Communication and dementia

How Talking Mats can help people with dementia to express themselves

Joan Murphy, Cindy M. Gray and Sylvia Cox

This report examines the effectiveness of Talking Mats, a low-tech communication tool, in helping people at different stages of dementia to express their views.

As dementia progresses, communication deteriorates and it becomes increasingly difficult to ensure that the person's views are heard. This study involved 31 people who were each interviewed about their well-being using both Talking Mats – a system of simple picture symbols – and usual communication methods.

The researchers compared the effectiveness of each method and found that:

- Talking Mats improved the ability of people at all stages of dementia to communicate, compared to usual communication methods

- this tool also reduced repetitive behaviour and helped to keep participants engaged in conversation.

The findings suggest that Talking Mats can play an important role in improving quality of care for people with dementia.

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"I do believe in this. I do believe this is good"
James McKillop. Scottish Dementia Working Group

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Acknowledgements

Summary

Enabling people with dementia to continue to communicate their views, needs and preferences as their condition progresses is essential for the development of person-centred services and care facilities. This project examines how one low-technology, highly accessible communication tool, Talking Mats, can help individuals with dementia express their opinions. Talking Mats use a system of simple picture symbols that allow people to indicate their feelings about a subject by placing the relevant image below a visual scale.

Thirty-one people at various stages of dementia (care staff who knew each person well estimated whether they were early, moderate or late stage) were asked about four topics that were considered important for their well-being: 'Activities', 'Relationships', 'Environment' and 'Self'. Three interview techniques were compared: Talking Mats, Structured Conversation and Unstructured Conversation. In the Unstructured Conversation interview, participants were simply asked to tell a fieldwork researcher about the things they did during the day, the people in their lives, their surroundings and themselves. In the Structured Conversation interview, each topic was subdivided into a number of options (for example, two of the options in 'Activities' were 'reading' and 'going for a walk') and the participants were asked how they felt about each option in turn. The Talking Mats interview was conducted in a similar fashion to the Structured Conversation interview, except the topics and options were represented in picture form and placed under a visual scale.

Talking Mats were shown to be more effective than both Structured and Unstructured Conversation in allowing people with dementia to communicate their views about their well-being. The communication framework improved participant understanding, researcher understanding, participant engagement and the amount of time the participant remained on track. These improvements were particularly evident in people with moderate- and late-stage dementia. In addition, Talking Mats reduced perseveration, increased the amount of time spent on task and improved the reliability of the information provided by the person with dementia. Finally, although people appeared to become less able to place the Talking Mats symbols as their condition progressed, some people with late-stage dementia were still able to express nuanced views and to make use of the entire three-point visual scale.

The problem of obtaining informed consent for research from people with dementia was addressed by using a three-stage consent procedure. This procedure involved approaches to staff and family members as well as to the people with dementia themselves. A policy of ongoing consent was also adopted. Furthermore, as the

project involved obtaining video recordings of fieldwork interviews with people with dementia, this aspect of the consent procedure was given particular consideration and has implications for future research.

Issues also arose over the use of staff estimates to assign participants to the early- moderate- or late-stage dementia groups. Inconsistencies were evident not only between staff from different organisations, but also between the staff members of individual dementia service providers and residential care homes. Accordingly, a new scale to assess the degree of communication impairment of a person with dementia was developed and piloted during the course of the project.

This project has clear implications for practitioners, commissioners and policy makers. First, it has found that people with early- and moderate-stage dementia are able to use Talking Mats effectively. Second, the framework allows people with moderate-and late-stage dementia to communicate their views more readily than either ordinary or structured conversation. Third, Talking Mats help people with early-stage dementia to stay on track and to make themselves understood. Fourth, as people with early-stage dementia can communicate effectively regardless of the medium used, Talking Mats may prove especially useful when they face difficult decisions (e.g. giving up driving). Here, the communication framework should help these individuals to order their thoughts, and to weigh up the benefits and drawbacks of a particular course of action more easily. Fifth, because discussions with Talking Mats usually take longer than simple conversations, the framework may also simply be enjoyed as an activity allowing people with dementia to occupy their time doing something that is personally meaningful to them.

The main outcome of this project will be the development of new Talking Mats packages containing advice and materials for using the communication framework with people with dementia. In addition, training programmes will be offered in order to provide staff at dementia service providers and residential homes with the skills required to use Talking Mats effectively with people with dementia.

Finally, further research is needed to look at issues such as how Talking Mats might aid people with early- and moderate-stage dementia in making key decisions about their life, and whether becoming familiar with Talking Mats in the earlier stages of the condition may make the framework easier to use as dementia progresses. Furthermore, it will be important to identify any facilitating factors that could encourage care staff and family members to use Talking Mats with people with dementia. Equally, any barriers that might prevent effective usage of the communication framework by staff and relatives should also be recognised in order that training/strategies can be developed to enable these obstacles to be overcome.

1 Introduction

> The goals of quality care giving should … be to prolong communication between patient and caregiver for as long as one can.
> (Carroll, 1989, p. 100)

The deterioration of communication between people with dementia and their carers is one of the most painful aspects of the illness. Depending on the type and cause of dementia the communication difficulties experienced may include:

- reduced vocabulary

- word-finding difficulty

- problems with reasoning

- repetition of thoughts

- lack of coherence

- losing track of topic

- distractibility (Bourgeois, 1991; Whitehouse, 1999).

As dementia progresses, the person becomes harder to reach, and it is increasingly difficult to ensure that their views are included and that decisions are made with their involvement.

The gradual, or sometimes sudden, deterioration in communication is a significant factor in many types of dementia-related conditions. Such deterioration may occur in the early stages of the illness, for instance due to a stroke, or at a much later stage when death is imminent (Allan, 2001; Clare, 2001). This variation in communication ability means that a wide range of staff in different settings such as GP surgeries, day centres, outpatient departments, hospitals, care homes and hospices may be challenged to improve their communication skills with people with dementia. At home, support and care staff, as well as family carers, friends and other relatives, may also wish to find ways to communicate more effectively.

Communication, quality of care and well-being

There are currently 700,000 people with dementia in the United Kingdom; the majority (62 per cent) have Alzheimer's disease, but vascular and mixed-type dementia are also common subtypes that account for a further 27 per cent of diagnoses (Alzheimer's Society, 2007). Although most people with dementia are over 65, a significant minority (at least 15,000) have early-onset dementia. The current cost of dementia to the UK economy is over £17 billion a year (Alzheimer's Society, 2007), and with the number of individuals diagnosed forecast to rise to over a million by 2025, the cost of care provision will likewise escalate.

Until relatively recently the tendency to medicalise dementia has meant that 'personhood' has often been neglected (Kitwood, 1997). This disregard for the identity of the individual becomes more apparent when someone cannot easily voice their own opinion. A person with dementia may become progressively disempowered if staff or carers have lowered expectations and reinforce dependency (Cheston *et al.*, 2000). Poor care, limited stimulation, depression and low self-esteem may also affect the perceptions of staff or carers of a person's capacity to communicate. As a result, service providers, and those regulating and evaluating care, may find it difficult to identify which aspects of the person's problems are due to organic impairment and which are due to other factors (Reifler and Larson, 1990).

Recent work demonstrating learning and adaptation in people with Alzheimer's disease suggests that appropriate interventions can improve quality of life (Clare, 2001). There is increasing evidence that people with dementia can articulate opinions about their well-being and quality of care even when their condition is fairly advanced (Mozley *et al.*, 1999; Barnett, 2000; Wilkinson, 2002). Nevertheless, there is continued reliance on observational methods such as dementia care mapping (Brooker, 2002) when assessing the well-being and needs of people with dementia. A major limitation of this type of approach is that observational techniques largely fail to take account of the views of the person with dementia themselves when developing appropriate care packages to enhance their quality of life.

The effectiveness of person-led approaches in improving service provision for people with dementia has been clearly demonstrated (Allan, 2001). This study concluded that there were several steps that could be taken to allow people with dementia to express their views more readily:

■ using carefully chosen pictures

■ making use of both verbal and non-verbal communication

- giving people opportunities to talk in indirect ways

- giving people time to express themselves

- providing resources to help staff communicate.

Such recommendations are often challenged by time constraints, limited staff support and difficulties in recording and collating views (Care Commission, 2005). However, in order to improve service planning and service delivery to care facilities, it is essential that the views of the users of these facilities are included (Barnes and Bennet, 1998). Unfortunately, many individuals with dementia may be unable to respond to conventional methods of canvassing people's viewpoints (for example, interviews or questionnaires), and because their views are seldom sought, there is a serious gap in knowledge about their needs and experiences (Midgley *et al.*,1997; Oldman, 2000; Appleton, 2002). It is therefore imperative to explore alternative ways of allowing people with dementia to communicate, and to help them have their say about service provision and its impact on their quality of life.

Policy and practice relevance

There is now recognition that poor communication must also be understood within the context of the marginalisation and exclusion of people with dementia (Cheston *et al.*, 2000; Innes and Capstick, 2001; Sabat, 2001). Complementing a medical model of dementia care, which focuses on dementia as a progressive disease (Gilliard, 2001), the social disability and citizenship models emphasise the social context within which care and services are provided (Cox and Keady, 1999; Wilkinson, 2002). There is now more emphasis on using health and social care outcomes, *and* the opinions that people with dementia have about these outcomes, to measure quality of care (Bamford and Bruce, 2000; Cox and Dick, 2000).

The thrust of UK government policy in health and social care (Scottish Executive, 2000b, 2005a; Department of Health, 2001, 2006a, 2006b) both for older people and for individuals with mental health problems, including dementia, is to:

- recognise service users as citizens

- end inequalities and social exclusion

- ensure that service users have more choice and control over the care that they receive.

Accordingly, in 2001 the Department of Health set out a programme of action and reform with a view to delivering higher quality services for older people. This National Service Framework for Older People aimed to:

■ provide person-centred care

■ promote older people's health and independence

■ fit services around people's needs.

The service development guide *Everybody's Business* (Department of Health and Care Services Improvement Partnership, 2005) builds on the National Service Framework (Department of Health, 2001) in setting out the essential components of a comprehensive mental health service for older people (including those with dementia). Inclusion and involvement are seen as the keys both to improving mental health and well-being and to delivering more effective and person-centred outcomes for individuals and their families. Other organisations have similarly highlighted the challenges around promoting and delivering better mental health and well-being for older people (Scottish Executive, Alzheimer Scotland and Short Life Working Group, 2004; Commission for Social Care Inspection, Audit Commission and Healthcare Commission, 2006; UK Inquiry into Mental Health and Well-Being in Later Life, 2006).

Specific guidance on dementia services in the UK addresses the organisation and delivery of health, housing and social care services for people with dementia (NICE/ SCIE, 2006; Scottish Intercollegiate Guidelines Network, 2006). The NICE/SCIE (2006) guidelines confirm the key principles of person-centred care by stating that:

■ Individuals with dementia should receive all available support.

■ Health and social care professionals must act in the best interests of the person with dementia.

■ The human value and individuality of people with dementia should be respected.

■ Heath and social care staff should identify the specific needs and preferences of people with dementia.

■ Care plans should address and record the views of the individual with dementia.

- Care plans should be based on the life history and individual circumstances as well as on the physical and mental health and current level of functioning of a person with dementia.

- Appropriate interventions should be used to ensure that communication difficulties do not become a barrier to accessing (or understanding) services, treatment or care.

- Independent activity should be maximised, and the person with dementia should be encouraged to adapt existing skills and to develop new skills.

- The delivery of health and social care services for people with dementia must be co-ordinated.

These principles are relevant to all the key service domains identified in the *Everybody's Business* report (Department of Health and Care Services Improvement Partnership, 2005), including primary care, home care, residential care, intermediate care and inpatient care. The principles also encompass day care services (both mainstream and specialist), specialist mental health services, memory assessment services, psychological therapies, housing, and assistive technology and telecare.

The NICE/SCIE (2006) report provides evidence-based good-practice advice to care practitioners and service commissioners across sectors, and forms a benchmark against which the outcomes of services should be assessed. The guidelines recommend that people with dementia should:

- be involved and in control of their own living arrangements and support on a day-to-day basis

- have their voice heard in person-centred care planning and reviews

- have their voice heard in the regulation, development and improvement of services and support systems

- be involved in decisions about key life choices and transitions

- be involved in decisions about care and treatment.

The UK Government is committed to the expansion of choice and control for service users, including people with dementia. As a result, the Care Services Improvement Partnership in England (Care Services Improvement Partnership, 2006) is currently

undertaking a nationwide trial of individual budgets that aim to give people who use public services more control over the support or services they receive. Similar pilots are also under way in Scotland (Scottish Executive, 2005b). Moreover, the National Audit Office will shortly publish the findings of a major investigation into person-centred service provision for older people with dementia (UK National Audit Office, forthcoming 2007). This report will provide recommendations on ways in which service providers can ensure that individuals with dementia can maintain good physical and mental health and a high standard of quality of life for as long as possible.

Finally, mental health legislation in the UK (Scottish Executive, 2000a; Department for Constitutional Affairs, 2005) is built on a number of key principles, including the assumption of mental capacity unless proved otherwise. Importantly, the law states that however limited a person's overall capacity, they are still likely to be able to make their own day-to-day care-related decisions. In practice, therefore, every effort must be made to communicate, using whatever means necessary, in order to engage people with mental health problems (such as dementia) in decision making and to maximise their involvement. Furthermore, acting in an individual's best interests should involve taking all practicable steps to establish their feelings, values and beliefs.

Talking Mats

In view of these moves towards inclusion in policy decision-making and towards person-centred care, it has recently been suggested (Care Commission, 2005) that a variety of simple communication tools should be made available to allow care staff and external care service evaluators to more easily ask individuals with dementia what they think of the services being provided. Talking Mats are a simple, low-technology device that was specifically developed to help people with a range of communication difficulties express their opinions (Murphy, 1998). Talking Mats consist of a textured mat on which picture symbols are placed as a conversation progresses (Figure 1). Three types of picture symbols are used to represent:

■ the topics to be discussed

■ the options relating specifically to each topic

■ the visual scale to allow people to indicate their general feeling about each option.

Figure 1 A Talking Mat
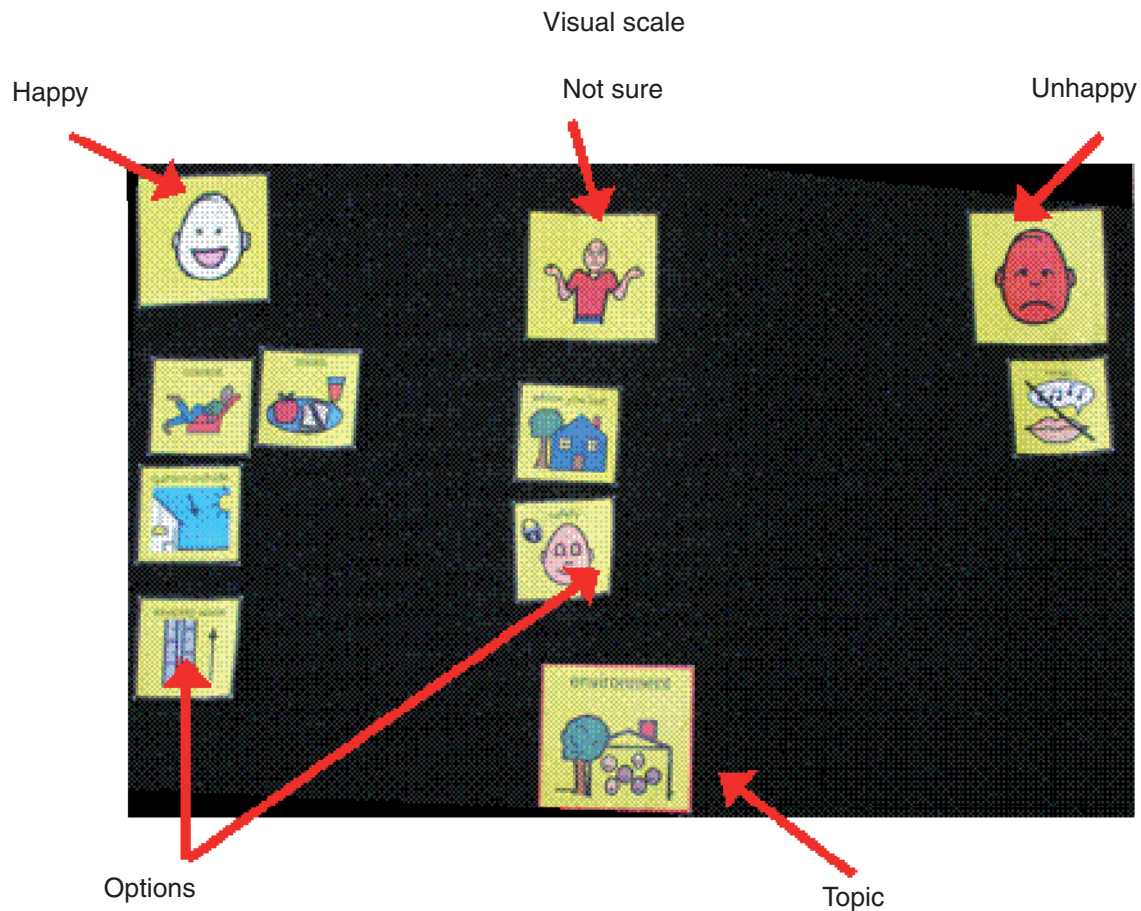
Over the past ten years Talking Mats have generated worldwide interest and have been used successfully with different client groups:

■ people with cerebral palsy (Murphy, 1998)

■ people with motor neurone disease (Murphy, 1999)

■ people with aphasia (Murphy, 2000)

■ people with intellectual disability (Cameron and Murphy, 2002).

