

**Enabling people with a communication difficulty,
as a result of stroke, to discuss quality of life issues.**

Grant Ref: K/OPR/15/10/F21

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Final Report to the Disability Research Committee

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February 2000

1. Summary:

This pilot study examined the effectiveness of **Talking Mats**, a low-tech communication framework developed by Joan Murphy, in allowing people with communication difficulties as a result of stroke to discuss issues concerning the quality of their lives. The study involved twelve people with communication difficulties as a result of stroke living in 4 different residential situations. Insightful observations about the use of the **Talking Mats** were obtained from participants and the framework was modified as a result of their involvement.

The findings show that the **Talking Mats** framework is a useful tool for people with a range of language impairment as a result of stroke. Not only does it allow people to express their feelings about their quality of life but it could also be used to obtain views about quality of service. In addition it could provide information relevant for discharge planning and could be used in an ongoing way as a low-tech communication aid in conjunction with other systems.

2. Original Aims:

Discussions with professionals in NHS stroke centres in Scotland and an examination of the literature confirmed that no suitable quality of life measures exist for people with a communication difficulty as a result of stroke.

The aim of this pilot study was to examine the effectiveness of **Talking Mats**, a low tech communication framework (Murphy 1998) to enable people with communication problems as a result of stroke to express their views about their quality of life. The following questions were addressed:

1. Does the use of the **Talking Mats** framework help people with a communication difficulty as a result of stroke to consider and comment on issues relating to quality of life which are important to them?
2. Does the use of the **Talking Mats** framework help to identify issues relating to quality of life, which are important to people with communication difficulty as a result of stroke?

3. Methodology:

The **Talking Mats** framework is based on 3 sets of picture symbols, which are presented to the person with the communication difficulty. The symbols used were Picture Communication Symbols (PCS) which were produced on the software package Boardmaker™¹. PCS were chosen for a number of reasons: they are cognitively easy to access without appearing childish; they can be adapted to represent the issues and concepts involved in discussing quality of life; they can be used to help people visualise concepts and relationships; they can act as a scaffolding for memory and cognition; they do not require literacy.

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

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

3. Represent possible positive and negative **factors** relating to each issue

Participants:

Ethical permission was obtained from Forth Valley Ethics of Research Committee and the Clinical Director of Central Scotland Healthcare Trust. Following discussion with the Stroke Team at Stirling Royal Infirmary and the relevant speech and language therapists, 12 people with communication difficulties as a result of stroke who live in Forth Valley and their families 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 12 participants were living in 4 different residential situations as outlined in the proposal. Their communication impairments ranged from severe receptive and expressive dysphasia to mild expressive dysphasia. The following table summarises details of the participants:

Gender	Age	Time since stroke	Communication	Residential Situation	Employment
Male	53	3yrs. 5mths.	Mild receptive & severe expressive dysphasia	At home with family	Retired architect
Male	51	6 mths.	Severe receptive & expressive dysphasia	At home with wife	Retired joiner
Male	53	1yr. 2 mths.	Severe receptive & expressive dysphasia	At home with family	Retired landscape gardener
Female	66	1yr. 3mths.	Mild receptive & severe expressive dysphasia	Home alone	Retired home help
Female	65	10mths	Moderate receptive & severe expressive dysphasia	Home alone	Retired Health Service manager
Male	51	7yrs. & 2yrs.	Severe dysarthria	Home alone	Retired management consultant
Male	72	2mths.	Moderate receptive & expressive dysphasia	Acute Ward	Retired farm worker
Male	76	3mths	Mild expressive dysphasia	Acute Ward	unemployed
Male	67	1mth.	Severe receptive & expressive dysphasia	Acute Ward	Retired drainage worker
Male	66	12yrs.	Severe receptive & expressive dysphasia	Long Stay Ward	Retired farmer
Female	71	12mths.	Moderate dysarthria & receptive dysphasia	Long Stay Ward	Housewife
Female	84	5mths.	Severe receptive & expressive dysphasia	Long Stay Ward	Housewife

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 main issues were as follows: **people; home; health; work; indoor interests; outdoor interests**. For those people on the acute and long stay wards **home** was replaced by **ward** 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. Five emotions were used ranging from 'very happy' to 'very angry'. Three people were presented with only a range of 3 emotions due to comprehension difficulties.

