abilities that are affected. Despite this, reports of use of augmentative and alternative communication with people with HD are scarce (Yorkston and Beukelman 2007).

HD is an inherited neuropsychiatric disease with progressive neural degeneration of the basal ganglia and gradual atrophy of frontal and temporal cortex. The estimated prevalence is 7–12/100 000, and the number of individuals with HD in Sweden is approximately 500–800. The disease is inherited via an autosomal dominant trait, which means that each child of an affected parent has a 50% risk of inheritance. The gene responsible for HD was located to a specific chromosome in 1993, and a genetic test can confirm that the individual carries the deficient gene. The diagnosis is usually made in adulthood, often years after the appearance of the first symptoms (Bates *et al.* 2002, Fagius 2006).

Symptoms typically appear in the fourth decade of life and include motor, emotional and cognitive disturbance. The motor disturbance mainly consists of characteristic involuntary, irregular movements (chorea) and abnormal voluntary movements (deficits in planning, sequencing, executing, and completing tasks). The motor abnormalities affect speech and swallowing as well as general body movements (Yorkston *et al.* 2004). The emotional disturbance often appears before the onset of motor or cognitive problems, and depression, irritability, impulsiveness and anxiety are common symptoms. The cognitive changes (gradually developing into subcortical dementia) affect concentration, memory and the acquisition of new information (Zakzanis 1998).

In addition to general cognitive dysfunction, there is increasing evidence of various language components being affected in HD (for a review, see Chenery *et al.* 2002), including lack of communicative initiative, reduced number of spoken words, decreased syntactic complexity and word-finding problems (Murray 2000, Murray and Lenz 2001, Teichmann *et al.* 2008). More attention has been given to language production than to comprehension, but a few studies describe reductions in discourse comprehension, difficulties understanding metaphors and ambiguities, understanding implicit information, making inferences, etc. (Chenery *et al.* 2002, Murray and Stout 1999, Saldert *et al.* 2009).

The speech disorder associated with HD is often described as hyperkinetic dysarthria, reflecting the underlying choreatic movement disorder. The involuntary movements may be superimposed on speech production or may interfere with it and affect respiration, phonation and articulation (Duffy 2005). Hartelius *et al.* (2003) reported primarily perceptual deviations related to speech timing (variations in speech rate, shortened phrase length, and prolongation of interword and intersyllable intervals) and phonation (increased pitch, harsh and strained-strangled phonation, and decreased pitch variation). In the latter study, individuals with mild HD were found to have dysarthric speech signs that were significantly less severe than in individuals with moderate HD. Consequently, dysarthria seems to evolve in line with the general disease progression.

The symptom development and severity vary considerably but are often described in a number of stages in which the symptoms gradually progress. Usually three stages, comprising roughly about six years each, are distinguished in the progress of HD (Shoulson and Fahn 1997). The symptoms may, nevertheless, vary within stages and between individuals. In the first, early stage the effect of motor abilities is only subtle and if dysarthria occurs, it is mild and not affecting intelligibility. Behavioural and cognitive changes arise in this early stage, although they are not necessarily salient. Nevertheless, in some cases behavioural and cognitive changes can cause severe problems in working life as well as in the contact with close others. The affected individual might begin to take fewer initiatives to conversation and may also have difficulties comprehending more complex information. In the second stage the motor as well as the cognitive and behavioural symptoms are more evident. Decreases in muscle functions affect speech and swallowing. Dysarthria may now be moderate and intelligibility is affected. Swallowing is usually also affected in stage two. Generally, individuals in this stage can not maintain their occupation and they often need assistance to manage their finances and household. In the late stages, stage three, the individual is dependent on assistance and support and care as the symptoms are more and more salient. Individuals in stage three usually do not initiate conversation and have a pronounced latency of response. This in combination with severe dysarthria makes communication very difficult.

In a recent interview study (Hartelius *et al.* 2009), eleven people with HD, seven family members and ten carers described their perceptions of communication and communicative changes in association with the disease. Family members and carers focused on the changes in terms of speech, language comprehension, the lack of depth in conversation and the need to make adjustments, while the people with HD focused on the effort and concentration demanded to communicate. They described the change they perceived in their communicative ability in terms of loss. All participants

thought that an emotional load had a negative impact on communication. Furthermore, individuals with HD stressed that other people's speed of communication had a negative impact. All participants acknowledged the need for increased participation in social life in order to enhance communication.

Intervention approaches and therapy techniques for management of speech and communication problems in HD must be responsive to the changing motor, cognitive, and emotional needs of the individuals. To date, there are very few published studies documenting efficacy of any type of communication intervention procedures in HD. In general, in cases of severe dysarthria and reduced communicative initiation, augmentative and alternative communication (AAC) is often introduced. However, few individuals with HD are given the opportunity to receive any such intervention or training. In a survey of AAC interventionists in Scotland, results indicated the HD proportion of the total AAC clinical population seen by these interventionists was very small. Individuals with HD represented only 0.8% of the interventionists' caseload (Yorkston and Beukelman 2007). The AAC systems for individuals with HD must meet the individual's needs, be simple to access and use, and be adaptable to the progressive nature of HD. External prompting systems have shown promise in assisting people with HD in maintaining communication and participating in structured conversations, for example, linguistic supplementation (Klasner and Yorkston 2001).

