Enabling people with MND to have control of their lives: the development of a communication tool

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Summary:

This pilot study examined the effectiveness of ***Talking Mats,*** a low-tech communication framework developed by Joan Murphy, as a way of allowing people with MND to discuss issues concerning the quality of their lives. The study involved five people with MND at varying stages of the illness. They all gave insightful comments about the use of the ***Talking Mats*** and the framework was modified as a result of their involvement. Overall their views of the ***Talking Mats*** were very positive and the final framework has the potential to be used with a whole range of people with MND, not only those with communication difficulties.

Background:

Deteriorating communication is one of the most distressing aspects of MND. As the disease progresses, the patient's lifestyle undergoes devastating changes including problems with mobility, activities of daily living, communication and relationships. It is at this very time, when the person's communication may fail, that important and often life dependent decisions have to be made.

An examination of relevant literature showed that there are no measures that allow people with communication difficulties to express their point of view. Bowling (1998) describes a wide range of health measures, but none of them take into account the specific difficulties people with communication difficulties have in completing any of these measures. In addition many existing measures are based on medical, not on social criteria and do not take into account issues such as difficulties with speech, language, fatigue, poor hand control and literacy while the patient is completing the measure.

It was with these difficulties in mind that this project was undertaken. Its aim was to examine the effectiveness and adapt the ***Talking Mats*** for adults with MND. The ***Talking Mats*** framework is based on 3 sets of picture symbols, which are presented to the person with the communication difficulty. The symbols are used to -

1. Illustrate the **issues** that are important for inclusion in the subsequent interview.
2. Depict different **emotions** in order to allow participants to indicate their feelings
3. Represent possible positive and negative **factors** relating to each issue

Participants:

Ethical permission was obtained from Forth Valley Ethics of Research Committee, the MND Research Register and the Clinical Director of Central Scotland Healthcare Trust. Following discussion with the Scottish MND Clinical Specialists and the relevant speech and language therapists 5 people with MND who live in Forth Valley were approached and given an information leaflet about the project (see appendix1). All indicated that they were interested in being involved and Joan Murphy then visited them at home to explain the details of the project and the nature of their involvement. All consented to take part and a date for each interview was agreed. The five participants were from different backgrounds and the illness was at different stages and showed different symptoms for each of them. The following table summarises this:

Gender	Age	Date of diagnosis	Mobility	Hand Control	Speech	Home Situation	Work situation
Male	57	May 1998	Severely limited	Severely limited	No useful speech	At home with family	Retired plasterer
Male	49	1980	No useful mobility	No useful ability	Severely impaired	At home with family	Retired architect
Male	78	Jan. 1999	Slightly limited	Not affected	Slightly impaired	At home with family	Retired foundry worker
Male	50	Aug. 1997	Mod. limited	Severely limited	Severely impaired	At home with family	Farmer
Female	58	Jan. 1997	Mod. limited	Mod. limited	Slightly impaired	At home with family	Housewife

Method:

Initial visit:

On the first visit to each participant Joan Murphy explained the project, showed the format of the interview and emphasised that this was a pilot project and that comments and criticisms would be particularly welcome. This initial visit also gave Joan Murphy and the participants the opportunity to get to know each other a little.

Preparation of pictures:

Following this visit, Joan Murphy prepared the issues, emotions and factors to be considered in the study. The six main issues were as follows: **people; home; health; work; indoor interests; outdoor interests** and within each a variety of different factors were displayed. It was emphasised that these were not in any order of importance and new factors could be added at any time throughout the interview. Similarly if any factors were not relevant to the participant they simply did not select them. Seven emotions were used ranging from 'very happy' to 'very angry'. (See appendix 2). The pictures were produced on the software package Boardmaker™ [1].

Selection of pictures:

For each of the six issues in turn, the participants were invited to select the factors that they considered affected their quality of life. They then placed each one, depending on how that factor helped or hindered their quality of life, under the relevant emotion on a second mat. Each participant selected the pictures in whichever way was most convenient for them e.g. some named the pictures, some pointed and some indicated with a head nod while the researcher scanned through them. Blank squares were always presented in order that the participants could add any other factors that were relevant to them. In this way the participants built up a picture of their views on how various factors affected their quality of life for each issue.

Scoring results:

Once the participants were satisfied that the composite picture was a true representation of their views, the researcher took a digital photograph of that Mat, then filled in the scoring grid, adding any additional relevant comments (see appendix 3). The researcher then removed the pictures and prepared the Mats for the next issue to be considered.

Use of video:

Originally it was intended that each interview would be video recorded in order to allow the researcher to confirm that she had interpreted the participants' views correctly. However, as the participants had plenty of time to verify their choices and all confirmed that their views were being accurately recorded it was felt that the intrusion of a video camera outweighed any benefits. One interview was video recorded as one participant was particularly keen to express his views about the process of using the ***Talking Mats*** in an interactive way with the researcher.

Results:

All five participants completed the interview and all felt it was a useful and innovative way of allowing them to consider issues relating to quality of life. The interview lasted approximately 1 hour with each person and no one indicated that they found it tiring or irrelevant. The actual views expressed by each person can be seen in Appendix 4, which are the photographs of each

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[1] The Picture Communication Symbols (PCS) are ©1981-1997 Mayer Johnson Co. and are used with permission - Mayer-Johnson Co., P.O. Box 1579, Solana Beach, CA 92075, USA

person's completed Mats. Because of their individual circumstances each set of Mats differs but clearly illustrates the views of each person.