Talking Mats helping people with dementia to communicate?

A more detailed description of Talking Mats and how they were used in this project can be found later in this report (see Chapter 2, 'Project overview'), but it is clear from Figure 1 that Talking Mats fulfil several of Allan's (2001) criteria:

- Talking Mats use pictures.

- Talking Mats allow people to communicate both verbally and non-verbally.

- Talking Mats are low-tech and inexpensive, and are therefore highly accessible for staff.

In addition, many people with dementia may not be officially diagnosed as having the condition. Consequently, the fact that Talking Mats can be used to improve communication with a number of client groups means that they should be more inclusive and less stigmatising for those being interviewed.

Finally, recent research has indicated that Talking Mats may help people with dementia communicate. As part of a study addressing quality of life issues in frail older people who had recently moved into care homes, Murphy *et al.* (2005b) used Talking Mats to successfully elicit the views of seven individuals with dementia whose communication difficulties meant they would have otherwise been excluded from the research. However, although encouraging, the small number of people interviewed means that it was not possible to generalise the findings from this project or to conclude that Talking Mats are effective with a range of people with dementia.

Aims of the project

The central aim of this project was to examine the effectiveness of Talking Mats as a communication resource to enable people with dementia to express their views about their well-being. There were two principal research questions:

1 Do Talking Mats help people with dementia communicate?

2 Are Talking Mats effective for all people with dementia, or do only those in the earlier stages of the illness benefit?

To address these questions, a number of participants at different stages of dementia were asked about the various aspects of their lives (e.g. relationships, environment and activities) that contribute to their social well-being. Each person discussed the same topics using Talking Mats and two forms of conversation. The three interviews were then compared to determine which means of communication was most effective for people in the early, moderate or late stages of dementia.

2 Project overview

The project ran over a 15-month period and comprised a number of key elements, some of which were concurrent. This chapter describes the design and data collection phases of the project: namely, participant recruitment; consideration of the subjects for discussion; designing the Talking Mats symbols; the pilot study; and the main fieldwork phase.

Participants

Participants were recruited through dementia service providers and residential care homes in Forth Valley. During the first three to four months of the project, suitable establishments were identified and senior members of staff approached to ask if they would be prepared to become involved. Two dementia service providers and five care homes agreed to take part:

■ Alzheimer Scotland, Falkirk Services

■ Joint Dementia Initiative, Falkirk

■ Burnbrae Residential Home, Falkirk

■ Forthbank Nursing Home, Stirling

■ Grahamston House, Falkirk

■ Randolph Hill Nursing Home, Dunblane

■ Westerlands, Stirling.

The next phase of the project involved approaching people with dementia themselves and their families to ask them if they would be prepared to become involved. The manner in which potential participants were approached was determined by senior staff members who identified those individuals capable of giving consent themselves, and those whose family should be approached in the first instance. Precise details of the procedures adopted here are given in Chapter 3, 'Obtaining consent from people with dementia'.

People were eligible to become involved in the project if they were native English speakers, had sufficient visual acuity to see the Talking Mats symbols and had a medical diagnosis of dementia (as confirmed by a staff member). Thirty-six people with dementia were approached: of these, two were unable to see the symbols; one did not have English as his first language; one did not consent to being videoed; and one became extremely anxious following the consent visit. The remaining 31 people (22 women, nine men: average age 79.4 years, range 54–90) were willing and eligible to take part in the project. Care staff were asked to provide a precise diagnosis of dementia type where possible. The most common diagnoses were mixed-type dementia and Alzheimer's dementia. A number of people also had multi-infarct dementia, vascular dementia and Korsakoff's syndrome. However, as Figure 2 demonstrates, a precise diagnosis was not available for over a third of participants.

Figure 2 Diagnoses of dementia
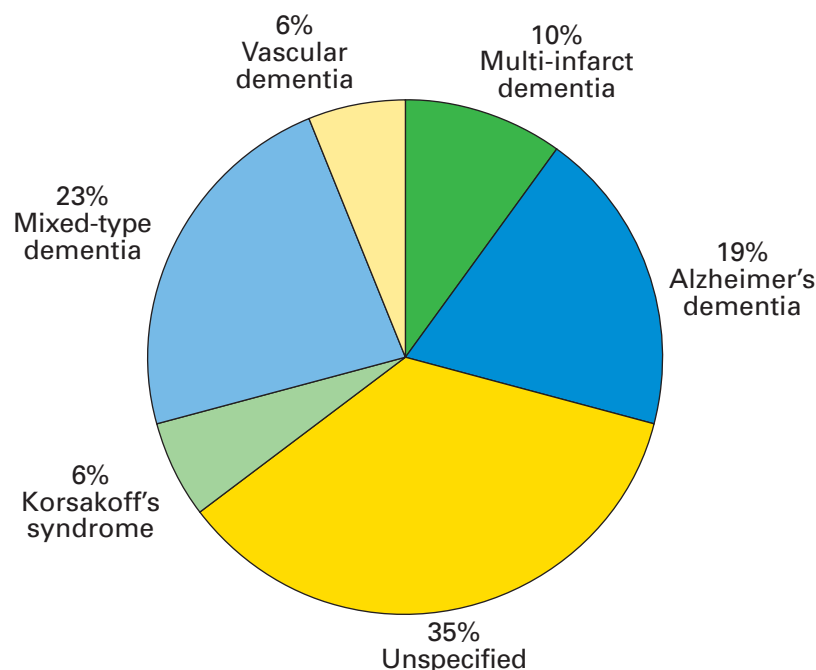
The methodology used in the project required participants to be assigned to different groups according to the stage of dementia they had reached. Advice was therefore sought from staff members at the relevant dementia service provider or care home as to what stage of dementia (early, moderate or late) best described each participant:

■ Ten people (five women, five men: average age 73 years, range 54–89) were estimated to have early-stage dementia.

- Eleven people (seven women, four men: average age 82 years, range 70–90) were estimated to have moderate-stage dementia.

- Ten people (ten women: average age 83 years, range 75–89) were estimated to have late-stage dementia.

Not surprisingly, those people estimated to have early-stage dementia tended to be younger than those estimated to have moderate- and late-stage dementia. There was no age difference between the moderate- and late-stage groups themselves.

The participants in the project either lived at home, had moved into sheltered housing or were residents in care homes. Table 1 shows that the majority of people with early-stage dementia remained in their own homes (either relatively independently or with support from family and paid carers) or had moved into sheltered housing. Most of the participants classified as having moderate dementia lived in care homes, although three remained in their own home with help from family and paid carers. All those in the late-stage group required full-time residential care.

Table 1 Usual living environment

	Own home	Sheltered housing	Care home
Early stage	4	2	4
Moderate stage	3	–	8
Late stage	–	–	10

Identification of subjects for discussion

The researchers in the current project were interested to hear what people with dementia felt about their lives, with the central theme of each interview being the participant's well-being. The choice of specific topics for discussion was primarily informed by previous research conducted to examine quality of life in frail older people (Murphy *et al.*, 2005b); but the researchers also took account of advice from members of the Project Advisory Group. Participants were questioned about four aspects of their lives:

- Activities (e.g. reading, chatting, going for a walk): this topic allowed participants to consider how they spent their time and to say which activities they liked or disliked.

- People (e.g. family, doctor/nurse, friends): personal relationships are fundamental to people's well-being, and this topic allowed participants to comment on their relationships with others.

■ Environment (e.g. noise, comfort, warmth): this topic dealt with specific practical aspects of people's lives with a particular focus on their surroundings.

■ Self (e.g. health, clothes, memory): this topic presented options relating to participants' views about their health and appearance.

The four topics were discussed under three interview conditions:

1 Unstructured (ordinary) Conversation: the researcher simply asked the participants to tell her about each topic, particularly about the things/people they liked or did not like.

2 Structured Conversation: each topic was subdivided into a number of options that were discussed in turn (in random order).

3 Talking Mats: similar to the Structured Conversation interview, but here the topics and options were converted into visual symbols (Figures 3 and 4) using Mayer-Johnson Boardmaker software[1] and placed under a visual scale (see Figure 7).

Figure 3 Talking Mats topic symbols

Figure 4 Talking Mats 'Activities' option symbols
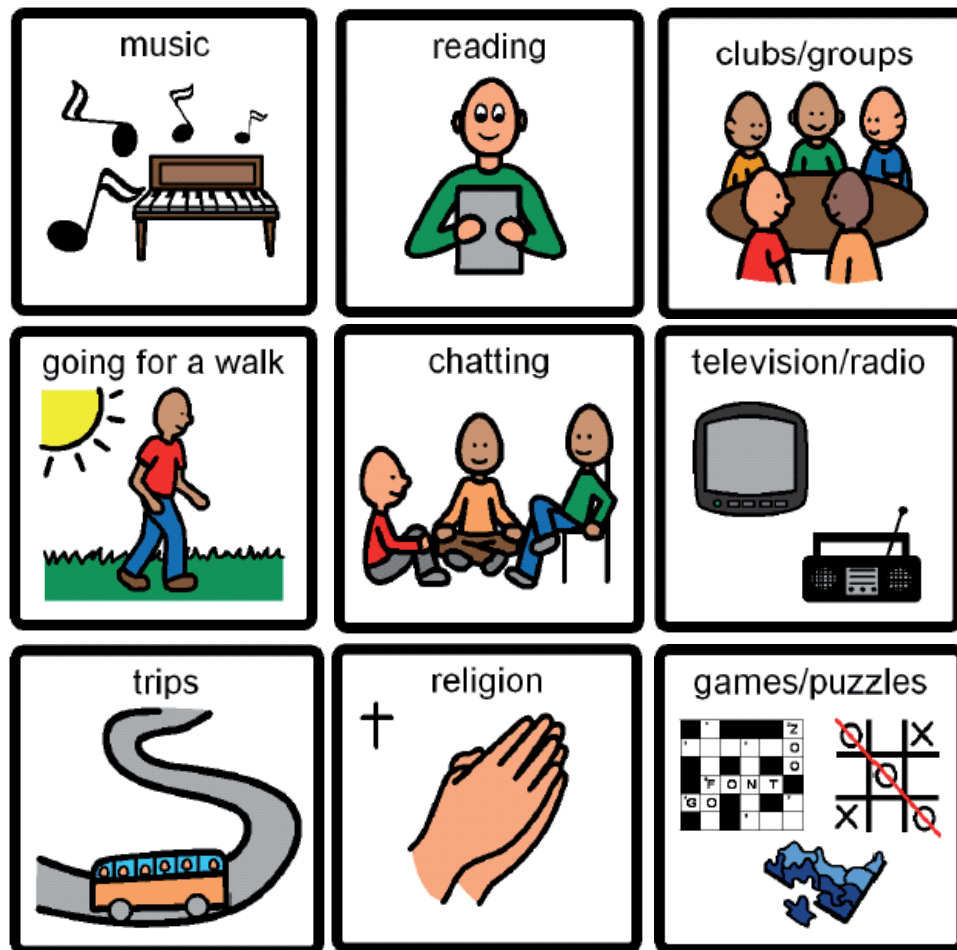
The choice of options relating to each topic was again primarily informed by previous research (Murphy *et al*., 2005b). In the current project, however, care had to be taken to use options that would be relevant to all participants regardless of their stage of dementia and usual living environment. The Talking Mats symbols used in the 'Activities' topic are depicted in Figure 4, and a full list of topics and related options is provided in the Appendix.

Designing Talking Mats symbols for maximum visibility

As people grow older their vision deteriorates naturally. However, individuals with dementia may have additional specific problems with seeing. For example, people with mild Alzheimer's disease have been shown to perform worse on tests of contrast sensitivity, visual attention and colour than people without dementia (Rizzo *et al*., 2000). Care was therefore taken during the design of the Talking Mats symbols to ensure that they would be highly visible:

- The option symbols were made larger than those ordinarily used (6 cm x 6 cm vs 5 cm x 5 cm).

- The symbol titles were displayed in Arial 20 pt (Arial 14 pt is traditionally used).

- The images were kept as simple as possible.

- A set of larger option symbols (8 cm x 8 cm, with titles in Arial 28 pt) were produced for individuals who had particular visual difficulties.

As colour contrast is particularly important for people with dementia (Brawley, 1997), the symbols were always displayed against a black mat. Versions of both sizes of symbols with yellow backgrounds (instead of the traditional white background) were also produced (Figure 5). Yellow is a highly visible colour that is often used to convey information in signs, both in everyday environments (Calkins, 2002) and in environments specifically designed for people with dementia (Marshall, 2003). Furthermore, the red/yellow end of the spectrum remains easier to distinguish with age than blues and greens (Wijk *et al.*, 1999).

Figure 5 Yellow Talking Mats 'Activities' symbols

At the start of the Talking Mats interview, participants were shown the white and yellow versions of one of the topic symbols and asked which they found easier to see. If people did not find any difference in visibility between the white and yellow backgrounds, they were simply asked which colour they would prefer to use. Over half the participants chose to use the yellow symbols, with that preference being especially pronounced in those with late-stage dementia (Figure 6).

Figure 6 Symbol colour choices
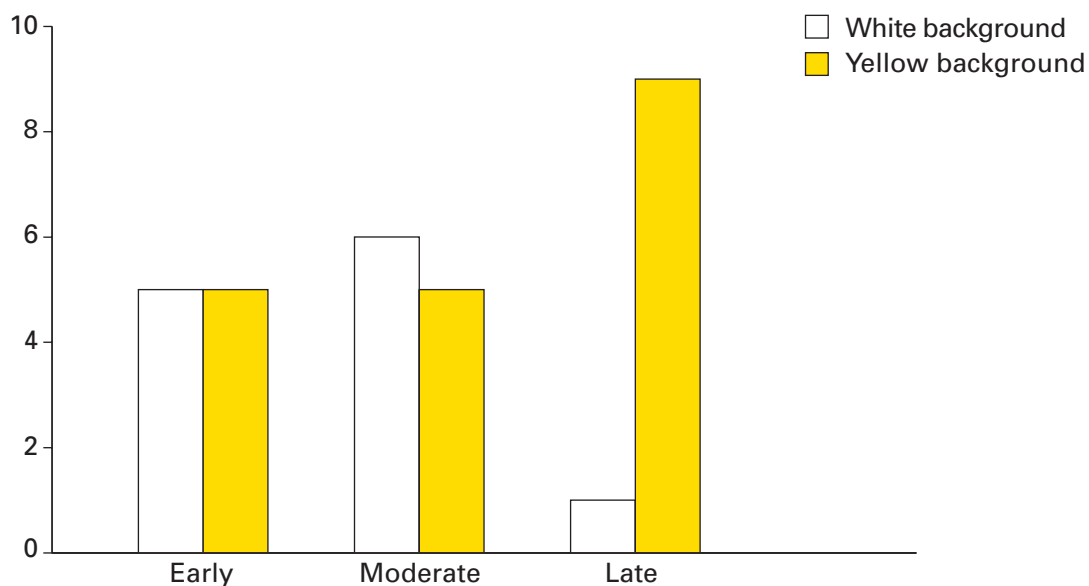
Pilot study

Before proceeding to the main fieldwork phase of the project, a short pilot study was conducted using six people with dementia: two early-stage, three moderate-stage and one late-stage. This pilot raised a number of issues that were addressed before the main data collection phase commenced. First, only two interview conditions had been planned initially: Talking Mats and Structured Conversation. However, it became apparent that the Structured Conversation interview was not representative of the usual type of interactions that would occur between people with dementia and their relatives, care staff or friends. A third condition, the Unstructured Conversation interview, was therefore added to approximate more closely to a real-life situation.