Talking Mats™ (TM; Murphy and Cameron 2006) is a low-technology visually based augmentative and alternative communication (AAC) resource which has been proven to support the communication of people with cerebral palsy (Murphy 1998), motor neurone disease (Murphy 1999), aphasia (Murphy 2000) and learning disability (Cameron and Murphy 2002). It has also been successfully used with frail older people (Murphy *et al.* 2005b). TM helps people with communication difficulties express their views about different topics and is used together with a person's ordinary communication system. TM consists of a textured mat and three sets of pictures representing the conversational topics to be discussed, options, that is, issues relating to the topic, and a visual scale allowing the person to indicate what she or he feels and thinks about the different options. TM has a thoroughly worked out methodology. Apart from relevant topics and options, which are discussed and approved of by the person before the conversation starts, TM presupposes an open-minded and respectful speaking partner who is well acquainted with the method. It is the partner's responsibility to initiate the process whereby any necessary changes in the person's life, as expressed by pictures on the mat, are taken care of. Only open questions are used. For example, if the topic is activities at home (represented by a picture on the mat) an option to discuss may be cooking. The picture of cooking is presented together with the question 'How do you feel about cooking?' The person places the picture of cooking under the picture in the visual scale that best represents her or his opinion.

Murphy *et al.* (2009) investigated the effectiveness of TM for people with dementia. Thirty one individuals with different types and stages of dementia talked about four topics that were important for their general well being: activities, people, environment and self. Each participant talked with an interviewer about each of the four topics in three different ways: (1) using TM and visual support (2) using a structured framework where specific questions about the topics were asked, and (3) using an unstructured framework, resembling the type of communication people with dementia experience in daily life. TM resulted in more effective communication than the structured and unstructured frameworks. When TM was used perseveration decreased and engagement and time spent in conversation, as well as the quality of the information provided by the people with dementia, increased. TM has also been used with people with HD but results of this usage have yet to be formally researched or published.

The complexity of the clinical symptoms in HD, and their influence on communication, urge for research focusing on AAC systems and strategies that can improve participation and quality of life for people with HD and their conversation partners. Based on the research by Murphy *et al.* (2009) and considering the symptoms typical for HD, it is reasonable to believe that TM could be effective in assisting the communication of people in the later stages of HD.

The purpose of the study is to examine if TM is suitable for people in the advanced stages of HD. Communicative effectiveness with TM was compared with effectiveness in unstructured and structured communication.

Methods

This is a descriptive intervention study including quantitative and qualitative analysis. The study was done within a three-year clinical project aiming at finding out and meeting the needs and requirements of individuals and families with HD, in terms of professional networks for healthcare and social activities.

Participants

Five individuals with HD, three women and two men (mean age = 61 years) participated in the study (Table 1). The participants were invited by their

Table 1. Participant characteristics

Participation code	Gender	Age (years)	Stage of Huntington's disease (HD)
F1	Female	51	2–3
F2	Female	71	3
F3	Female	52	3
M1	Male	65	3
M2	Male	66	2–3

contact person in the Huntington team at the Sahlgrenska University Hospital. All participants known by the team were considered. Inclusion criteria were that the person was (1) thought to benefit from TM, (2) in a physical condition such that she or he could participate, and (3) in the second or third stage of HD. The members of the Huntington team who had long experience in working with people with HD decided who should be invited to participate in the study. Cognitive, linguistic and motor skill levels were not relevant inclusion criteria and, for the purpose of the study, no formal assessments were done. The only information about the participants' functioning that reached the researchers prior to the onset of the study, apart from general social and demographic information, was stages of HD.

Material

The material used was Talking Mats (TM) and the Effectiveness Framework of Functional Communication (EFFC; Murphy *et al.* 2005a, 2005b, 2009, Cameron *et al.* 2008). TM involved textured mats (60 × 40 cm) and three sets of pictures for the visual scale (Figure 1), topics (Figure 2) and options (Figure 3). Picture Communication Symbols PCS (6 × 6 cm) were used (Mayer-Johnson™ 1981–2009). Labels on topic and option pictures were written in Arial 16 pt and 14 pt, respectively. A piece of Velcro on the back of pictures allowed these to be attached and moved around on the mat.

The EFFC is a rating protocol that measures the effectiveness of communication. It is further described under analysis.

Conversations were video recorded using the SONY Digital Handycam DCR – TRV 80E and the mats were photographed using the digital camera HP Photosmart R707.