Interview:

Instructions and a simple explanation of each symbol was given as well as a demonstration of how to use the mats. For each of the 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 attempted to name the pictures (one using his electronic communication aid), 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 2). The researcher then removed the pictures and prepared the Mats for the next issue to be considered.

Use of video:

Each interview was video recorded in order to allow the researcher to confirm that she had interpreted the participants' views correctly.

Feedback:

I believe that an essential part of research is feedback to the participants and that the actual process of research should provide direct benefits to participants. With the exception of one (who had become very ill) all participants were visited

a few weeks after their interview and given a copy of the photographs of their completed Mats.

4. Results:

All 12 people were able to express their views using the symbols. Eight people completed all sections of the interview. One man on the acute ward became tired and the interview was stopped after 2 issues had been discussed. The 3 participants living on the long stay wards were presented with 2 issues only to consider – **people** and **ward** which were adapted to include health and indoor issues - as it became apparent that issues such as **work** and **outdoor interests** were inappropriate.

The full interview lasted approximately 1 hour. One participant, who gave each issue a lot of consideration, indicated she was becoming tired but wanted to continue the interview the following week. It was therefore completed over 2 sessions.

Analysis of results:

Two methods were used. Firstly, a coded framework was designed to allow for inter-judge reliability between the researcher and an independent observer recruited from the Psychology Department at the University of Stirling. The framework required each observer to code the participants' responses to each issue on a scale of 1-5 as follows:

(1		5)
Understanding of task (facial expression)		Not understanding
Confidence (motor act)		Hesitancy
Confirmation accepted		Confirmation not accepted/ ignored
Satisfied with result		Dissatisfied with result
Comments:		

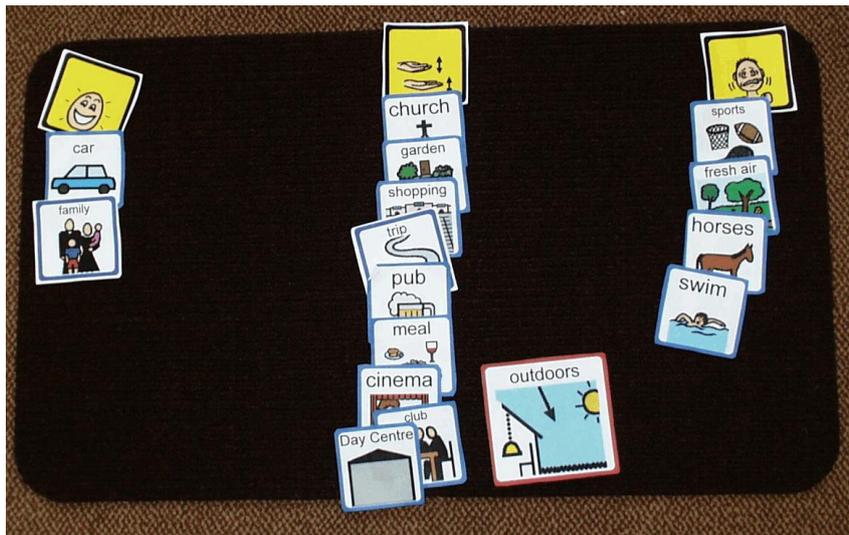
In this way a crosscheck was made of the interpretation of results as well as any misunderstandings which may have occurred. There was agreement between the researcher and the independent observer for 10 of the 12 interviews. For the 2 with some discrepancy, one was related to the participant tiring and the independent observer scoring him as being less satisfied with the results than the researcher. The second participant had very limited facial expression and the independent observer scored him lower in relation to his understanding of the task.