Second, there were concerns over the reliability of asking staff to estimate the stage of dementia of each participant. Staff estimates often varied, not only between establishments, but also between staff members within a single organisation. The researchers therefore developed a new means of estimating stages of dementia based more closely on an individual's capacity to communicate. The development

of this Communication Difficulties Scale and its implementation are described in Chapter 6, 'Stages of communication'.

Third, when using Talking Mats, the interviewee should take ownership of symbol placement wherever possible. However, although people with dementia may be physically capable of putting symbols on the mat, the increased cognitive load involved in placing each option symbol appropriately led to some of the pilot participants becoming increasingly confused and agitated. Consequently, the researcher avoided this problem in the main fieldwork phase by offering more help to those participants who seemed unsure about how to place the symbol.

Fourth, there was occasional confusion over what the option symbols were supposed to represent. For example, one person in the pilot study thought the road in the 'trips' symbol (see Figure 4) was a snake. She therefore refused to place it under the 'happy' emotion even though she did enjoy going on trips with her support worker.

Finally, the original symbols chosen to depict the visual scale included a red triangle to represent the 'unhappy' emotion (Figure 7, Panel A). Some pilot participants said that this image reminded them of danger rather than of unhappiness. The 'unhappy' symbol was therefore changed to show a facial expression. The colour of the 'happy' face was also altered to be clearer against a yellow background (Figure 7, Panel B).

Figure 7 The visual scale

| Happy | Not sure | Unhappy |
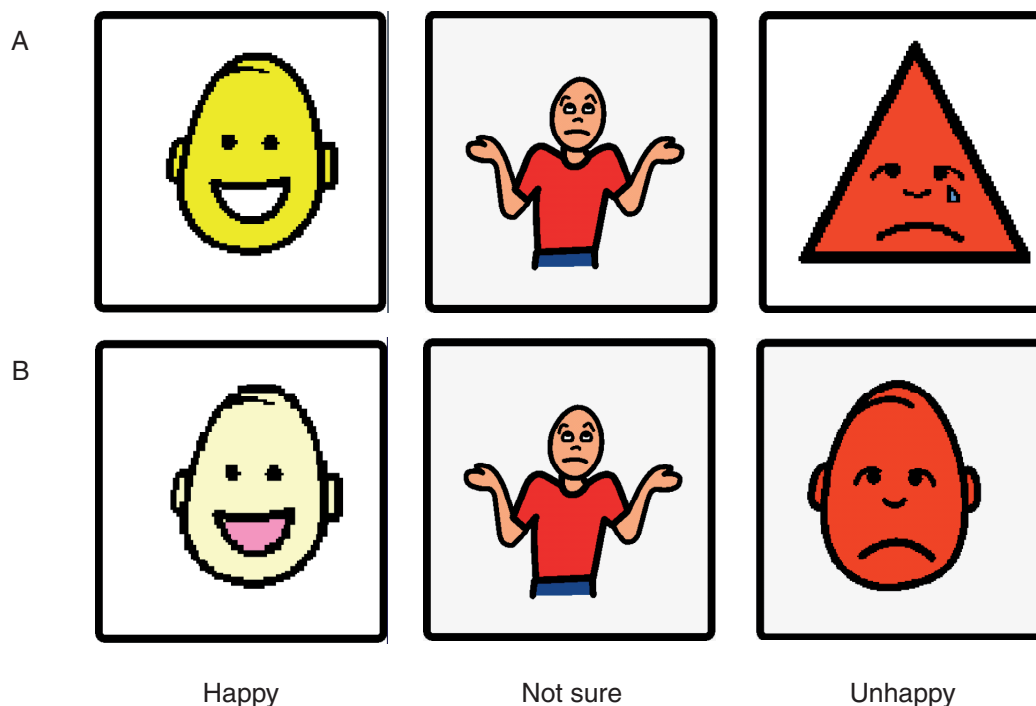
Panel A shows the emotion symbols used for pilot study. Panel B shows the revised version used during fieldwork.

Fieldwork

The main data collection period lasted seven months. Each individual with dementia was visited on at least three occasions. The first visit was primarily to inform the participants about the study and to ask if they would be willing to take part (see Chapter 3, 'Obtaining consent from people with dementia'). This visit was also used to obtain some background information about the participants, for example asking a third party who knew the person well (most often a care staff member, but occasionally a relative) for information about what activities the person enjoyed doing.

The three interviews were conducted and recorded during the second and third fieldwork visits. The order of the interviews was counterbalanced: half the participants did the Talking Mats interview during the second visit; the other half did the Conversation interviews first. The Conversation interviews were conducted during the same visit, with the Unstructured Conversation always preceding the Structured Conversation as the reverse order might have appeared unnatural.

The topics were also always discussed in the same order: 'Activities', 'People', 'Environment', 'Self'. This order was maintained as the options in the 'Activities' topic were the most concrete and easiest to understand, while the options in the 'Environment' and 'Self' topics tended to be more abstract and therefore more difficult to comprehend. Where a participant's responses indicated that they were tired or uncomfortable, the interview was stopped.

During both the Structured Conversation and Talking Mats interviews, the options were presented to participants one at a time in random order. Open questions were used wherever possible (e.g. 'How do you feel about reading?'), and participants were given plenty of time to respond. At the end of each topic in the Talking Mats and Structured Conversation interviews, participants were asked if there was anything else they would like to talk about to ensure that nothing relevant was left out.

When using Talking Mats, participants were encouraged to place the options symbols under the visual scale themselves (Figure 8). Where this was not possible, the researcher placed the symbols according to the participant's verbal (e.g. speech and other utterances) and non-verbal (e.g. facial expression, eye contact, pointing, gesture and body language) behaviours. Where participants did not express any opinion about particular options, these were left off the mat. At the end of the Talking Mats interview, the researcher went over the completed mat with the participant to confirm that she or he was happy with the views expressed, and a photograph of the mat was taken to provide a record of the person's views on each topic (Figure 9).

Figure 8 A participant using Talking Mats

Figure 9 One participant's completed mats
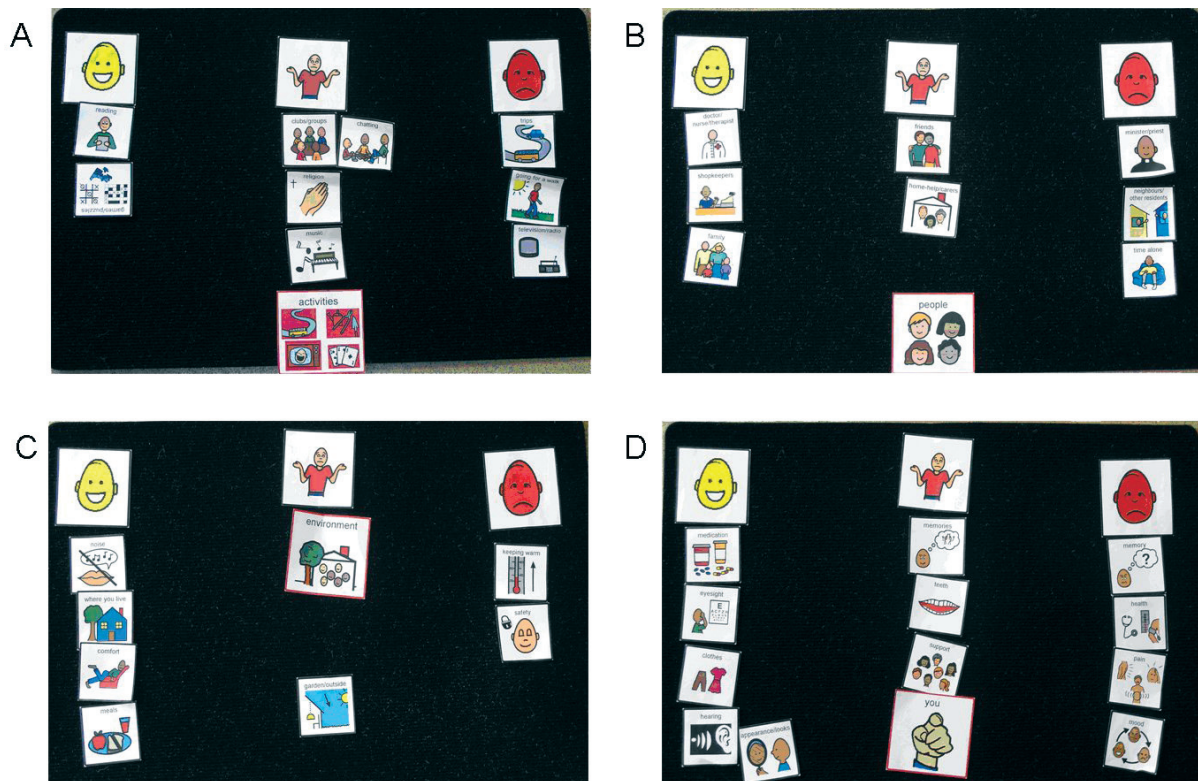
Panel A: 'Activities'; Panel B: 'People'; Panel C: 'Environment'; Panel D: 'Self'.

Summary

This chapter describes how the project fieldwork was conducted, and in particular considers some of the issues encountered when using Talking Mats with people with dementia.

- The option symbols should be as simple as possible with large text to make them clearly visible. The interviewer should make sure the person with dementia can see the symbols before starting an interview and be prepared to enlarge them if necessary.

- People with dementia may prefer to use symbols with yellow backgrounds to increase colour contrast.

- People with dementia may need help with placing the symbols on the mat. The interviewer should make use of verbal and/or non-verbal communication when considering the person's intent.

- The interviewer should be prepared to change the images used in the symbols if an individual with dementia misinterprets the picture.

3 Obtaining consent from people with dementia

Obtaining full and informed consent is a fundamental principle of all ethical research. However, when, as with people with dementia, individuals have a communication difficulty that impairs their ability to express any reservations or concerns, the issue of informed consent becomes particularly important (Lloyd *et al.*, 2006).

Until relatively recently, the widely held assumption has been that people with dementia were unable to play any meaningful role in the consent process. Consequently, the families of potential participants would be asked to give consent on their relatives' behalf to their involvement in any research. This practice is now being fiercely challenged (Cheston *et al.*, 2000; Allan, 2001) and in the current project it was considered of paramount importance that the participants should be treated autonomously, and that every effort should be made to enable them to give informed consent themselves.

On the other hand, the researchers had to conform to the Adults with Incapacity (Scotland) Act (Scottish Executive, 2000a), which specifies that where a person is unable to give informed consent to participate in research, consent must be obtained from a guardian, welfare attorney or the adult's nearest relative. Therefore, following the example of Allan (2001), a three-stage consent process was adopted. First, the families of potential participants were sent information about the project and asked whether they would be happy for their relative to take part. Second, the researcher visited the individual with dementia themselves, explained the study to them and asked *them* if they would like to participate. Finally, a policy of ongoing consent was followed whereby the researcher made sure at each subsequent visit that the participants were fully aware of what was expected of them and were happy to proceed.

Consent Stage 1

The main aims of Consent Stage 1 were:

- to inform the families of individuals with dementia about the research and to ask them to consent to their relatives being approached to take part in the project

- to give families the chance to become actively involved and to make sure they felt able to approach the research team at any time if they had any concerns about the project.

The first step in the consent process for most participants was to send their relatives the Family Information Sheet (see Appendix) describing the background to the study, the principles behind Talking Mats and what the involvement of their family member would be. Although it was essential that the Family Information Sheet should give a full account of the project, it was equally important to ensure that the relatives were not overburdened with unnecessary detail. Care was therefore taken to use simple language to describe the project, and anyone wanting more information about the study was invited to contact the researchers directly.

When a family member had indicated that they were happy for their relative with dementia to be approached, the fieldwork researcher telephoned the family member to make certain that they had understood the Family Information Sheet and were fully aware of what their relative would be asked to do. The family member was also invited to be present at the fieldwork visits: nine out of the 36 families approached accepted this offer and attended one or more fieldwork visits (six relatives came to all three visits). For those who did not attend, the main reasons were:

■ they felt their presence might be disruptive

■ work commitments meant they were not available

■ they did not want to be involved

■ they lived too far away.

Consent Stage 1 was carried out for all participants in the moderate and late stages of dementia. However, for many (8/10) of the participants in early-stage dementia, the service providers felt that it would be more appropriate for the researcher to approach the potential participant direct. For these people the consent process began at Consent Stage 2.

Consent Stage 2

The main aims of Consent Stage 2 were:

■ to establish whether the person with dementia wanted to take part in the project

■ to gain informed consent from the participants

■ to introduce the participants to Talking Mats by allowing them to complete a 'training mat'

- to ascertain that the participants were able to see the symbols clearly enough to be able to understand what they represented

- to make it clear that the subsequent interviews would be videotaped, and to confirm that participants were happy with this aspect of the procedure.

It was important to make sure that the participants were fully informed about the study before they were asked to consent to take part. It was also essential that each person was given plenty of time to come to their decision and to ask questions about anything they had not understood (Cameron and Murphy, 2007). The Participant Information Sheet (see Appendix) made use of large print, very simple language and photographs/images. The researcher guided the potential participant through the sheet, ensuring that they understood every section fully.

Each participant was also introduced to Talking Mats and invited to do a mat on the topic of 'Animals'. 'Animals' was chosen for this 'training mat' as it is a simple topic to grasp: all the options are concrete and most people have some sort of personal experience of animals that they can easily refer to when placing the symbols. For example, many people in the project placed 'cats' or 'dogs' under the 'happy' symbol because they used to have cats or dogs as pets.

Finally, the video camera that would be used during subsequent visits was shown to each participant. The person with dementia was encouraged to examine the camera and the researcher conducted a short mock recording to allow the participant to experience what would be involved (Cook, 2002, 2003).

After being told about the project and about their potential involvement, the participant was asked to complete and sign a Participant Consent Form (see Appendix), which again made use of large print, simple language and pictures. The Participant Consent Form was designed to make the person with dementia consider what the project was about, whether they were happy to take part, and to make them aware that there would be no negative consequences if they said no (Cheston *et al.*, 2000). The participant had to answer 'Yes' to seven questions such as:

- Have you read the information sheet, or had it explained to you?

- Do you understand that it is your choice to take part in the study?

- Do you understand that you can stop at any time? (You do not have to say why you want to stop.)

Importantly, if the participant was not able to answer 'Yes' to any of the seven questions, they were not considered to have fully consented to taking part.

Although it was of primary importance that the person with dementia was the focus of the consent visit and felt in control of the situation at all times (McKillop and Wilkinson, 2004), it was also necessary that these first meetings between the participant and the researcher were observed by a third party (Cohen-Mansfield, 2003). This third party (a paid carer who knew the person well or a family member) was asked to testify that the person with dementia felt comfortable with the researcher and with what they were being asked to do, and had not been coerced in any way (see Appendix).

Video consent

Video recording of the second and third fieldwork visits was essential to allow scoring of the interviews to take place at a later date. However, obtaining a video record of a person's viewpoint may place them in a vulnerable position as the tape may be used in ways that the interviewee had not considered. Moreover, as people with dementia may be particularly vulnerable in this regard (Cook, 2002; Knight, 2005), it was essential that the participants in this project were not placed at risk of being compromised in any way.