Procedure

Communication across three conditions was examined: (1) unstructured communication, (2) structured communication, and (3) communication with TM (Murphy *et al.* 2009). In each condition, and in the same order, three topics were discussed; interests and activities, personal information and communication. Talk about issues other than the illness is important for people with HD (Klasner and Yorkston 2001) as well as for people with other disabilities (Murphy *et al.* 2009). Therefore, topics such as interests and activities and personal information were included. Communication is an important issue for people with HD (Hartelius *et al.* 2009) and hence was included as a topic in the study.

Each participant was visited at home by the second and third authors (who were both researchers and communication partners) three times. In the first visit TM was demonstrated. The participant reconfirmed participation in the study and suggested the time for the next visit. There were approximately two weeks between the first and second visit. In the second and third visits communication in the three conditions, between the person with HD and one of the researchers/communication partners, was video recorded. The same researcher communicated with the same participant in all three conditions. For all participants, visits two and three were conducted within a period of 6–8 days. One visit was devoted to unstructured and structured communication and one to TM. The conditions were counterbalanced between participants through randomization. Unstructured communication always preceded structured communication. All participants received the same instructions in the three conditions, with minor modifications to meet the language needs of each participant.

In the unstructured condition an introductory open and general question was asked for each topic. For example, 'What do you like to do during the day?' was the first question asked for the topic interests and

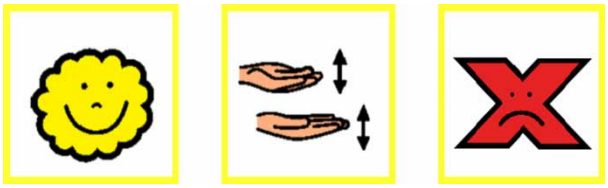

Figure 1. Pictures representing the visual scale: positive, neither positive nor negative, and negative.

Figure 2. Pictures representing the topics: interests and activities, personal information, and communication.

Figure 3. Examples of options relating to the topic interests and activities: do sports, listen to music, watch television, and go for walks.

activities. If the person did not answer and in order to make conversation proceed, additional questions were asked. These questions were also open and conceptually wide in character, for example, 'What do you usually do?' In the unstructured condition all participants received the same introductory questions for each topic. The number and types of additional questions asked depended on the responses and engagement from each participant. In the structured condition ten to twelve open but specific and predetermined questions were asked for each topic. For example, with respect to interests and activities the following questions were asked: 'How do you like doing sports?', 'How do you like cooking?' and 'How do you like cleaning?' (see the appendix). In the structured condition all participants received the same questions but these were presented in a randomized order. Each topic was ended by the researcher asking the participant if she or he wanted to add or clarify any information. Communication with TM included ten to twelve options/questions and followed the same procedure as the structured condition except that three mats, one for each topic, and pictures were used. Before the mat communication commenced, topics and options were presented for the participant. Using the mat, the participants were asked to place the option pictures under the picture in the visual scale that best matched her or his opinion. The same options (questions) were given to all participants but in a randomized order. If needed, the conversation partner assisted in placing the pictures on the mat as indicated by the participant. When all options relating to a topic had been discussed the participant was allowed to move pictures on the mat as she or he wanted. Photographs of the completed mats were given to the participants at the end of the study.

In all conditions, pauses were used when needed; after the pause communication was resumed and completed. The participants were given the time they needed to answer the questions. If a person did not want to talk about an option it was dropped. The participants were allowed to ask questions and the partner asked complementary open questions when needed.

Analysis

Four factors of EFFC that are relevant in the study of communication of people with dementia were assessed. (1) Participant's understanding of options presented. (2) Participant's engagement with interviewer and task. (3) Participant's ability to keep on track. (4) Interviewer's understanding of participant's views. A five-point scale ranging from zero to four, representing a grading from high (four) to low (zero) communicative effectiveness was used. Acceptable communicative effectiveness, which means communication functions satisfactorily, exists if a person gets twelve or more points from a maximum of 16 (Murphy *et al.* 2009).

The rating followed the guidelines set out by Cameron *et al.* (2008), who also established that the validity and reliability of the EFFC is high. The two researchers did the ratings at the same time but independently, that is, watched the video recordings in the same room but did not talk with each other. Both researchers rated each topic, in each condition, for each participant, resulting in 18 ratings for all participants. After each independent rating of a topic, the scores were discussed. The consultation of ratings between researchers could result in a change of a score for one or both of the researchers but the researchers did not have to come to an agreement. Thereafter, the scores were put together and a mean score for each participant and topic in the three conditions was calculated, resulting in a total of nine scores for each participant. As each topic was rated separately communicative effectiveness across topics could be compared. Finally, the scores for the three topics of each participant were compiled into one total score for each condition and the mean for total communicative effectiveness for each participant was calculated.