Secondly, the video recordings were analysed using cognitive mapping (see Jones 1985), whereby their completed mats were studied and a 'map' was drawn to represent each participant's views and the connections between them. Once the participants' individual maps were drawn, they were combined to make a further map in order to compare patterns and highlight unique reflections.

The following generalisations can be made in relation to the 4 different residential groups.

At home with family: Those who lived at home with their family rated family members highly in contributing to their quality of life. However they were also able to express that some family members added more to their life than others e.g. one man indicated that one daughter added to his quality of life more than the other (who had 2 young very boisterous children who tired him out). Spouses were present during the interview for all 3 participants who lived with their family. All were surprised by some of the views expressed. For example - one man indicated that he disliked going out in the fresh air whereas his wife had assumed that he enjoyed being taken out in his wheelchair.

Figure 1.



At home alone: All 3 who lived alone indicated that the garden was a source of anxiety as they were no longer able to look after it. Two indicated that some family members upset them and 2 found shopping stressful. Swimming, shopping and his garden frustrated the man who completed this mat. He requested a second car symbol to express how his car hampered his life when it was off the road but greatly improved his quality of life when it was working.

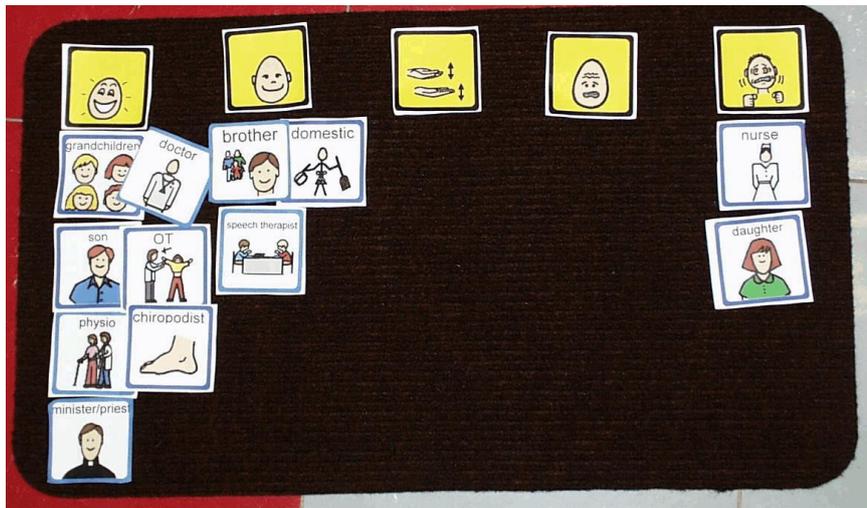
Figure 2.



Talking Mats allowed some people to raise issues of frustration and unhappiness with their situation. Ten participants indicated frustration with aspects of their quality of life especially those related to speech and mobility difficulties and the 3 people living in long stay wards expressed unhappiness with their residential situation. During the interviews care was taken to acknowledge the participant's feelings and to restore and affirm the participant's feeling of self worth.

For example, one participant initially indicated that she felt that there were no people in her life but the researcher was able to show her by her completed mat that in fact she had selected a number of people whom she considered improved her quality of life.