Accordingly a Video Consent Form (see Appendix) was designed to make the participants and/or their relative/paid carer fully aware of all the potential ways that the video might be used in the future:

- educational purposes within Stirling University

- educational purposes outwith Stirling University

- professional publications

- press/media publications

- exhibitions/displays/presentations

- future research.

Again the participants and their relatives/paid carers received a full explanation of each category of use and were given plenty of time to think about whether they

would be happy to consent to each category. It was emphasised that if there was any doubt in their mind about a category then they should tick the 'No' box. Moreover, it was stressed that a 'No' decision would not affect the participation of the person with dementia in the research.

Prior to this project, the policy of the AAC Research Unit (like many other research centres) had been to retain all data, including video recordings, indefinitely. However, given the vulnerable nature of the participants in this project, it was felt appropriate that they, and/or their relatives, should be invited to specify a time limit for the retention of the tapes (General Medical Council, 2002). Interestingly, although the majority chose not to impose any time limit, a significant number of people (over 29 per cent) wanted their tapes to be destroyed after a certain period (Figure 10). These figures strongly suggest that when using video (or similar) recordings in research with individuals with dementia, they and their families should be allowed to specify how long their tapes should be retained.

Figure 10 Video time limit decisions
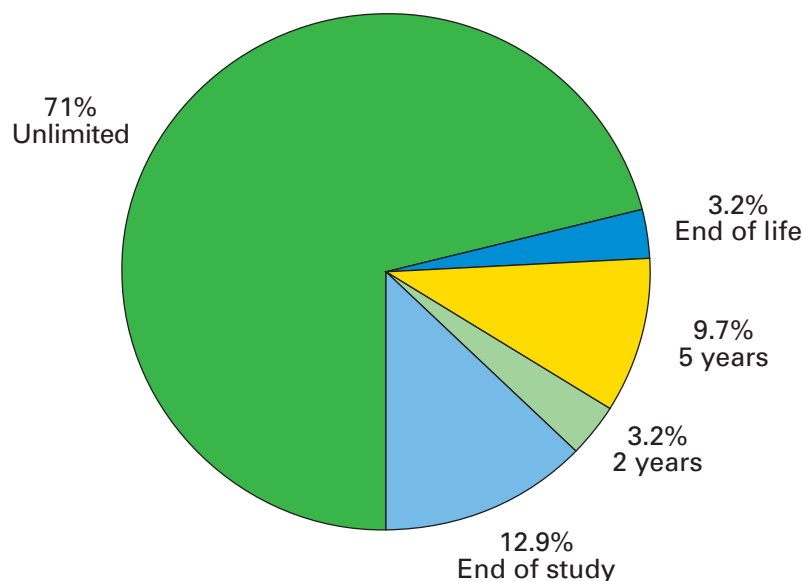
Finally, in order to maintain the focus on the participant and to emphasise their autonomy during the consent process, the person with dementia was asked wherever possible to sign the Video Consent Form. However, the propriety of asking people with dementia to consent to the existence of a videotape for a lengthy period of time has been questioned (Cook, 2002). Consequently, it was considered essential that a third party (usually a family member, who would be better placed to recall the existence of the video at a later date) should also sign the Video Consent Form.

Consent Stage 3

The main aims of Consent Stage 3 were:

■ to ensure that the participant could withdraw consent at any time

■ to take into account any indication, verbal or non-verbal, that the person did not want to continue with the research (either just on that particular day, or at all).

Steps were taken to remind the participants of their involvement in the project between fieldwork visits: the information sheet was left with the person with dementia, and staff were asked to discuss the project with them before the researcher arrived. However, it was still felt that many of the participants might struggle to remember exactly what the project was about and what they had consented to do. In order to address this problem, a policy of ongoing consent was adopted (Hubbard *et al.*, 2001). At the start of each visit, the researcher summarised the project for the participant and asked if they were happy to continue being involved. Moreover, as the interview proceeded, if the person showed any signs (either verbal or non-verbal) of being unwilling to participate, the researcher would terminate the visit.

Debriefing

It is important that when people with dementia take part in research, they should feel that their contribution has been valued (McKillop and Wilkinson, 2004). Accordingly, the researcher made a point of terminating each interview by thanking the participant for their time, and stressing how well they had done and how interesting their views had been. Moreover, at the end of their involvement in the project the participants were presented with a small gift and a card to show the appreciation of the researchers. Each individual was also given photographs of their Talking Mats to help to remind them of their involvement in the project and of the views they had expressed at the time. The researcher used this occasion to go over the mats once more with the participants and to check that they were happy to have taken part in the project.

Issues arising from the consent procedure

The consent procedure appeared to work well overall. Although a large number of families (> 60) were asked if they would be willing for their relative to be involved in

the project (Consent Stage 1), only around half (31) responded, and three of these said they did not want their relative to take part. These numbers suggest that the families did not feel under any pressure to co-operate with the research.

When the participants themselves were approached (in Consent Stage 2), only two were not happy to take part: one person did not want to have a video taken; a second agreed to take part during the consent visit, but later became agitated and appeared confused about what she had been asked to do. The fact that relatively few people with dementia withheld consent is likely to be a reflection of the fact that several of the care homes selected only those residents they felt would be happy to participate. Where this initial screening did not occur, the approach to the families may have resulted in permission only being given for the researcher to visit those people with dementia who would be likely to want to become involved.

The efficacy of the ongoing consent procedure (Consent Stage 3) was evidenced by the following:

- In the Talking Mats interview, one participant did not complete all four topics and a further five preferred to complete them over two visits.

- In the Structured Conversation interview, two participants failed to complete all four topics and one participant preferred to complete them over two visits.

- Although no participant in the main project withdrew their consent during the fieldwork phase, one pilot participant did withdraw completely from the study at the start of the second visit.

Nevertheless, the consent procedure was not perfect. First, initial access to people with dementia was dependent on the families and/or staff at the care homes or dementia service providers. Therefore, some individuals with dementia who might have enjoyed being involved may have been excluded. However, given the constraints imposed by the Adults with Incapacity (Scotland) Act (Scottish Executive, 2000a), this problem appears unavoidable.

Second, despite the attempt to use highly simplified language in the Participant Information Sheet, Participant Consent Form and Video Consent Form, it was evident that these documents were still too complicated for some people in the later stages of dementia. This problem was circumvented through the researcher helping participants to read through the documents and simplifying the information where needed. In future, however, it would be better to have at least two versions of such documents so that a suitable level of complexity of information could be provided for each participant.

Third, under ideal circumstances, participants in a research project should complete any consent forms themselves. Unfortunately, most of the participants in the current project were unable to do this, and the researcher had to complete the Participant and Video Consent Forms according to their verbal instructions. In addition, three of the participants were unable to sign the consent form, and four could not even give verbal consent (here, the families were made aware of the situation and asked to consent on their relatives' behalf). These limitations meant it was particularly important that a third party was available to testify that the consent process had been properly conducted.

Finally, although the Participant Information Sheet was left with participants to remind them of the project before subsequent fieldwork visits, it was clear that this approach was not always effective. The researcher often noticed that the Participant Information Sheet remained where she had left it, or had disappeared completely. This problem appeared to be more prevalent in the care homes than in the day care centres: day care staff were generally able to remind individuals as they arrived that the researcher would be visiting later that day. Where participants were interviewed in their own homes, the researcher phoned before each visit to remind the person about the project and to make sure they were happy to continue their involvement.

Summary

This chapter discusses how the difficult issue of gaining informed consent from people with dementia was approached in the project. Although the three-stage consent procedure appeared to have worked well overall, there were two issues that arose from its implementation that should inform subsequent research. These were:

■ People with dementia and their families should be allowed to specify the duration of retention of any videotapes (or similar).

■ Although individuals with dementia should, wherever possible, be encouraged to be involved in the consent process with regard to video/DVD recordings, consent must also be obtained from a third party (ideally a family member) who would be more likely to recall the existence of the video at a later date.

4 Talking Mats and effectiveness of communication

Following the completion of the fieldwork phase, the videotapes were watched by three researchers who scored each interview for effectiveness of communication. The results were then analysed to examine:

- whether Talking Mats can help people with dementia communicate

- whether Talking Mats were effective for people at all stages of dementia (when stages of dementia were defined by staff estimates).

This chapter therefore describes the main findings of the project and the methodology adopted to ensure that scoring was consistent and unbiased.

Number of topics completed

The people with dementia were asked to participate in three discussions about their well-being. Four topics, 'Activities', 'People', 'Environment' and 'Self', were covered in each interview and many hours of videotape were generated. Each participant was asked to contribute a great deal of time and effort to the research. Therefore, in the first instance, it was interesting to review the extent to which people coped with what had been asked of them. Encouragingly, most participants managed very well:

- Unstructured Conversation – all 31 participants completed the four topics.

- Structured Conversation – all participants in the early and moderate stages of dementia completed the four topics; two people in the late-stage group only managed to complete three topics and one further late-stage participant became restless during the Structured Conversation interview because she had been to stay with her family the previous weekend and was anxious that her mother might be waiting for her. The researcher stopped the interview after two topics, but returned a few days later to complete the interview when the participant was more settled.

- Talking Mats – 25 participants completed the four topics in one session.
    - One early-stage participant managed two topics initially, but asked if she could do the remaining two topics another day as she wanted to go for a walk with her support worker.

- An unexpected visitor interrupted the Talking Mats interview of one man with moderate-stage dementia after one topic. The remaining three topics were completed at a later visit.
- A second moderate-stage participant became anxious that one of the care home staff had her cigarettes and stopped the interview after two topics. She was happy to complete the remaining topics later that afternoon.
- One person with late-stage dementia only completed three topics in the Talking Mats interview before losing interest.
- A second late-stage participant wanted to leave after two topics and asked the researcher to come back another day to complete the interview.
- A third late-stage person appeared unhappy to be left alone with the researcher who stopped the interview after one topic. The remaining three Talking Mats topics (and the two Conversation interviews) were conducted with her family present to reassure her.

In summary, although most participants were able to complete all three conditions, several did find the interviews too much for a single session. This problem was particularly evident when using Talking Mats as four people asked the researcher to come back on another occasion. Two further participants (early-stage) asked to take a cigarette break midway through the Talking Mats interview. It must therefore be recognised that people with dementia may find Talking Mats more cognitively demanding than a simple conversation, and they should be offered regular breaks to ensure that they do not tire (McKillop and Wilkinson, 2004). This proviso notwithstanding, many of the participants in the project did appear to enjoy using Talking Mats. For example:

- One early-stage day care user later informed a dementia service manager that she had appreciated the opportunity to do something that seemed really meaningful.

- Another early-stage participant declared to her support worker after she had completed two Talking Mats topics: 'Look … I can do it. I didn't think I would be able … but I can do it'.

- One care home resident told the researcher that '[Talking Mats] were really good'.

Time taken to complete the topics

The increased need to take breaks when using Talking Mats may, in part, simply be due to the extra time taken to complete this condition. Although each Talking Mats topic did not take significantly longer to discuss than each Structured Conversation topic (Figure 11), when the Talking Mats confirmation phase (where the researcher went over the completed mat with the participant to ensure that she or he was happy with the views expressed) was included, the average time taken for each Talking Mats topic was significantly greater than that taken for each Structured Conversation topic.[1] Moreover, the Talking Mats[2] and Structured Conversation[3] interviews both took more time than the Unstructured Conversation interviews. The brevity of the Unstructured Conversation interviews was due to the fact that many participants were unable to provide much information about the topic being discussed. This lack of elaboration persisted even when the participants were prompted to talk about the things (or people) that they liked or did not like.

Figure 11 Average time taken for each topic
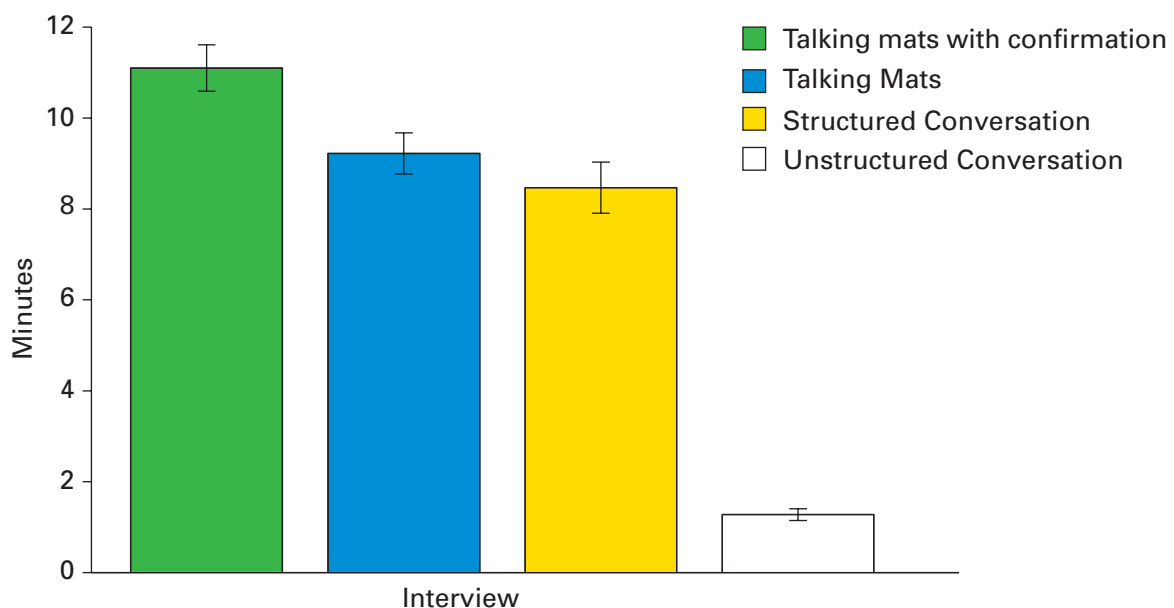
*   Error bars in all graphs represent ± 1 standard error of mean.

The demonstration that Talking Mats discussions take longer than either simple or more structured conversations has important practical implications. The ability to make plans for the day becomes diminished in individuals with dementia and they often end up with 'nothing to do but sit with vacant time and empty thoughts' (Mace and Rabins, 1999, p. 162). Using Talking Mats allows paid carers and relatives to spend more time with a person with dementia; and, crucially for person-centred care, the person with dementia is engaged in an activity that is highly personally significant to them (Kitwood, 1997).

The large quantity of video material generated during the fieldwork phase meant that it was impractical to watch each interview from start to finish. Therefore only the first three options for each topic were considered when scoring the Talking Mats and Structured Conversation interviews for effectiveness. However, as the options had been presented in random order, the options that were scored differed from one condition to the next, and from one participant to the next. The Unstructured Conversations were generally much shorter than the other two conditions and the researchers watched these interviews in their entirety.

The effectiveness framework

Assessing the effectiveness of an interaction must, by its very nature, be subjective. Furthermore, no simple tools have been developed to date to measure the effectiveness of functional communication between partners (Kagan and Gailey, 1993; Bartlett and Bunning, 1997; Grove, 2000). The current project therefore employed a refined version of a coding framework that had been developed for a previous study (Murphy *et al.*, 2005a) and demonstrated to speech and language therapists in the UK, Scandinavia, Germany, South Africa, Brazil and Australia. These professionals agreed that the indicators used in the coding framework were relevant and summarised succinctly the basic requirements for interpersonal communication.

Indicators of effective communication in people with dementia

The version of the effectiveness coding framework used in the current project looked at four important indicators of effective communication: participant understanding, participant engagement, the extent to which the participant remained on track, and researcher understanding (Figure 12). Light (1988) defined one of the main functions of communication as the transmission of information between two people. Accordingly two of the indicators, 'participant understanding' and 'researcher understanding', relate directly to this function. When assessing understanding, it is important to take into account both verbal (speech and other vocalisations) and non-verbal (eye contact, gesture, facial expression and body posture) responses.

■ An example of participant understanding based on verbal responses comes from a late-stage participant who was profoundly hearing impaired and had very little conversation. When she was handed the 'television/radio' symbol the researcher asked her what she felt about television. However, she looked at the symbols and said 'Radio … I'm no daft about …' without any further prompting. The researcher interpreted this utterance as meaning that the participant did not enjoy listening to the radio.