In the rating, body communication as well as the participant's and the conversational partner's vocal contributions were considered. The factors of EFFC are not mutually exclusive (Murphy and Cameron 2006). To get a high score on *participant's understanding of options presented* answers should be unambiguous and presented in such a way that there were no doubts that the person had understood the questions. Left out or irrelevant answers or repeated misunderstanding of

questions resulted in low scores. *Participant's engagement with interviewer and task* aimed at measuring the relation developed within the situation. Communicative behaviours such as joint attention, feedback through words and gestures as well as topic development were observed. To get a high score the participant should show an active interest in the communication through for example eye contact, the use of feedback words (for example, m, yes and no) or humour (laughter or words). Thus, a quiet participant could get a high score. A participant that stayed on topic in answering questions received a high score on *participant's ability to keep on track*. Sudden and unmotivated topic shifts resulted in a low score as did answers that drifted away from the original topic in an inadequate way. A low score was also given if the participant answered in such a way that it was impossible to make an assessment of her or his ability to keep on track. The *interviewer's understanding of participant's views* was measured on the basis of what could be observed in the video recordings that is, not on the basis of the researchers' experiences from the situation. The partner's feedback and reactions to the participant's answers were assessed. A high score was given if the researcher was active in the communication and, in relation to the participant's communication, gave relevant feedback so that the conversation proceeded.

The time spent in the three conditions was measured. In the unstructured and structured conditions communication started when the first questions were asked and ended when the participant indicated that she or he had nothing more to say. Communication with TM started when the picture of the first topic was presented and ended when the participant indicated that she or he had nothing more to say. The video camera was turned off during pauses. Pauses did not influence the total communication time.

As a complement to the ratings with EFFC and the specification of time, descriptive analyses of communication as observed in the video recordings were done by the researchers. The analyses included details concerning the participants' communication in general and in the different conditions. At this point, behaviours and experiences of the conversation partners (that is, the researchers) were also considered.

Statistical analysis

SPSS 16.0 was used for analysis. Wilcoxon Signed Rank test was used to determine significant differences ($p < 0.05$) between the three different conditions for each participant.

Two external raters were used to assess inter-judge reliability. They rated 20% randomly selected sections of the recorded material and their mean score was compared with that of the researchers. External inter-judge reliability was assessed using intra-class correlation (ICC) and was found to be 0.91. Internal inter-judge reliability, between the two researchers, was determined prior to the calculation of mean score and was found to be 0.94 before the consultation of ratings and 0.96 after, using ICC.

Ethical considerations

The study builds on recent research and is part of a project that aims to increase the knowledge about HD. Ethical guidelines for clinical research were followed. The recruitment of participants was free from force, incentives and other factors that could counteract voluntary participation. The participants were given oral and written information about the study. When needed, a member of the Huntington team who knew the person well, or a close partner, helped clarifying information.

Results

Results will be described first in terms of communicative effectiveness as measured with EFFC and time spent in the three conditions. The section ends with a qualitative description of communication.

Communicative effectiveness

Results show that the group's mean score of communicative effectiveness was significantly higher for communication using TM compared with unstructured and structured communication (Table 2).

The difference between communication with TM and the two other conditions was significant. Consequently, communication with TM was more effective than unstructured and structured communication as measured by EFFC. In addition, structured communication had a significantly higher communicative effectiveness compared with unstructured communication. For each of the five participants, communicative effectiveness followed the same pattern, where communication with TM had the highest and unstructured communication the lowest scores. Only two of the participants reached acceptable communicative effectiveness (a score of 12) (Figure 4).

The three topics, interests and activities, personal information and communication showed differences in communicative effectiveness. Interests and activities and personal information reached the highest scores and communication the lowest, regardless of communication condition. In the structured and TM conditions, interests and activities reached higher scores

Table 2. Group mean of communicative effectiveness for the three different conditions

	Minimum	Maximum	Mean	SD, Sign UC, Sign SC
Unstructured communication (UC)	3.33	9.83	7.20	2.44, –, –
Structured communication (SC)	5.50	13.00	10.00	2.84, $p < 0.05$, –
Communication with TM (TMC)	6.17	14.67	11.33	3.42, $p < 0.05$, $p < 0.05$

Note: Range (minimum – maximum), mean and standard deviation (SD). *p*-values indicate significant differences between conditions.

on effectiveness than the two other topics. The group mean shows that only communication with TM about interests and activities reached acceptable communicative effectiveness (Table 3).

For each participant, communicative effectiveness varied depending on topic. For a couple of participants, the variation was larger and for others, the differences were small (Figure 5).

Time spent in the three conditions

All communications were timed in minutes. Results show that communication with TM had a significantly longer duration compared with the two other conditions. The largest variation was found in the structured condition (Table 4).

Communication with TM had a significantly longer duration compared with unstructured communication. Structured communication also took significantly longer time than unstructured communication. However, there was no significant difference between time spent communicating with TM compared with structured communication. Four of the five participants spent significantly more time communicating with TM (Figure 6).