Some specific and very individual observations can be made. For example, one participant had, with time, come to accept many of the limitations which the illness had imposed on him and identified many positive factors in relation to his quality of life. In contrast, another was still very angry about how the restrictions on his mobility, speech and swallowing had damaged his quality of life. For another participant, being able to continue a life long hobby to a modified degree greatly contributed to the quality of his life. For one person the church was a great source of strength whereas for another the minister was an irritation. Four people acknowledged that the personal care they received improved their quality of life while one person was upset at having to accept help. Gardens were a mixed blessing – some people enjoyed sitting in their garden whereas for others no longer being able to look after the garden was a source of stress. The car greatly improved the quality of life for one participant but was a source of frustration for another person who could no longer drive. There are many more specific points relating to each person but the most significant aspect of these findings is how personal each set of mats is and how clearly they represent the participants' feelings.

A few generalisations can be made.

- Some participants realised that despite their illness, there were a number of positive factors in their lives.
- For some participants the use of the ***Talking Mats*** confirmed that they had come to accept many of the changes and limitations in their life as a result of the illness.
- Relationships and support from family are crucial for people's quality of life.
- Having an interest or hobby that can be continued, even in a limited way, is important in maintaining quality of life.
- Factors relating to the issue of health do not necessarily overwhelm someone with MND

The issues and factors selected appeared to be relevant to all five participants irrespective of their backgrounds and they all found the use of pictures both helpful and enjoyable.

The following comments made by the participants illustrate their views of the ***Talking Mats.***

" A very clever idea"
"It lets you get behind the disability""
"The pictures are interesting and fun"
"The control is with the person with MND"
"The pictures help me think about the issues"
"It's like looking in a mirror"
"It's made me think"
"I said more than I would normally say and I suppose that's good"
"It's given me food for thought"

It's very good"
"It's easy to do and could be done by anyone"
"It covers just about everything"

The spouse of one participant commented *" That's the most he's talked for a long time"* and another spouse said, *"It's let him express his feelings"*

When I asked the participants how they imagined the results from the ***Talking Mats*** could be used they suggested the following:

- To give feedback to individuals
- To compare how people's views changed with time (one participant felt that his views would mellow and he would become more content)
- To allow people to think about their lives
- To give feedback to carers, MND clinical specialists, Rehabilitation Teams etc. about how the person with MND feels about things
- To compare patterns of views across a large number of participants from different situations and at different stages of the illness
- To be used initially to "take the temperature of an individual" but also allowing the opportunity to come back and explore some issues in more detail

This study has confirmed that the following features of the ***Talking Mats*** are relevant for people with communication difficulties when considering quality of life issues:

- Using ***Talking Mats*** is non-threatening in that there are no right or wrong answers
- The results can be compared by carrying out the interview on different occasions with the same person
- The factors which influence the quality of life issues can be easily personalised for individuals
- People with limited hand control and/or those who fatigue easily can use the ***Talking Mats*** instrument simply by eye pointing or using listener scanning.
- The ***Talking Mats*** are simple and enjoyable to use
- The participants can take as long as they require to consider the pictures, select them, move them around and change them until they are happy that the final composite picture truly represents what they mean
- The final pictorial representation can be photographed as a permanent record of the participant's views and used in order to bring about change

Four alterations to the original tool were made as a result of the comments made by the participants and the observations of the researcher.

1. Some of the emotion pictures were altered e.g. *frustration* was added
2. Instead of each emotion having a descriptive label it was felt it would be simpler and more relevant to give each emotion a grading from 1(very positive) to 7 (very negative).

3. The development of a coding grid with a space for comments allowed for a more detailed summary of the person's views than simply having a photograph of each Mat.
4. Some new pictures were added e.g. *hospice, family mealtimes, sense of purpose*

Feedback to participants:

I believe that an essential part of research is feedback to the participants and that as well as producing materials and reports the actual process of research should provide direct benefits to participants. Each participant appeared to find the actual involvement in the research enjoyable and interesting and several commented that it gave them considerable food for thought. No one found it distressing or negative. In several instances their spouses were present and they too found it a useful exercise. They have all been given a copy of the photographs of their completed Mats and the option of receiving a copy of this report once accepted by the Scottish Motor Neurone Disease Association.

Conclusion:

This adapted tool appears to be an effective way of allowing people with MND, both with and without a communication difficulty, to consider their quality of life and express their views on what factors improve and what factors hinder their lives. The real value of the tool will depend on how a person's quality of life is improved by patients, carers and staff making appropriate changes as a result of the views expressed on the mats.

Dissemination and Future Plans:

- The findings from this project will be presented at the Scottish MND Association's Annual Conference in Stirling in September.
- Joan Murphy will present a poster display on this project at Communication Matters Seminar in Lancaster in September.
- The poster display will be presented at the MND/ALS Symposium in Vancouver in November.
- Papers will be submitted for publication in relevant journals.
- Joan Murphy is planning to publish this tool as a training package for use by others involved with people with MND.
- The training package will be available for loan from the Scottish MND Association's library and for purchase from the University of Stirling.
- It could be used by a range of people providing support and services for people with MND, such as MND clinical specialists, nursing staff, speech and language therapists, social work staff, rehabilitation teams
- It would be valuable to use the tool with a greater number of people from a wider range of backgrounds
- The tool could be used over time to compare how people's views and attitudes change.
- Joan Murphy will provide training in the use of the tool for the clinical advisors of the Scottish MND Association
- Joan Murphy has recently received funding from the Scottish Office to carry out a similar project with people with communication difficulties as a result of Stroke.

References:

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