Figure 12 Effectiveness coding framework

	4 **Always**	3 **Often**	2 **50:50**	1 **Occasional**	0 **Never/none**
Participant's understanding of issue for discussion					
Participant's engagement with person					
Participant keeps on track					
Researcher's understanding of participant's views					
Comments:					

Another main function of communication is 'the construction and enjoyment of relationships with others' (Locke, 1998, p. 27), captured by the 'engagement' indicator. Again, when assessing engagement, it is essential to take both verbal and non-verbal responses into account. For example, a participant could be said to be engaged either when talking about the subject under discussion, or when silently contemplating the Talking Mats symbol and considering where to place it.

Finally, problems with topic maintenance are often evident in people with dementia from the early stages of the illness onwards. Individuals will tend to digress or go off at a tangent and, although they may initially be conscious of this difficulty, their awareness decreases as the disease progresses towards the moderate stages (Bayles, 1985; Kempler, 1995; Dijkstra *et al.*, 2004). Because of the prevalence of problems with topic maintenance in dementia, it was considered appropriate to add the 'on track' indicator to the effectiveness coding framework used in this project. Unlike the other indicators, a participant's verbal responses were most important when scoring the 'on track' indicator: to score well, a participant's utterances had to be relevant to the subject being discussed.

A consensus approach to obtaining inter-rater reliability

When using any new intervention in research or clinical settings, it is important to be able to assess whether that intervention is effective. However, because people's opinions and professional backgrounds can differ widely, any two people viewing the same interview subjectively may reach very different conclusions, thus raising the problem of poor inter-rater reliability and bias (Ashton, 2000; Roulstone, 2001; Carter and Iacono, 2002). In order to address this issue, the following strategies were employed in this project:

■ There were three raters from different professional backgrounds: the fieldwork researcher, a speech and language research therapist and a psychology undergraduate.

■ The raters watched several pilot tapes to ensure that their scoring criteria were simple, well-defined and clearly understood before they scored the fieldwork videos.

■ The videos were always rated in the same setting – the AAC Research Unit at Stirling University.

■ Each participant's interviews were all scored during the same session.

Most importantly, however, the three raters always watched the videos together and used a consensus approach to scoring (Ashton, 2000). The three-stage consensus approach adopted in this project was closely based on a scoring system that had been developed in a previous Talking Mats project (Murphy *et al.*, 2005a):

■ Stage 1, 'Independent scoring': the raters watched the video together, but scored each indicator independently without any consultation.

■ Stage 2, 'Consultation': the raters revealed their scores to each other and justified their decisions.

■ Stage 3, 'Adjustment': where discrepancies existed, each rater took into account their colleagues' justifications of their decisions before deciding whether they should adjust their own scoring. The raters were *not* required to reach complete consensus if, after consideration, their views still differed from those of their colleagues.

Assessment of the consensus approach

All instances of inter-rater agreement and disagreement were recorded to examine the efficacy of the consensus approach. The average inter-rater agreement *after* consultation was 92.0 per cent (range 77.4–100 per cent). These figures are well above 70 per cent, the common lower bound for an acceptable level of agreement (Aspland and Gardner, 2003). Interestingly, inter-rater agreement was significantly lower for the late-stage group (average 87.8 per cent) compared to the early-stage group (average 91.3 per cent).[4] This finding reflects the fact that the interviews of late-stage participants were harder to score and created most discussion between the raters.

Importantly, however, on average only 54 per cent of the scoring decisions produced inter-rater agreement *before* consultation. This figure is obviously well below the 70 per cent acceptable agreement level, suggesting that the consensus approach can be extremely useful in improving the consistency (and therefore the reliability) of subjective ratings.

Do Talking Mats help people with dementia communicate?

In order to ascertain whether effective communication was achieved in each interview, the 'adjusted' scores of the three raters were averaged and the four indicator scores totalled for each topic. Following Murphy *et al*. (2005a), a total score of 12 or more was considered to represent effective communication. Figure 13 shows the average total effectiveness scores across all four topics and clearly suggests that Talking Mats can improve communication with people with dementia:

- In early-stage dementia, people communicated effectively regardless of whether they were using Talking Mats, Structured Conversation or Unstructured Conversation.

- In moderate-stage dementia, effective communication was only achieved when Talking Mats were used (mean score 14.5, range 13.1–15.9). Moreover, Talking Mats scored significantly higher than either Structured Conversation[5] or Unstructured Conversation.[6]

- In late-stage dementia, communication remained below the effectiveness level for all three interview conditions. However, once again Talking Mats scored significantly higher than Structured Conversation[7] and Unstructured Conversation.[8]

Interestingly, although 12 is the score at which communication is definitely effective, scores of between 10 and 12 can be considered to represent interactions which are borderline effective (cf. Murphy *et al*., 2005a). Many people with late-stage dementia produced Talking Mats effectiveness scores of 10 or more (mean score 10.5, range 5.3–14.9). Nevertheless, there was a high degree of variability in this participant group and, with three participants scoring less than 7, it is clear that not all people with late-stage dementia can use Talking Mats effectively.

Figure 13 Effectiveness scores
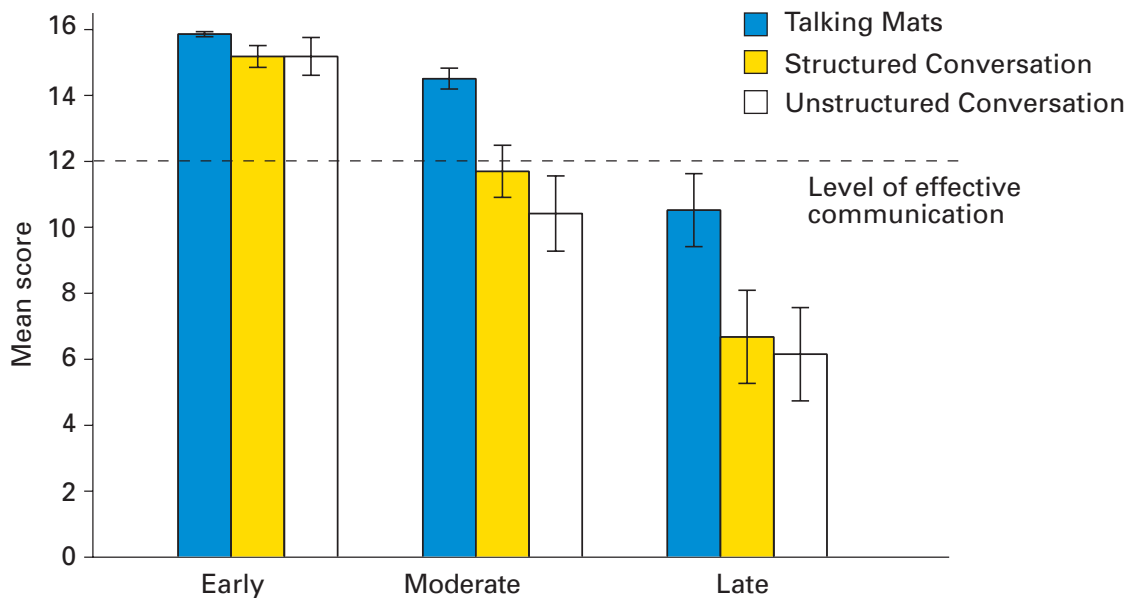
Individual effectiveness indicators

The initial results of the project suggest that Talking Mats do improve the effectiveness of communication in people with dementia, particularly in those who have reached the moderate and later stages of the illness. The following sections therefore examine the individual effectiveness framework indicators to establish which of these important elements of communication are augmented by Talking Mats in people with early-, moderate- and late-stage dementia.

Participant understanding

Figure 14 clearly demonstrates that using Talking Mats enhances the understanding of a person with dementia of the subject under discussion. However, this improvement was most evident in the more advanced stages of the illness:

■ In early-stage dementia, as expected, people's understanding was good regardless of the method of communication used.

■ In moderate-stage dementia, Talking Mats significantly improved people's understanding compared to both Structured Conversation[9] and Unstructured Conversation.[10]

■ Similarly in late-stage dementia, Talking Mats significantly improved people's understanding compared to both Conversation conditions.[11]

Figure 14 Participant understanding
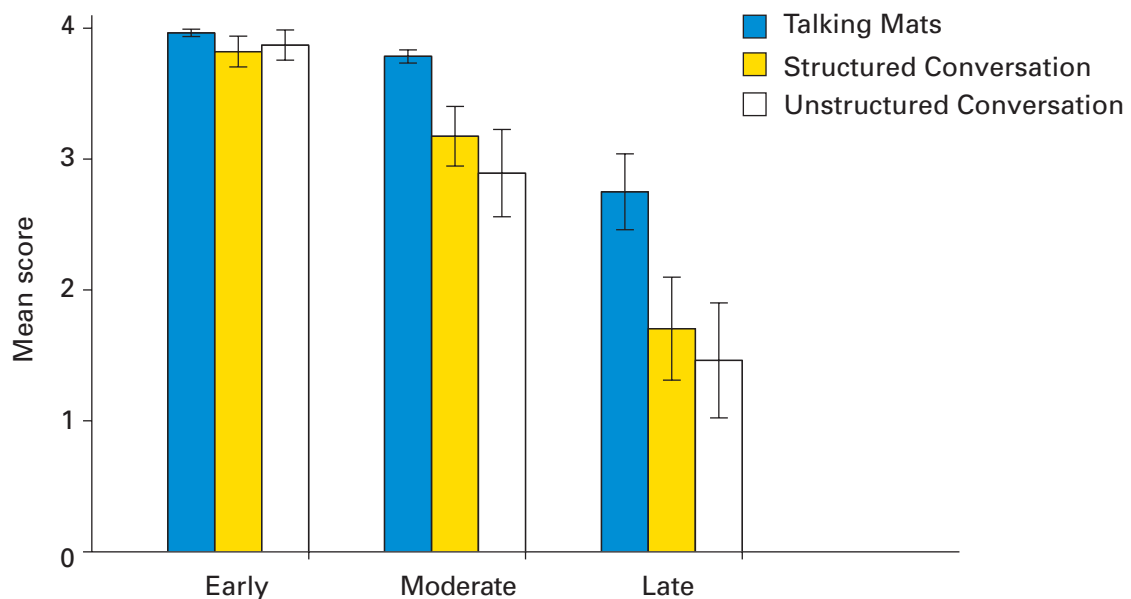
Engagement

Overall the level of participant engagement was greatest in the Talking Mats interview. However, as Figure 15 shows, people in the later stages of dementia appear to benefit most from using Talking Mats:

■ Early-stage participants were equally engaged in all three conditions.

■ Moderate-stage participants were more engaged when using Talking Mats than when using Structured[12] and Unstructured[13] Conversation.

■ Late-stage participants were more engaged when using Talking Mats than when using Structured Conversation,[14] but the difference between the Talking Mats and the Unstructured Conversation was not significant.[15]

On track

Difficulties with topic maintenance are often evident from the earliest stages of dementia (Kempler, 1995), and Figure 16 indicates that Talking Mats do increase the extent to which people with dementia remain on track:

Figure 15 Participant engagement
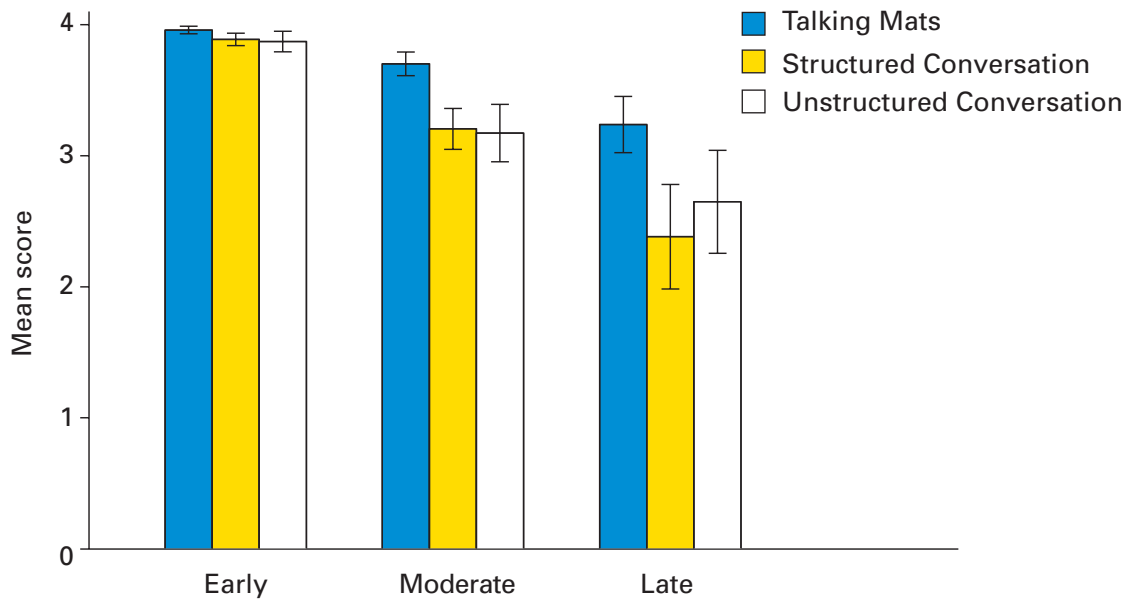
- People in the early group scored marginally better for the 'on track' indicator when using Talking Mats than when using Structured Conversation.[16]

- People in the moderate group remained more on track when using Talking Mats than when using both Structured[17] and Unstructured[18] Conversation.

- People in the late group also remained more on track when using Talking Mats than when using both Structured[19] and Unstructured[20] Conversation.

Figure 16 On track scores
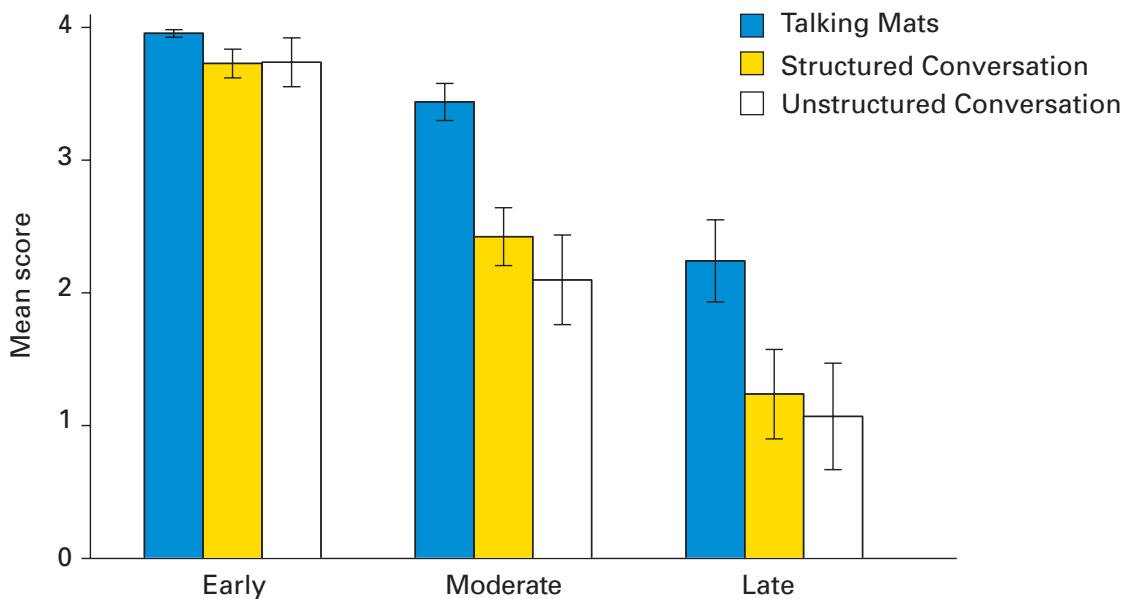
Researcher understanding

Finally, Figure 17 clearly shows that Talking Mats improves the extent to which the views of people with dementia are understood:

- In people with early-stage dementia, there was a significant difference between the three interviews,[21] with Talking Mats scoring better than either of the Conversation conditions.