Descriptive observations of communication

In the following, the observations of each participant's communication are briefly described.

F1 had frequent choreatic movements of the trunk, upper extremities and facial musculature. Despite this, facial expression and body language was only slightly affected. Her speech was intelligible, although vocal loudness was fluctuating. She was somewhat uncertain in her replies and sought confirmation from her personal assistant who was in an adjacent room. An obvious example of her insecurity was her comment: 'What do I think, … [assistant's name]?' During structured communication echolalia was very frequent. Both echolalia and insecurity in answering was reduced in communicating with TM. F1 used the entire visual scale (Figure 7). She suggested own options connected to the different topics and took away options that were not relevant. The impression of the conversation partner was that F1 was more engaged in the communication when TM was used in that she was more secure in her answers and did not call upon her assistant to confer.

F2 had moderate choreatic movements in her trunk and upper extremities. Her speech was sometimes

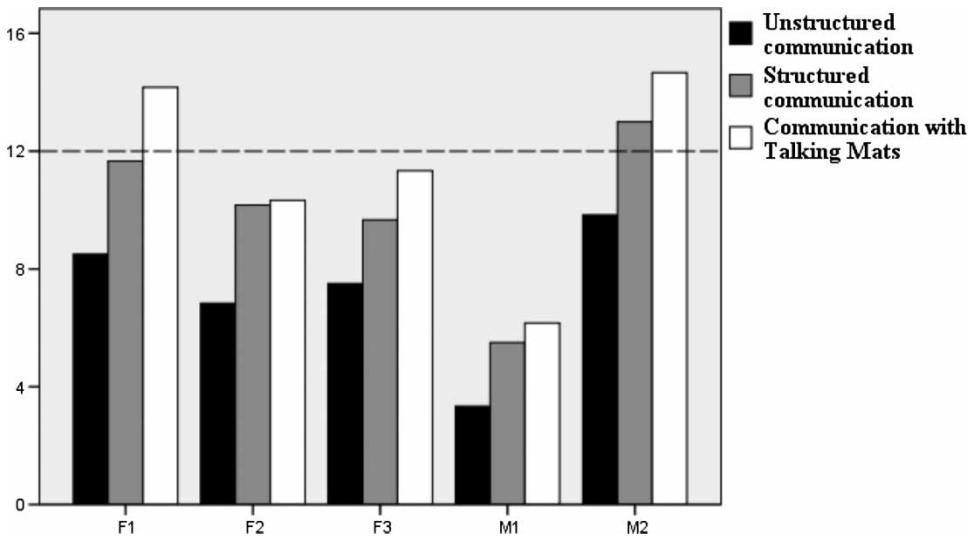

Figure 4. Mean communicative effectiveness for each participant across conditions, averaged over topics. Dashed line indicates acceptable communicative effectiveness.

Table 3. Group mean of communicative effectiveness for the three different conditions and the three different topics

	Minimum	Maximum	Mean	SD
Unstructured communication about interests and activities	2.0	12.0	7.8	3.63
Unstructured communication about personal information	5.0	11.5	8.3	2.56
Unstructured communication about communication	3.0	9.0	5.5	3.00
Structured communication about interests and activities	5.0	14.0	11.0	3.59
Structured communication about personal information	6.0	12.0	9.9	2.36
Structured communication about communication	5.5	13.0	9.1	2.75
Communication with TM about interests and activities	7.0	16.0	12.2	3.35
Communication with TM about personal information	7.0	16.0	11.5	3.57
Communication with TM about communication	4.5	14.0	10.3	3.70

Note: Range (minimum – maximum), mean and standard deviation (SD).

difficult to understand. F2 needed help to place the pictures, in particular when she had a decidedly spoken opinion, but did not know how to place the picture near the corresponding scale step. She used only the positive and the negative end of the visual scale. F2 was evidently fatigued after communicating a while, which decreased communicative effectiveness. This was observed under all three conditions. The impression of the conversation partner was that the use of TM increased understanding in interaction for both communication partners.

F3 had no visible chorea but hypomimia and very limited body language. Her speech was sometimes difficult to understand. F3 had a marked verbal latency under all conditions, and occasional perseverations were noted. In the structured communication F3 misunderstood the questions at times. When TM was used, her understanding of questions was higher. She took an obvious interest in the mat and placed the pictures carefully. She used the entire visual scale and said the mat helped her. F3 removed options that she was not interested in discussing. The impression of the conversation partner was that communicating with TM was easier than unstructured and structured communication for F3 and that, with the use of TM it felt more natural to wait quietly until F3 was ready to answer. From the video recordings it was obvious that the conversation partner allowed F3 more time to answer questions when TM was used.