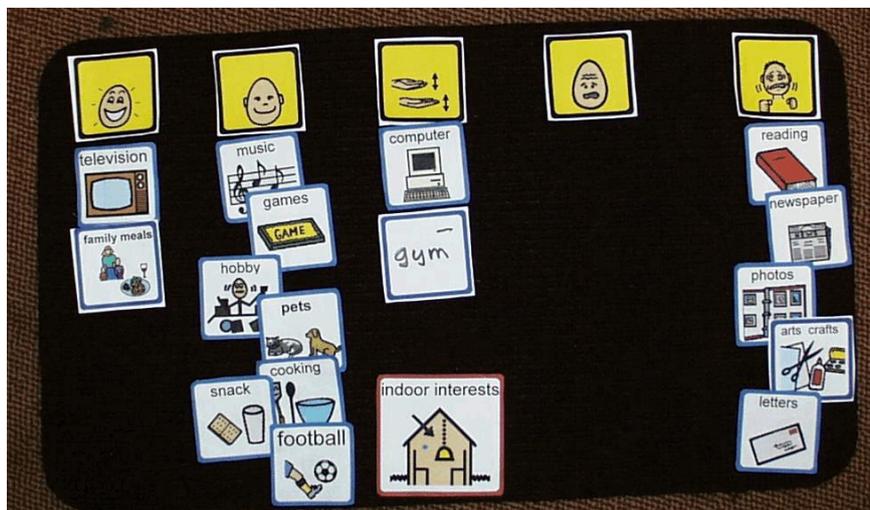
Figure 5.



For some, it showed them that not everything was as bleak as they had thought while for others it highlighted areas that could be altered to improve their quality of life.

For example one man indicated that he felt upset that he could no longer read and as a result his wife took him to the library and borrowed audio books for him. His key worker also investigated getting him involved with the local photography club.

Figure 6.



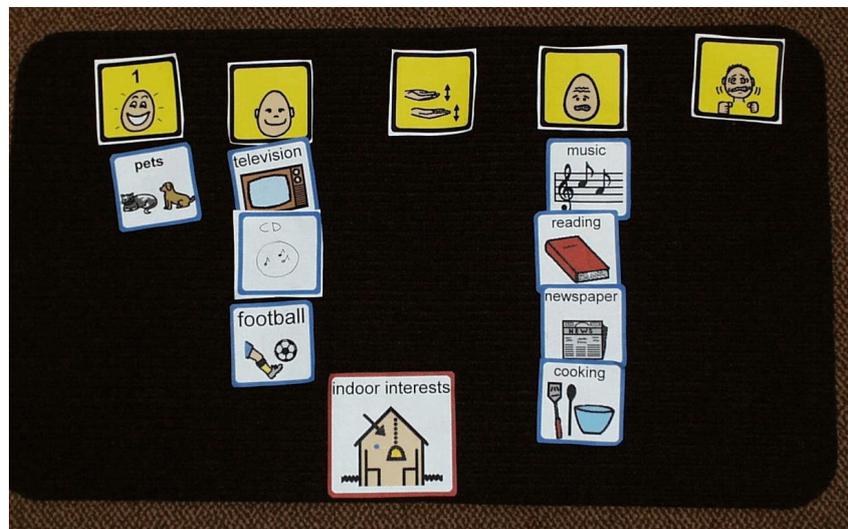
Patterns of language difficulty affected the ability of the participants to use the framework only in as much as those with a receptive difficulty took longer to complete the interview. However, they found it just as fulfilling as those whose speech was only mildly affected. The one man who appeared to become confused was only just 1-month post onset and was probably not neurologically stable. When he was followed up once discharged he had improved significantly. When he was shown his completed mats, and had no recollection of having been interviewed.

It is significant to note the factors which people omitted as well as the factors that they selected as being important in their lives. For example all but 2 participants omitted their consultant as a factor in their health and several omitted money, indicating that it was no longer important to them.

At the feedback visit all the participants affirmed that their involvement in the research had been enjoyable and interesting and no one indicated that they had found it distressing or negative. They all believed that the issues presented to them had covered the main aspects of their lives. Spouses were present with all 3 who lived with their families and all took on board some of the views expressed by their husbands.

For example, one spouse noted that her husband had indicated that he missed his dog and had subsequently got another one from the RSPCA.

Figure 7.



Alterations:

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

1. The range of emotions was altered depending on the receptive abilities of the participant – e.g. for some people the number was reduced from 5 to 3
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 very positive to very negative.

3. Some new pictures were added e.g. **other residents/patients** and **tradesmen** were added to the **people** factors and **holiday** was added to **outdoor interests**.