- For the moderate group, there was a clear difference in researcher understanding between Talking Mats and both Structured[22] and Unstructured[23] Conversations.

- In the late group, Talking Mats clearly enhanced researcher understanding compared to Unstructured Conversation.[24] The improvement in researcher understanding between Talking Mats and Structured Conversation was marginally significant.[25]

Figure 17 Researcher understanding
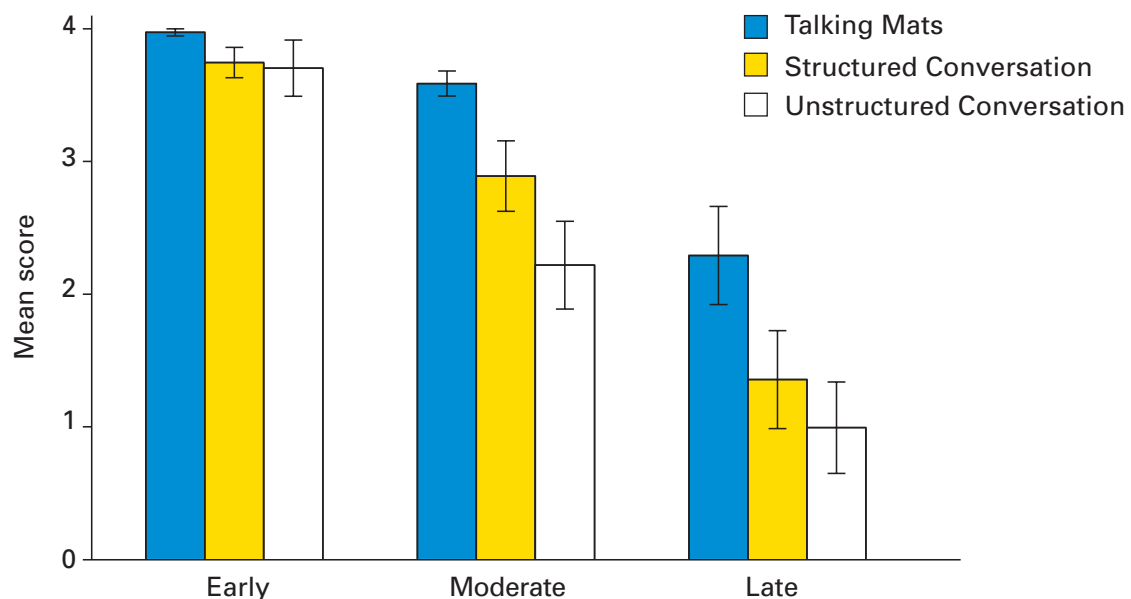
This last finding most likely reflects the fact that there was a high level of variability in the researcher understanding scores for the late group, in both the Talking Mats and Structured Conversation conditions. Importantly, however, whereas seven people with late-stage dementia scored 3 or more for researcher understanding in at least one topic during the Talking Mats interview, only three late-stage participants scored 3 or more in the Structured Conversation interview. These figures confirm that the views of people with late-stage dementia are more likely to be understood when they use Talking Mats.

Summary

This chapter addresses the principal research questions of whether using Talking Mats helps people with dementia to communicate, and whether Talking Mats are effective for people at all stages of the condition. The key findings are:

■ People with early- and moderate-stage dementia are able to use Talking Mats effectively.

■ Many people with late-stage dementia are also capable of using Talking Mats.

■ For people with moderate- and late-stage dementia, Talking Mats provide a more effective means of communication than simple or structured conversation. Improvements are evident in participant and researcher understanding, engagement and the extent to which individuals remain on topic.

■ For people with early-stage dementia, the main improvements when using Talking Mats are found in the extent to which they stay on track and the extent to which their views are understood by a third party.

■ As people with early-stage dementia can communicate effectively regardless of the medium used, they may benefit most from using Talking Mats when they face difficult decisions (e.g. giving up driving). In these situations, Talking Mats may allow people in the early stages of dementia to order their thoughts, and to weigh up the benefits and drawbacks of a particular course of action more easily.

■ Discussions with Talking Mats usually take longer than simple conversations. Therefore, in addition to being used to augment communication and decision making, Talking Mats may also simply be enjoyed as an activity allowing people with dementia to occupy their time doing something that is personally meaningful to them.

5   The wider impact of Talking Mats on communication in dementia

When assessing the effectiveness of communication in people with dementia, the indicators discussed in the previous chapter (namely, participant understanding, engagement, staying verbally on track and researcher understanding) are considered to be most relevant (Bayles, 1985; Light, 1988; Kempler, 1995; Locke, 1998; Dijkstra *et al.*, 2004). However, several other factors are also important when considering how well people with dementia communicate. This chapter therefore describes how these additional aspects of communication were affected by the three types of interview.

Secondary indicators

Perseveration

A commonly observed phenomenon in dementia is that people will repeat previously used words, phrases and ideas that no longer appear relevant to the topic of discussion (Bayles, 1985; Kempler, 1995; Dijkstra *et al.*, 2004). For example:

- One late-stage participant told the researcher how she liked her 'own people' during the Unstructured Conversation interview, and repeated this sentiment (changing it variously to 'old people', 'old friends' and 'Highland people') on a number of occasions during all four Structured Conversation topics.

Many participants also made repeated (apparently inappropriate) references to events and people in their childhoods, and some exhibited other forms of perseverative behaviour:

- During the Structured Conversation interview, one late-stage participant kept running her fingers along the border of her cardigan, and another (who had been a tailoress) repeated the action of sewing a hem.

The above examples were all considered to be acts of perseveration, and the occurrences of such behaviours were noted and scored as a secondary indicator. Figure 18 indicates that Talking Mats can reduce the instances of perseveration in people with dementia: participants in all three groups exhibited fewer perseverative behaviours when being interviewed using Talking Mats than when being interviewed using Structured Conversation[1] and Unstructured Conversation.[2] This finding is

extremely interesting because it suggests that people with dementia may be able to focus their attention to a greater extent and become more involved in an interaction when they are using Talking Mats.

Figure 18 Perseveration
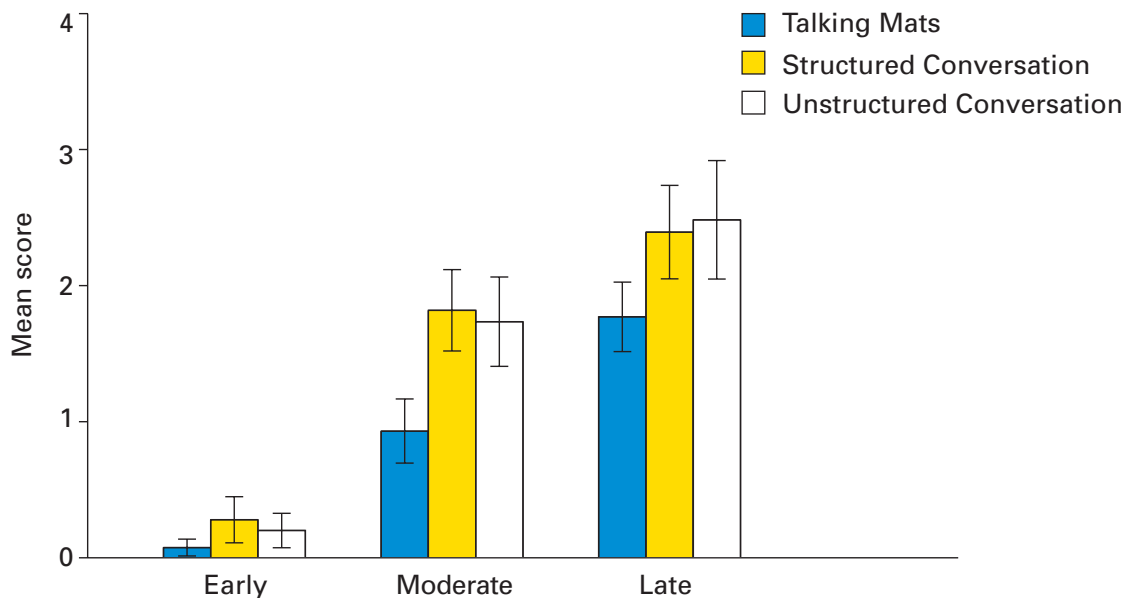
Confidence

Murphy *et al.*'s (2005a) original coding framework contained an indicator that assessed the confidence of people with intellectual disability when using Talking Mats. This indicator was removed from the coding framework in the current project as it was felt that it might be difficult to assess the confidence of people with dementia in the Conversation conditions. Moreover, the preservation of social skills in dementia means that people with the condition can often mask their communication difficulties (Mace and Rabins, 1999). Consequently, the perceived confidence of a person with dementia may not accurately reflect their ability to communicate. Nevertheless, as the use of goal-directed, purposeful behaviours is considered an important facet of social skills behaviour (Segrin and Dillard, 1993; Hargie *et al.*, 1994), it was agreed that participant confidence should be rated alongside the main effectiveness indicators.

However, although Figure 19 suggests that using Talking Mats to communicate may lead to increased confidence in people with moderate- and late-stage dementia, the observed differences between the Talking Mats and two Conversation interviews were not reliable. Moreover, perhaps not surprisingly, given the ability of people with dementia to adopt a façade to cover their communication problems (Mace and

Rabins, 1999), the raters found confidence extremely difficult to score and were often unable to fully justify their decisions.

Figure 19 Confidence
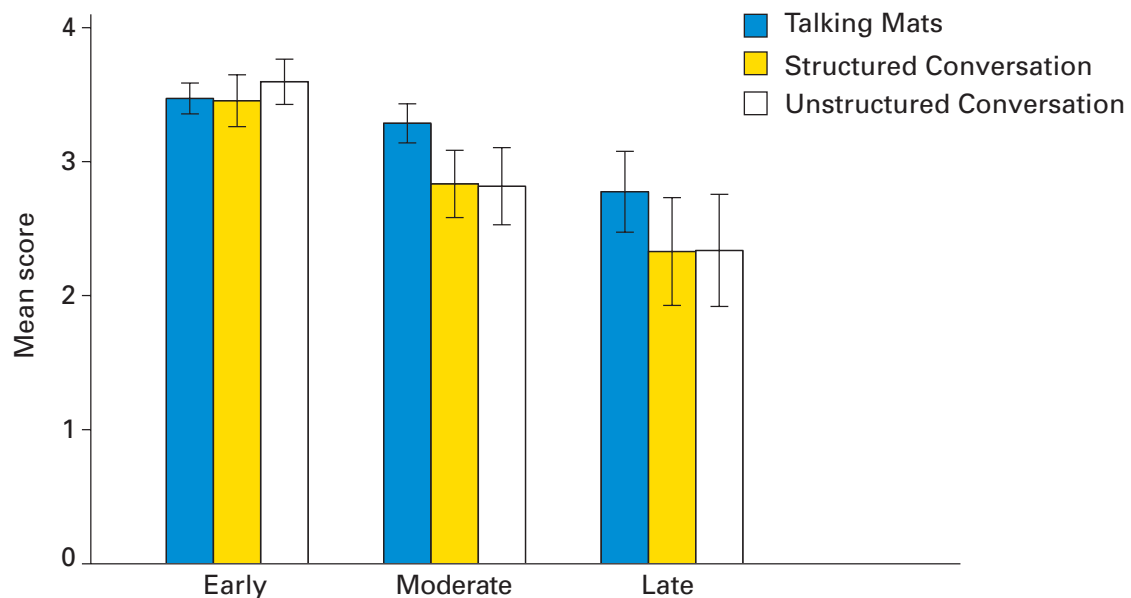
Time spent 'on task'

The foregoing findings have relied on the subjective interpretation of the videotaped fieldwork interviews and suggest that Talking Mats do aid communication in people with dementia. Nevertheless, despite the steps taken to ensure that the scoring of the videos was reliable (see Chapter 4, 'A consensus approach to obtaining inter-rater reliability'), the possibility remains that the findings could reflect researcher bias.

A fourth-year undergraduate student therefore undertook an additional 'on task' analysis to determine whether Talking Mats would retain their advantage over Structured and Unstructured Conversation under more objective scoring conditions. This analysis focused on the proportion of time each participant spent engaged in 'on task' and 'off task' behaviours during the 'Activities' topic. A time-series analysis of all three interview conditions was used to record the occurrence of seven target behaviours at ten-second intervals.

'On task' behaviours were defined as:

■ making purposeful eye contact with the interviewer

■ making purposeful eye contact with the visual stimuli connected with the interview

■ showing active engagement: attending to the interview process and being responsive to interview prompts and stimuli.

'Off task' behaviours were defined as:

■ being verbally off topic

■ being distracted by the Talking Mats symbol

■ experiencing a minor distraction (no positional change)

■ experiencing a major distraction (involving positional change).

Behaviours were only recorded as 'on task' or 'off task' if the student was certain that they corresponded to one of the target behaviours. All other behaviours were recorded as 'undecided'.

The average percentage of 'undecided' behaviours remained relatively low across the three conditions (Talking Mats 8 per cent, Structured Conversation 11 per cent, Unstructured Conversation 9 per cent). Moreover, there was no significant difference in undecided behaviour between the early-, moderate- and late-stage groups. These findings suggest that the actions defined above as being 'on task' and 'off task' accurately capture the behaviour of most participants throughout the interviews. Figure 20 suggests that using Talking Mats increases the amount of time that people with dementia remain 'on task', particularly those in the later stages of the illness. Participants exhibited more 'on task' behaviours when using Talking Mats than during both the Structured Conversation[3] and the Unstructured Conversation.[4]

Content of interviews

The previous sections have examined the dynamics of the three interviews, but have largely ignored their content. Although it appears that many of the participants were able to understand what the researcher was asking them, and that the researcher was often able to understand their views, it is less clear how closely these views represent the reality of the participant's day-to-day life.

Figure 20 Time spent 'on task'
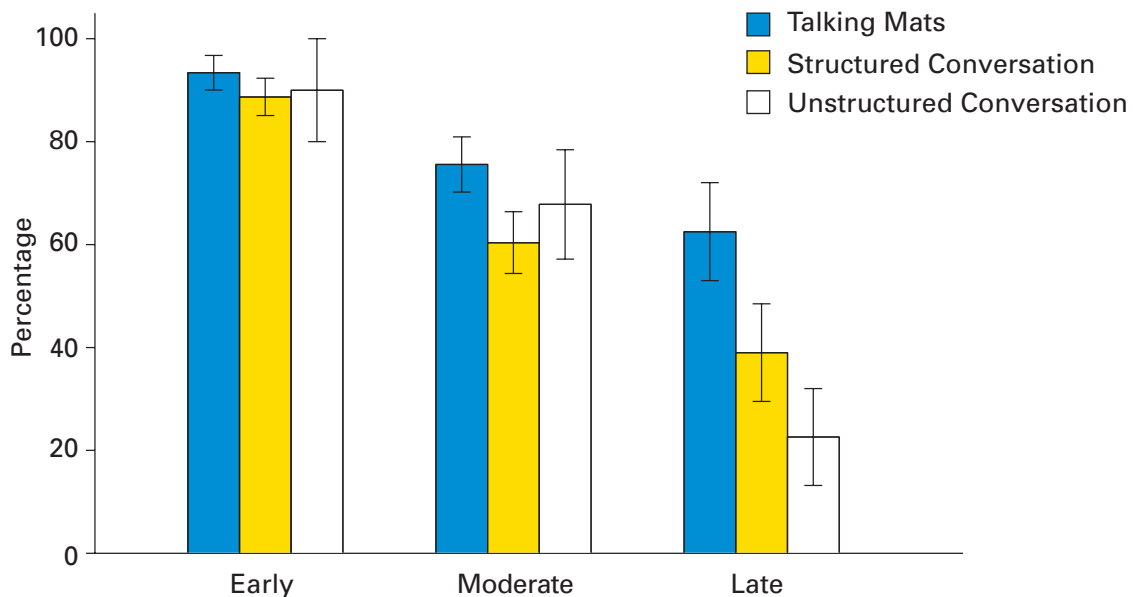
In order to address this question, a member of staff who knew the participant well was asked to complete a Participant Background Questionnaire (see Appendix), which covered many of the subjects discussed during the interviews. This information was compared to the information given by participants during the 'Activities' topic in the Talking Mats and Structured Conversation interviews. The Unstructured Conversation interviews were not included in this analysis as they were often extremely short and yielded very little information. Importantly, staff always had the option to respond 'Don't know' where they did not feel they knew the person well enough to answer a particular question. These questions were excluded from the comparisons.