M1 had severe dystonia. He had limited mobility and hypomimia, which made his body language difficult to interpret. M1 needed a lot of manual support when placing the pictures. He used the entire visual scale but the majority of the pictures ended up being on the positive side. M1 had limited verbal output and iterated certain expressions, such as 'that's fine'. His speech was very difficult to understand. The impression of the conversation partner was that it is very difficult to ask M1 open questions and to solve misunderstandings. Communicating with TM made M1 more engaged which made it easier to create a more equal interplay.

M2 had no visible chorea but hypomimia, reduced vocal loudness and monotony. His speech was easy to understand but verbal latency was pronounced, which was most obvious in the structured condition. Latency was somewhat reduced in the TM condition. M2 used the entire visual scale and removed options that he did not want to discuss. The impression of the partner was

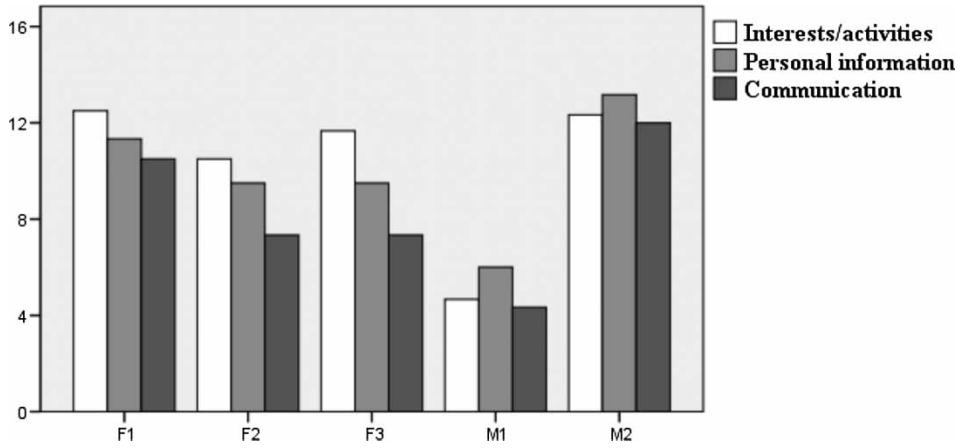

Figure 5. Mean communicative effectiveness for each participant across topics, averaged over conditions.

Table 4. Group mean of time spent in each condition

	Minimum	Maximum	Mean	SD, Sign UC, Sign SC
Unstructured communication (UC)	1.93	5.13	3.67	1.36, –, –
Structured communication (SC)	6.82	28.22	15.19	8.01, $p < 0.05$, –
Communication with TM (TMC)	22.28	34.23	28.13	5.57, $p < 0.05$, $p = 0.08$

Note: Range (minimum – maximum), mean and standard deviation (SD). *p*-values indicate significant differences between conditions.

that understanding M2's views and thoughts was facilitated by the use of TM. This was due to the fact that M2 was reasoning aloud in a very clear way when he placed the pictures on the mat. In addition, the conversation partner found it more natural to wait for his answers in communicating with TM. Observations showed that the conversation partner was more proficient at giving M2 time to answer questions when TM was used.

Discussion

Communication was more effective when TM was used than when conversation was unstructured or structured by verbal means only. This result is positive and in line with observations in research including people with similar cognitive and communicative difficulties (for example, Murphy 1999, Murphy *et al.* 2005b, 2009).

Several components of TM, which do not exist in other types of communication, may have contributed to the positive effects. With TM, topics are presented in a structured way with visual support. Thus, topics are made concrete which may facilitate comprehension of language and task and reduce demands on memory. Questions are answered by means of placing pictures on the mat which may be easier for people with cognitive and communicative difficulties. Further, in visually based communication the speaking partner tends to use fewer words, pinpointing the most important information, and speaks slower. As a result, the total communication rate slows down. All these factors may have been beneficial for the present participants who, to varying degrees, had problems with concentration, difficulties understanding abstract concepts and complex spoken language, difficulties staying on topic, echolalia, verbal latency and expressive problems due to dysarthria. Perhaps the most important finding, adding to the validity of the results, was that all participants seemed to enjoy using the mat and three participants, F1, M2 and F3, spontaneously stated that the mat was useful for them.

Lack of time in talk with others is an impediment for people with HD (Hartelius *et al.* 2009) who often need more time than others in order to follow conversations and contribute themselves (Hartelius *et al.* 2009, Yorkston *et al.* 2004). When the mats were used in the present study, the partner focused on the pictures and gave the person with HD more time to respond. This study, as the study by Murphy *et al.* (2009), shows that communication with TM takes more time than other types of communication. In clinical practices methods that demand little with respect to human resources may be seen as the most effective and efficient. However, considering the situation of people with cognitive and communicative disabilities, time alone can not be the decisive factor but must be regarded in relation to the needs of the person and the quality of the communication.