5. Discussion:

As the numbers in this pilot study were small no broad conclusions can be made but for this group of people the **Talking Mats** were successful in allowing them to think about their lives and express their views. It appears that this 'story telling' format is more comfortable and successful for people with a communication difficulty than a structured interview or questionnaire. 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. Although for some participants some issues were painful, they all found it satisfying to be able to express their views in a concrete way with a tangible result.

The **Talking Mats** could be used initially to "take the temperature of an individual", both in hospital and at home, providing the opportunity to come back and explore some issues in more detail. Using photographs in conjunction with **Talking Mats** allows feedback to be given, not only to the participants but also (with their permission) to family, carers, and professionals. For several participants some aspects of their lives were changed as a result.

Talking Mats could be used to allow people to comment on quality of service such as food, privacy, warmth, staff attitudes in hospitals and nursing homes as well as to consult with people prior to discharge from hospital and provide information to ward staff and social work staff.

6. Conclusions:

This tool appears to be an effective way of allowing people with a range of communication difficulties as a result of stroke to consider and express their views on their quality of life.

It also helps people identify the factors that are important for them and to indicate how these either improve or hamper their lives.

It could be used simply to allow people to express their views but it could also be used to help with planning someone's discharge from hospital, to alter aspects of their home situation or to obtain views about quality of service. The real value of the tool, however, will depend on how a person's quality of life is improved by family, carers, staff and patients themselves making appropriate changes as a result of the views expressed on the mats.

References:

- Bowling, A. (1998) *Measuring Health* Open University Press
Murphy, J. (1998). *Talking Mats: Speech and language research in practice. Speech and Language Therapy in Practice*, Autumn 1998, 11-14.

Acknowledgements:

I would like to thank the 12 participants and their families for their involvement and willingness to share their thoughts with me. Thanks also to the Speech and Language Therapy Department and Ward Staff at Stirling Royal Infirmary. Particular thanks to Barbara Kettlewell, Joyce Seaward and Anne Marie Irving for their invaluable observations and insights.

7. Importance to NHS:

Policy makers could use this tool if they genuinely wish to obtain the views of consumers on service evaluation. All too often family and carers are asked to comment on behalf of people with communication difficulties. In addition this framework could be considered where public consultation is involved.

Health Service Managers, whether it be in hospital wards or therapy departments, could make use of this framework to consider patients' views in discharge planning and evaluation of quality of service, thus ensuring that dysphasic patients' views are included in audits and surveys of patient satisfaction.

Service Providers such as Speech and Language Therapists, Occupational Therapists, Rehabilitation services and Ward staff could use this tool in a range of situations to involve people with communication difficulties

8. Future research

- Joan Murphy is investigating the development of this framework as a package for use by Speech and Language Therapists and others involved with people with stroke.
- Future research is needed to validate this framework and to confirm its reliability with a larger number of participants.
- The framework could be used to compare patterns of views in different situations.
- It could be used to compare patients' views over time, as their communication situations and /or living situations change

9. Dissemination:

- Joan Murphy discussed the project and presented preliminary findings at an AAC study day in Oxford in January 2000.
- Joan Murphy has been invited to present a workshop based on this study in Fife in March 2000.
- Joan Murphy has been invited to present findings to and run workshops for staff of Forth Valley Primary Care NHS Trust
- Joan Murphy has been asked to submit a paper to ADA (Action for Dysphasic Adults)
- The findings from this project have been submitted for presentation at ISAAC International Conference in Washington DC in August 2000.
- Joan Murphy will present a poster display on this project at Communication Matters Seminar in Lancaster in September 2000.
- Papers will be submitted for publication in relevant journals.

10. Research workers:

Joan Murphy was the sole researcher on this project. She was responsible for the planning and implementation of the research and the writing of the final report

Barbara Kettlewell was employed as administrative assistant. Her duties included organising the ethical permission, producing the pictorial symbols,

acting as independent observer in the analysis of the video data and carrying out administrative duties

11. Financial statement:

The finance office at the University of Stirling will provide this.