The results suggest that people with dementia produce more reliable information when using Talking Mats than when being interviewed using a Structured Conversation.[5] Figure 21 indicates that the improvement may be more pronounced in people with moderate- and late-stage dementia, but there is also evidence that people in the early stages of dementia may provide more reliable information when they are using Talking Mats. For example, after the Talking Mats interview with one early-stage man, the researcher noted that the participant appeared '[happy to take part] as before, but I feel I got a much more accurate idea of what he does/feels'.

Figure 21 Agreement between participant and care staff
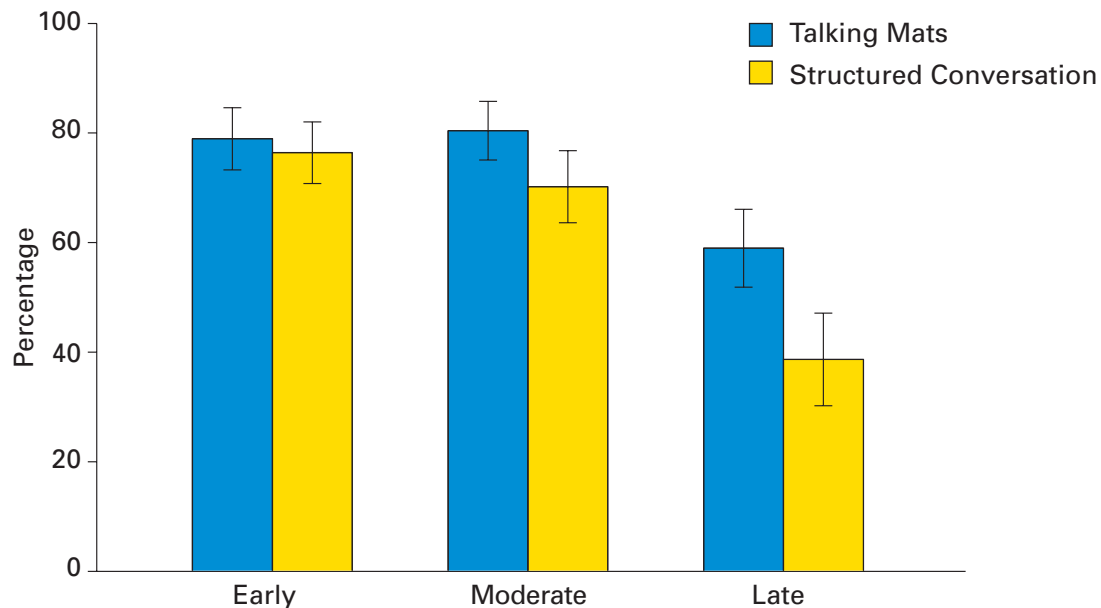
An important caveat to the foregoing interpretation of the 'Content of interviews' results is that there was no assessment of the accuracy of the information supplied by staff. In an attempt to ensure that this information was as valid as possible, all questions where staff members had indicated that they were unsure of whether the person enjoyed a particular activity or not (by answering 'Don't know') were excluded from the analysis. More accurate information about a person's daily activities could have been obtained using other techniques, such as direct observation. Unfortunately, given the relatively short (seven months) duration of the data collection period, such techniques were not practical.

Using Talking Mats

The results reported thus far have largely focused on comparisons between Talking Mats, Structured Conversation and Unstructured Conversation when asking people with dementia about their well-being. However, it is also essential when considering the effectiveness of Talking Mats with people with dementia to examine how individuals actually use the communication framework. The remainder of this chapter will therefore reflect on two important elements of Talking Mats: placing the option symbols and the visual scale midpoint.

Symbol placement

One of the principal attributes of Talking Mats is that they encourage an interviewee to assume control of an interaction. Talking Mats allow people to build up a picture of their views, and then to consider, change and confirm these views in their own time (Murphy, 2002). Ideally, the interviewee should decide where each option symbol should be placed on the mat. However, when people are not able to physically place the symbols themselves, they should be able to eye-point or give verbal directions that allow a communication partner to move the symbols on their behalf.

It became evident early in the project that some people with dementia were not physically capable of placing the symbols themselves. Moreover, other participants, who were physically able, were unable to give any explicit direction as to where the symbols should go. For these people, the cognitive load of relating the option symbols to the emotion symbols on the visual scale, and/or the visuospatial problems often evident in people with dementia (Perry *et al.*, 2000), may have impacted on their ability to take ownership of the Talking Mats interview. Consequently, the researcher used the content of the participants' discourse and their non-verbal behaviour to determine where to place the symbols.

It was important, therefore, to examine to what extent the participants in this project were able to assume ownership of the placement of the Talking Mats symbols. Accordingly, a Likert-type scale (Figure 22) was used to record which conversation partner decided where the option symbols would be placed. Figure 23 shows the extent to which participants were able to direct symbol placement:

- Everyone in the early-stage group demonstrated a high degree of autonomy.

- Many (6/11) people with moderate dementia were also largely able to direct symbol placement.

- Only one person with late dementia showed any real indication of being able to take ownership of symbol placement.

Even when a participant was unable to give explicit directions where the symbols should be placed, they were given another opportunity to exert some ownership during the confirmation phase. Here, the researcher discussed with the interviewee where she had put each option symbol. The person with dementia could then direct the researcher to move any symbol whose position did not correspond to her or his views.

Figure 22 Talking Mats symbol placement scale

0	1	2	3	4
Always interviewer	Usually interviewer	50:50	Usually participant	Always participant

Figure 23 Placement of Talking Mats symbols
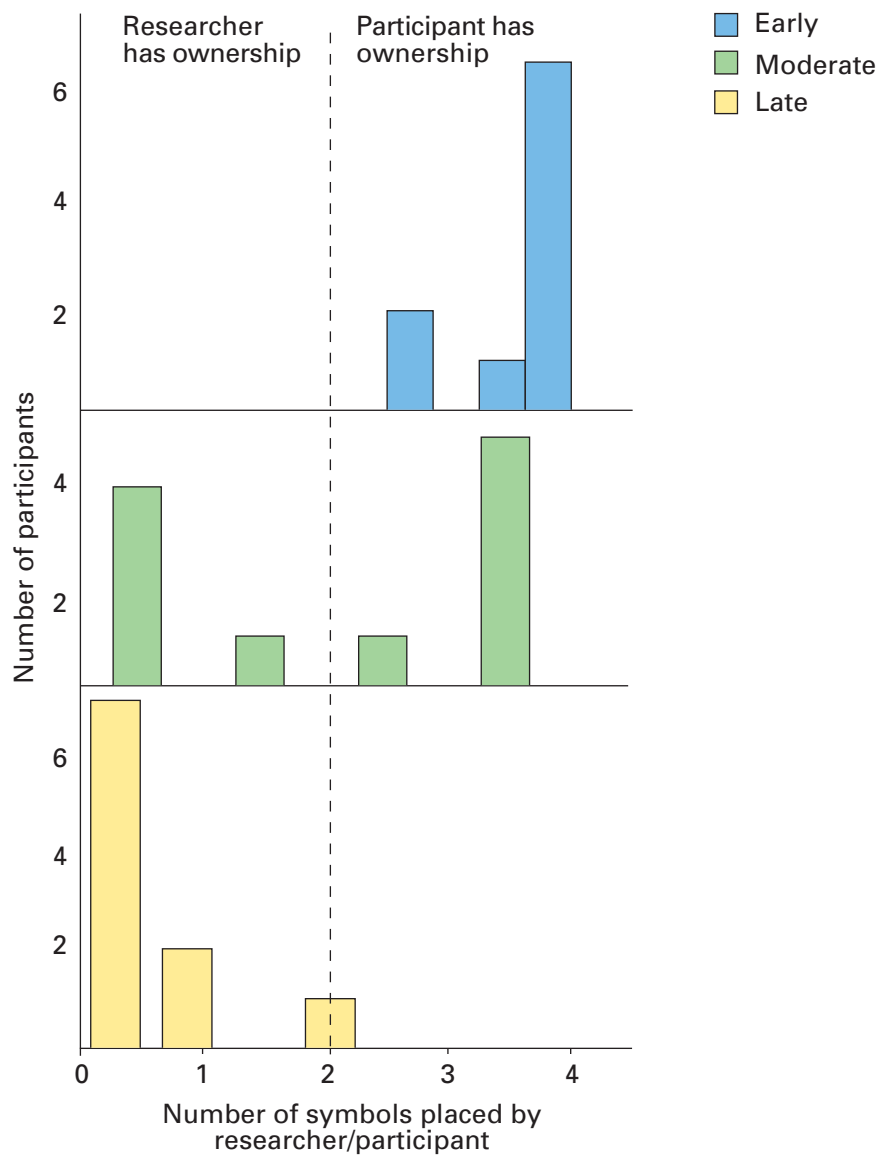
Use of the midpoint

The three-point visual scale (Figure 7, Panel B) used for most participants allowed them to place the Talking Mats option symbols according to whether they were 'happy', 'not sure' or 'unhappy' about the subject being discussed. However, the visual scale is highly adaptable and can easily be changed according to the cognitive capacity of the individual using it. Accordingly, for four people with late-stage dementia, the 'not sure' symbol (the midpoint) was removed from the scale as it was evident from the 'training mat' (where the 'Animals' topic was discussed) that they would not be able to use it.

All the participants who were given a three-point visual scale made use of the midpoint on at least one occasion during the Talking Mats interview. Indeed, Figure 24 clearly shows that many people used the midpoint quite extensively. Moreover, there was no real difference between the three stages of dementia (when those members of the late-stage group who only had a two-point visual scale were excluded). These findings suggest that people with dementia can retain the ability to express nuanced opinions even during the later stages of their condition. Moreover, it appears likely that people in the early (and in some cases moderate) stages of dementia would be able to make use of a more sophisticated (five-point) visual scale that would allow them to express their views with more precision.

Figure 24 Using the midpoint
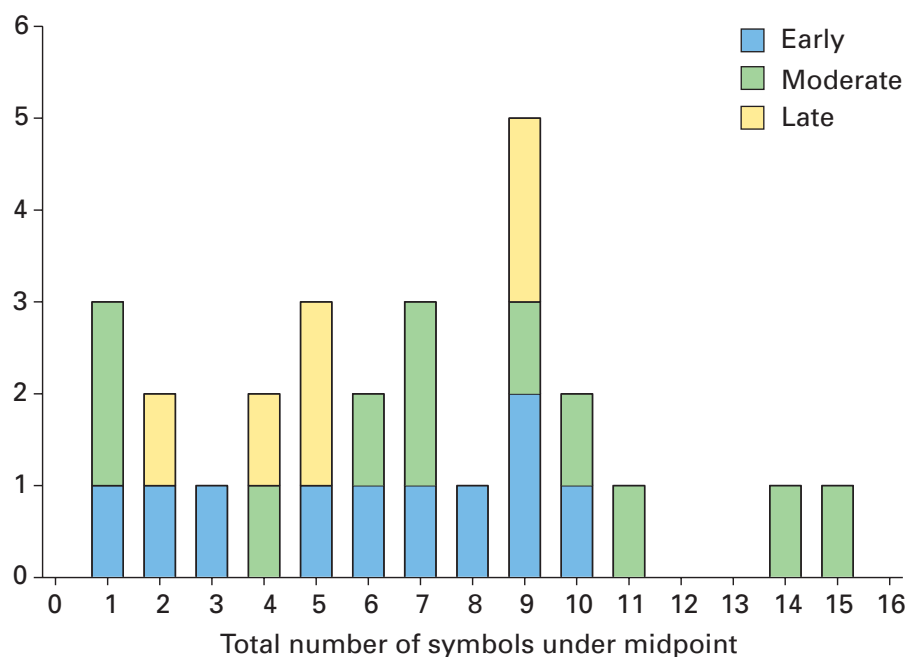
Summary

This chapter has built on the results of the previous chapter and provides further evidence that Talking Mats are more effective than conversation in helping people with dementia communicate their views. Talking Mats appear to:

■ reduce instances of perseverative behaviour

■ increase the amount of time spent 'on task'

■ enhance the reliability of information provided by people with dementia.

Significantly, the largest differences between Talking Mats and conversation are evident in people with moderate- and late-stage dementia. Furthermore, although people with late-stage dementia may be less able to take ownership of the Talking Mats discussion, many continue to be able to express nuanced views by making full use of a three-point visual scale. Accordingly, Talking Mats can play an important role in improving the quality of care experienced by people with dementia by prolonging the period during which they can communicate their views about their well-being and daily lives. By extension, therefore, Talking Mats may help people with dementia to continue taking an active role in shaping and controlling decisions about their lives.

6 Stages of communication

Using staff estimates of each participant's stage of dementia proved problematic from the start of the project. The main difficulty was that staff with different professional backgrounds often had very different opinions about the severity of people's conditions. For example:

■ A person described as having fairly advanced dementia by staff in a day care centre might be considered as having early (or early-moderate) dementia by staff in a care home.

In addition, differences of opinion were sometimes found between staff members within a single dementia service facility. For example:

■ One participant in a day care centre had been identified as having early-stage dementia by a service manager, but the day care organiser was adamant that the person was one of the most advanced cases she had ever dealt with.

■ Care home staff who had daily contact with residents did not always agree on their stage of dementia.

A further problem with relying purely on staff 'stage of dementia' estimates was that staff were basing their opinions on people's all-round functioning, whereas the primary focus of this project was on people's ability to communicate. A search of the published literature failed to reveal any means of assessment that would provide a quick, simple estimate of people's ability to communicate socially. The researchers therefore decided to develop a new scale, which would be brief and simple to administer, to specifically assess the social communication capacities/incapacities of people with dementia.

The Communication Difficulties Scale (CDS; see Appendix) comprises 13 statements that are based on existing definitions of the communication problems commonly experienced by people as dementia progresses (Kempler, 1995; Health Education Board for Scotland, 1996):

■ In early-stage dementia, the person may have difficulty coming up with words and may tend to digress and repeat themselves.

■ In moderate-stage dementia, the person may find it hard to understand what is said to them, particularly when being given complex information; may have difficulty maintaining a conversation topic without losing track; may use

semantically empty words (e.g. thing, stuff) in place of content words; and may be difficult to understand.

■ In late-stage dementia, the person may make little sense; may not be able to understand what is said to them, even when simple language is used; may often repeat what other people have said to them; and may communicate mainly in non-verbal ways.

The Communication Difficulties Scale requires a third party who knows the person with dementia well (a paid carer or family member) to assess various aspects of their communication on a five-option scale (Figure 25). People are asked to circle the option that most closely describes the person in question. However, the instructions stress that the circle should be placed midway between two options if this more accurately reflects a person's communication abilities.

Figure 25 Communication Difficulties Scale example statement

Each CDS option is assigned a score: for example, in Figure 25, 'Never' = 0, 'Sometimes' = 1, 'Often' = 2, 'Always' = 3 and 'Says too little for me to judge' = 3. A person's CDS rating is obtained by totalling their scores for all 13 statements. CDS ratings can therefore range from 0 to 39, with a higher rating indicating a greater degree of communication difficulty.

Communication Difficulties Scale pilot

A short pilot study was carried out to test the validity of the Communication Difficulties Scale:

■ Staff at one of the care homes taking part in the main project completed the CDS anonymously for residents with diagnoses of dementia.

■ A speech and language therapist completed the CDS anonymously for a number of clients with diagnoses of dementia.

■ Family or paid carers of the six people who took part in the fieldwork pilot study completed a CDS for each participant.

A stage of dementia estimate was also obtained for the 33 people who had a CDS completed on their behalf:

■ Five people were estimated to have early-stage dementia.

■ Thirteen people were estimated to have moderate-stage dementia.

■ Fifteen people were estimated to have late-stage dementia.