The finding that communication was more effective in the structured than in the unstructured condition is

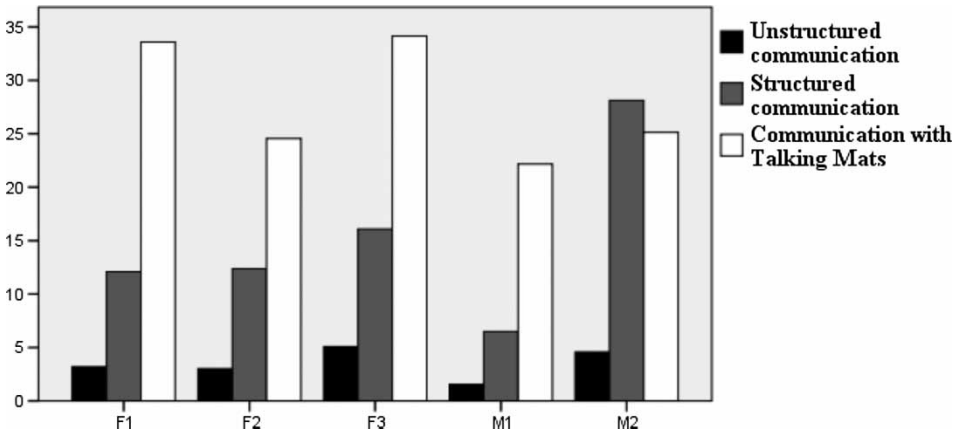

Figure 6. Time spent in each condition for all five participants.

Figure 7. A mat done by F1 on the topic activities and interest.

relevant from social and clinical perspectives. It means that a certain degree of verbal structure, in this study represented by open but still specific and focused questions, can help people with HD communicate more effectively. However, the structured condition at times turned into an interrogation rather than a conversation, which is not a desirable effect. For all participants, but especially for F2, F3 and M1, the unstructured condition was more complicated than the structured and TM conditions. The participants had difficulties answering the open more general questions and additional questions from the partner did not lead to more comprehensive answers. The unstructured condition was short in duration for all participants and their difficulties were reflected in low scores on EFFC. The conversations were not developed content wise; they were qualitatively poor and quickly came to an end. The people with HD that participated in this study were disadvantaged in the unstructured condition indicating that, at least for them, such a condition was not positive for their communication.

Importantly, TM was supportive for the conversation partners too. The descriptive observations showed that echolalia and verbal latency decreased when TM was used, the participants' engagement and certainty in answering questions increased, and there was more verbal reflection in relation to topics and options. As a consequence, it was easier for the conversation partners to follow the participants' lines of reasoning. The mat and the pictures gave the dyad a common focus of attention and more equal interaction patterns were established. Since the participants were more competent communicators when TM was used, the conversation partners felt more comfortable.

An unexpected and interesting finding is that effectiveness differed between topics. Effectiveness was higher for interests and activities and personal information than for communication. As it seemed, interests and activities as well as personal information were pleasant topics that engaged the participants. Interests and activities did not focus on the disease (cf. Klasner and Yorkston 2001) and the options were concrete, for example, 'How do you like watching TV?' With the progression of the disease, general and more specific cognitive problems including difficulties understanding abstract concepts and complex language are common (Chenery *et al.* 2002, Murray and Stout 1999, Saldert *et al.* 2009, Zakzanis 1998). The options in the communication topic were abstract and related to the disease and accompanying difficulties, for example, 'How do you think it works finding words?' These factors may have influenced the participants' engagement in conversation and, as a result, scores on effectiveness. Talk about communication in the unstructured condition was overall ineffective, indicating that in order to be able to talk about their own situation and problems people with HD need some kind of external support. Communication was the last topic in each condition which also may have contributed to lower effectiveness.

The combination of more severe cognitive and physical difficulties that can be found in the later stages of HD could hinder effective use of TM. The participants in the most advanced stages of the disease also received the lowest EFFC scores. However, the results of this study clearly illustrate that people with HD have different symptoms, and meet the challenges posed by communication in very different ways, even

though they are in the same stage (cf. Saldert *et al.* 2009). Each person must be treated individually. For example, M1, F2 and F3 were all in stage 3. They were all more effective communicators with TM than without TM, but their skills varied. For M1, reduced motor functions and cognitive restrictions had negative effects on his ability to understand and use the mat effectively. F2 was easily fatigued and had problems placing the pictures on the mat, from both physical and cognitive perspectives. Although she received help TM was too demanding for her. F3 understood the method and had no problems placing the pictures. In addition, she said the mat helped her. Altogether, these results show that people in the later stages of HD should be given the possibility to try TM as well as other AAC strategies that could support their communication.

We do not know if people in the earlier stages of HD could benefit from using TM. However, F1 and M2, who were in the transition of stages 2 and 3, reached the highest scores on communicative effectiveness and also seemed to appreciate TM the most. Both F1 and M2 reached high scores on structured communication too and managed fairly well in the unstructured condition. At first sight F1 and M2 did not seem to need the kind of support offered by TM but they said they liked it a lot. As it seemed, TM facilitated and gave structure to their thinking about different issues (cf. Murphy *et al.* 2005b). This finding suggests that people in the earlier stages of HD also may benefit from TM.

Limitations of study

Only five individuals in the advanced stages of HD participated in the study and the results can not be generalized to the population of people with HD. An inclusion criterion was that the person was thought to benefit from communication support. Hence, it is not surprising that the participants gained from using TM. However, the degree of communicative effectiveness and the type of gains obtained with TM were surprising and suggest that other people with HD also could benefit from this kind of support.

Communication is a complex phenomenon and assessment of communicative effectiveness a complex process. The validity and reliability of EFFC is high and the protocol is well documented (Cameron *et al.* 2008). Despite this, it was at times difficult to rate the effectiveness of the participants' communication. Some important factors such as the advantages of decreased verbal latency and insecurity in participants when TM was used, as well as the conversation partner's communicative behaviours, may not have been completely captured by the EFFC. In order to take these factors into consideration interaction analysis is needed. More detailed analyses than the observations of communication performed in this study would have rendered even more comprehensive pictures of the dyads' communication.

The researchers were both conversation partners and assessors and thus rated their own communication. Rating of the *interviewer's understanding of participant's views* was sometimes demanding with respect to objectivity. Internal and external inter-judge reliability coding was done with satisfying results. The agreement between the first raters and the external raters was 0.91 (ICC). The researchers' valuable experiences from communicating with the participants were taken into consideration in the descriptive analyses.

The same options were presented to each participant twice. In order to avoid decreased interest and over learning of questions and answers, options were presented in a randomized order. It is possible that the participants' answers were less exhaustive the second time a question was asked. Using different options for topics in the different conditions was not a choice since it would have been difficult to determine if it was the questions or the conditions, or both, that made a difference. The participants were not uncomfortable about discussing the same options a second time. Only one participant commented that a question had already been asked.

Conclusions and clinical implications

Communication support for people with Huntington's disease (HD) has received little attention (Yorkston and Beukelman 2007) and this study helps filling parts of the existing gaps in knowledge. We have shown that communication in individuals with HD can become more effective with the visual framework Talking Mats (TM). We have also shown that if talk is verbally structured by means of open and specific questions communicative effectiveness may increase. Looser conversational structure is not favourable for people that have HD. Type of topic is also important. TM, or other kinds of visual support, is strongly recommended when more abstract and demanding topics are discussed. According to the comparisons done in this study, TM is time consuming but effective from qualitative perspectives. It also makes the partner feel at ease. Social relations with others are important and may be lacking for people with HD (Hartelius *et al.* 2009). TM can be appreciated as a social activity in itself, an activity that may render possibilities for communication that is more meaningful than people with HD are used to.

TM could be a valuable resource for individuals with HD and their conversation partners. Professionals, friends and relatives could be trained in using TM for

the purpose of talking about everyday issues as well as more important things. TM could help when a person with HD has become socially restricted and could be used in different assessments. In particular, TM could increase participation and serve important functions in life planning where a person's own views are important and decisions need to be made. However, it is important to remember that all these possibilities depend upon the support given by professionals and other significant communication partners. Use of TM will not be initiated by a person with HD and a TM conversation can not proceed unless the conversation partner prepares the talk and has the skills required. Hence, the main responsibility rests upon the partner who also needs to be trained in the method.

Future research

This study should be replicated with a larger number of participants, including people in the earlier stages of the disease. Analyses of the conversation partners' behaviours (for example, number of words used, pauses and body communication) could also be done. Evaluations of close partners' opinions about using TM with people that have HD could be examined and TM in group activities for people with HD is another area worth investigation.

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Appendix

Table A1. Topics and options in structured communication and communication with Talking Mats

	Topics		
	Interests and activities	Personal information	Communication
Options[a]	Sport	Contact with family	Speak
	Cooking	Housing	Make oneself understood
	Cleaning	Staff	Understand
	Be alone	Vision	Find words
	Social life	Hearing	Initiate communication
	Television	Sleep	Use communication aids
	Go for walks	Eat	Communicate with unknown people
	Reading	Drink	Use the phone
	Music	Toilet	Write by hand
	Singing	Medicine	Write with the computer
		Mobility	Speak for a long time
		Walking/wheelchair	

Note: [a]Options were presented with open questions like 'How do you like …?', 'How does it work …?'

Table A2. Topics in unstructured communication

Topics		
Interests and activities	Personal information	Communication
What do you like to do during the day?	Could you tell me about yourself?	Could you tell me about how it works to communicate?
[a]What do you usually do?	[a]Could you tell me about your health?	[a]How did your communication change when you got the disease?

Note: [a]Examples of additional questions.