Figure 26 demonstrates that as the estimated severity of dementia increased, the CDS rating also increased. Moreover, there was a clear distinction between the CDS ratings of people with moderate dementia and the CDS ratings of people with late dementia.[1] On this occasion the average CDS ratings for people with early and moderate dementia did not differ significantly, but this was likely to be because of the small number of people in the early-stage group ($n = 5$).

Figure 26 Communication Difficulties Scale pilot ratings
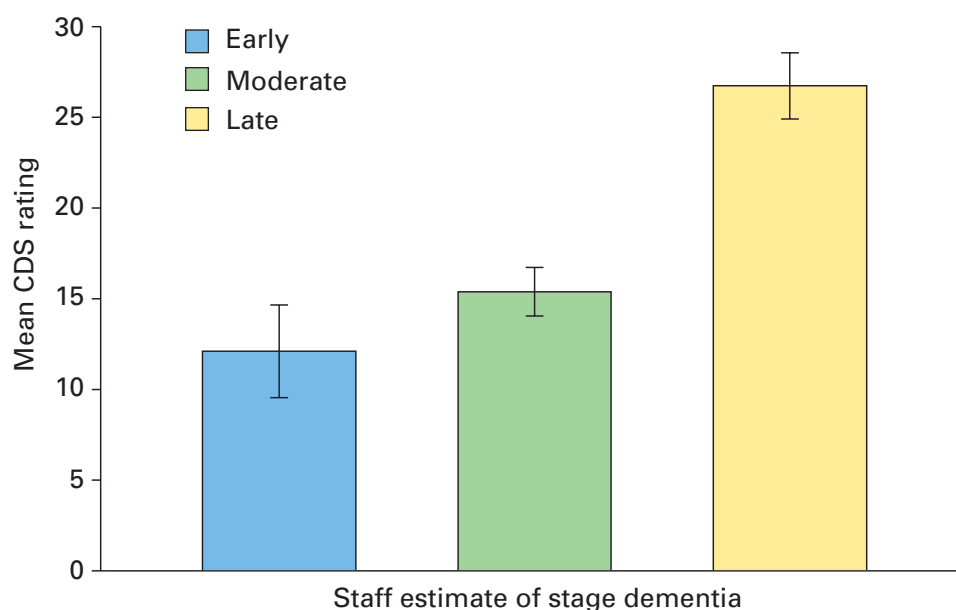
Indeed, the small number of participants overall in the CDS pilot, as well as the restricted sampling procedure (21/33 participants were residents in a single care home), means that the demonstration that the CDS can distinguish between people at different stages of dementia cannot be considered to be entirely reliable. Nevertheless, these preliminary results are highly encouraging and indicate that a more extensive study should be conducted to further establish the efficacy and validity of the CDS.

Estimates of communication in people with dementia

Using the Communication Difficulties Scale to classify the participants in this project according to their 'stage of communication difficulty' required the CDS 'cut-off' scores for membership of the early, moderate and late communication groups to be defined. The lack of 'staff estimate' early-stage participants in the CDS pilot meant that this group could not be used to define the 'cut-off' scores. Therefore, the mean and standard deviations from the moderate group (mean 15.4, S.D. 4.8) and late group (mean 26.7, S.D. 7.1) were used.

Applying the equation 'CDS "cut-off" rating = mean CDS group rating ± S.D.', the following stage of dementia group definitions were produced:

■ CDS ratings between 0 and 10.5 = early stage

■ CDS ratings between 11 and 19.5 = moderate stage

■ CDS ratings between 20 and 39 = late stage.

Categorising the fieldwork participants according to their CDS ratings changed the profile of each group slightly. Most people's staff estimate groups corresponded to their CDS stage groups; however, one man with early dementia, who appeared to have a specific speech production problem, became a member of the CDS moderate group; one man with moderate dementia, whose speech production (and possibly understanding) had been severely disrupted by his illness, was classified as CDS late stage; and two women with late-stage dementia became members of the CDS moderate group.

The final CDS groups were made up as follows:

■ early – nine people (five women, four men: average age 73 years, range 54–89)

■ moderate – 13 people (nine women, four men: average age 82 years, range 70–90)

■ late – nine people (eight women, one man: average age 82 years, range 75–89).

The CDS and effectiveness of communication

Grouping participants according to their CDS ratings gave highly similar results for effectiveness of communication (Figure 27) as did grouping them according to staff estimates of their stage of dementia (Figure 13). People in the early CDS group could communicate effectively regardless of the medium. People in the moderate CDS group communicated effectively (i.e. scored 12 or more on the effectiveness coding framework: see Murphy *et al.*, 2005b) only when using Talking Mats. Moreover, for moderate participants, Talking Mats were more effective than both Structured[2] and Unstructured[3] Conversation. Finally, the late CDS group as a whole did not achieve effective communication in any condition; nevertheless, four late CDS individuals produced Talking Mats effectiveness scores over 12 and Talking Mats scored higher than Unstructured Conversation[4] and marginally higher than Structured Conversation.[5]

Figure 27 Effectiveness scores for CDS groupings
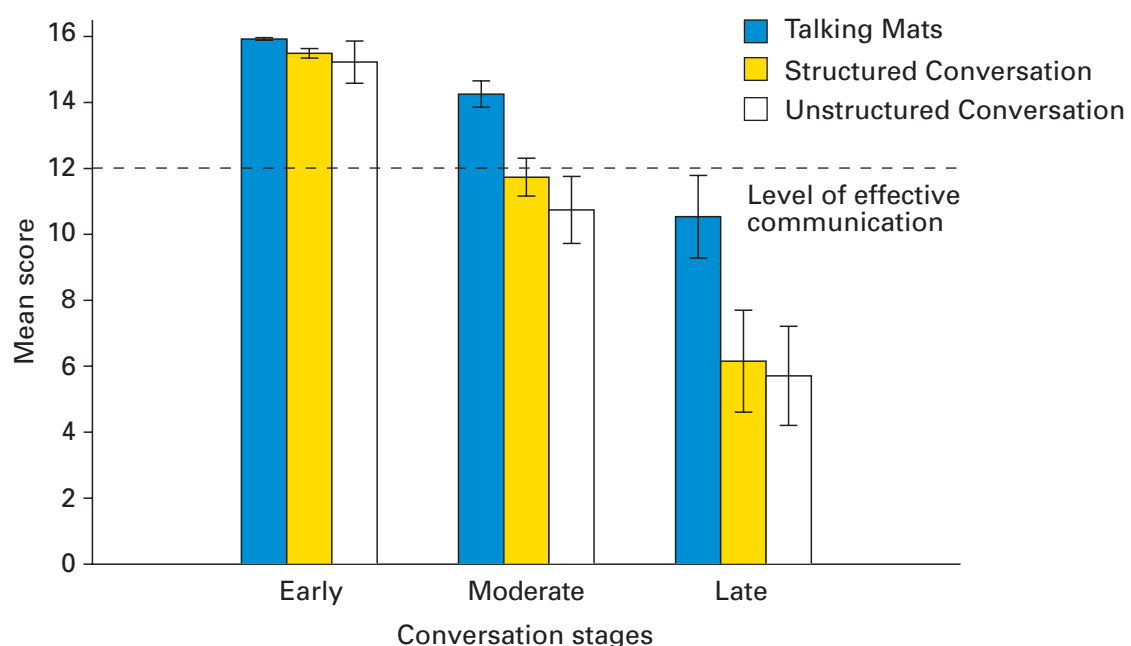
The Communication Difficulties Scale therefore appears to be a valuable indicator of whether a person with dementia will be able to use Talking Mats. Most people with a CDS score below 20 should be able to use Talking Mats effectively. Moreover, although people with higher CDS scores may be less able to use Talking Mats, the framework may still augment their communication.

Factors to consider when using the CDS

Speed of administering

The fieldwork researcher did not always directly oversee the completion of the CDS, as the most appropriate member of staff was often not available during the fieldwork visits. Where monitoring did take place, the CDS appeared to be reasonably quick to complete: most people managed to make all 13 judgements within five minutes.

Scoring the CDS is also quick and straightforward. Each option (e.g. 'Never', 'Sometimes', etc.) is assigned a score between 0 and 3 (marks placed midway between two options are given the average of the two adjacent scores). The scores for the 13 statements are then totalled to provide a rating that reflects the extent of a person's communication difficulties.

The speed with which the CDS can be administered and scored makes it highly suitable for general use with people with dementia. Moreover, although for the purposes of this project, staff or relatives were asked to complete the form, in practice it could be completed by any health professional or care manager following an interview with the person being assessed.

Clarity

Although the preliminary findings suggest that the CDS is a valid way to measure communication difficulties in people with dementia, a couple of the questions did cause some confusion. In particular, several people struggled to understand the difference between Question 6 (see Appendix), which dealt with the person's ability to understand simple language, and Question 8, which dealt with the person's ability to understand single words.

This problem could be resolved by redesigning the CDS or by providing a more thorough instruction/training session to anyone intending to use it on a regular basis. Training should also give people confidence about their judgements. When the researcher had an opportunity to go over the CDS with the person who had completed it, many people showed a degree of uncertainty and changed their minds about some of their decisions. Finally, training could be used to emphasise the importance of scoring midway between two options where appropriate. Although the possibility of using these 'midpoints' was expressly stated in the scale's instructions (see Appendix), only three out of 33 scorers in the CDS pilot study and nine out of 31 in the main project did so.

Specificity

It must be stressed that the CDS only measures the communication difficulties of a person with dementia. The scale does not purport to assess the progression of dementia per se. Nonetheless, it would appear that CDS estimates of communication difficulties often correspond closely to staff estimates of stage of dementia.

Summary

This chapter has introduced a new scale, the Communication Difficulties Scale (CDS), specifically developed to assess the extent of the communication problems experienced by people with dementia.

- A CDS score of less than 11 indicates that the person should be able to use Talking Mats successfully, but may be equally capable of conversing effectively.

- A CDS score of between 11 and 19.5 suggests that the person should be able to use Talking Mats effectively, and will likely be able to express their views better when using Talking Mats than when simply conversing.

- A CDS score of 20 or more suggests that although the person may not be able to use Talking Mats effectively, they may still be able to express their views better when using Talking Mats than when conversing.

The Communication Difficulties Scale may therefore provide a highly useful tool for the care staff, clinicians and practitioners involved in assessing the needs of people with dementia. The CDS is brief, straightforward and quick to complete, and provides a clear assessment of the communication abilities of a person with dementia. However, a more extensive examination of the reliability and validity of the CDS should be conducted before the scale is made generally available.

7 Implications of the research

The current project has clearly demonstrated that Talking Mats do help people with dementia express their views. People in the early and moderate stages of the illness are able to communicate effectively using Talking Mats; individuals with late-stage dementia are also capable of using the low-technology communication framework. Importantly, Talking Mats allow people with moderate- and late-stage dementia to communicate their views about their well-being more effectively than either simple or structured conversation.

When considering which aspects of communication were improved by Talking Mats, it was demonstrated that the communication framework increased participant understanding, researcher understanding, participant engagement and the amount of time the person with dementia spent talking about the subject being discussed. Talking Mats also appeared to reduce perseveration, to increase the amount of time spent 'on task' and to enhance the reliability of the information obtained from the people with dementia. As the severity of dementia increased, although people appeared to be less capable of taking ownership of symbol placement, the completed mats of many late-stage participants made full use of the three-point visual scale. This observation suggests that these individuals were still capable of expressing nuanced opinions.

Why do Talking Mats work with people with dementia?

In exploring ways to enable staff in a variety of settings (including day care establishments, residential homes and hospitals) to consult people with dementia about the design and delivery of the services that were available to them, Allan (2001) made several recommendations about how communication with people with dementia could be improved. Specifically, Allan suggested that staff should be encouraged to:

- make use of carefully chosen pictures

- use both verbal and non-verbal communication

- give people opportunities to talk in indirect ways

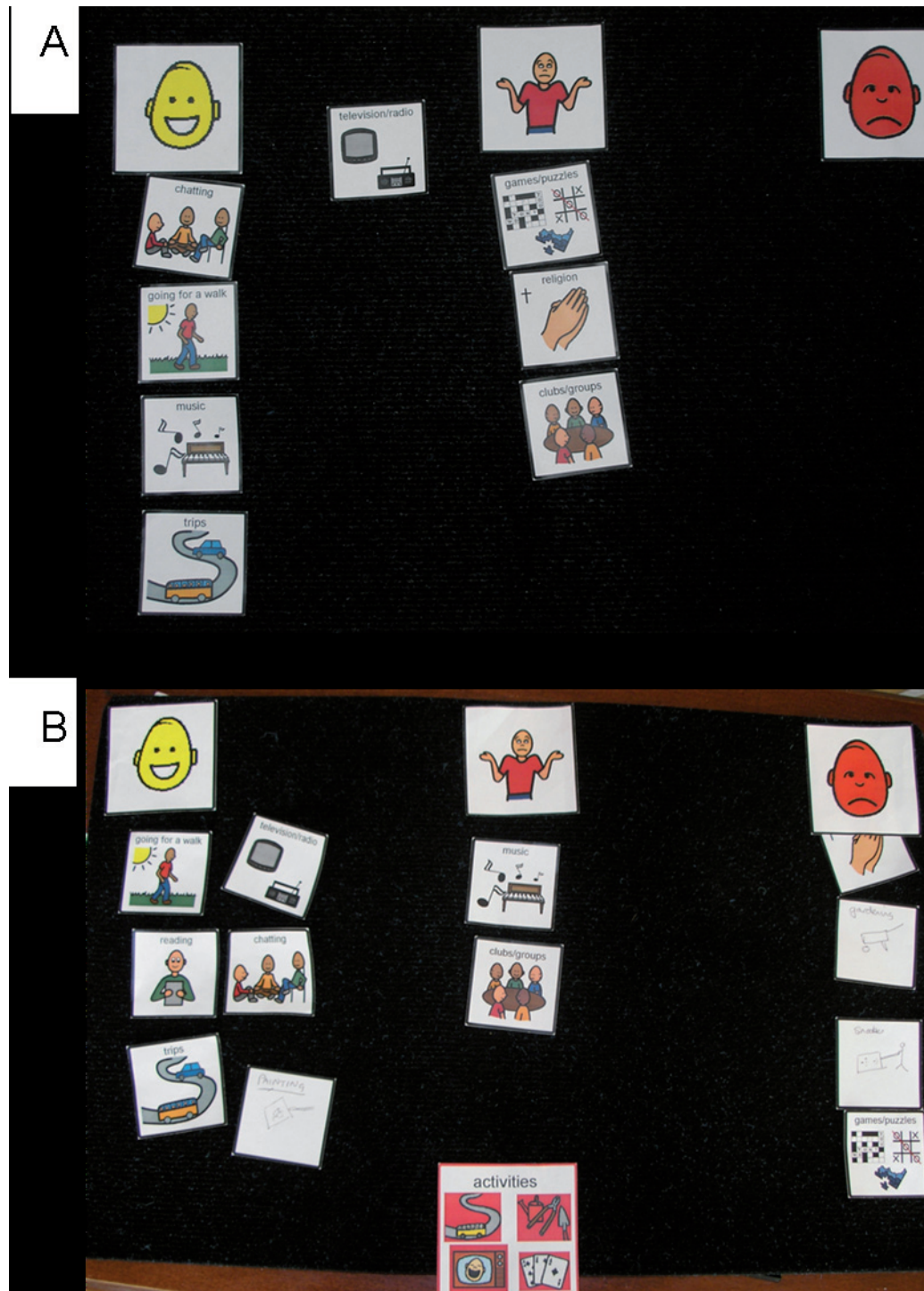- give people time to express themselves.

The Talking Mats communication framework clearly fulfils the foregoing recommendations. First, Talking Mats make use of simple pictorial representations of the topics and options being discussed. These images can be easily tailored to suit the preferences and requirements of each individual. For example, people with poor visual acuity can use larger Talking Mats symbols, and many people with dementia may prefer to use high-contrast symbols, such as those with yellow backgrounds. Importantly, the images used to depict each idea can be adapted for each individual to enhance their understanding of the subject being discussed. Moreover, staff can employ different subsets of topic symbols depending on the particular circumstances of the person who is involved in the discussion.

Second, in addition to allowing people to articulate their views verbally, Talking Mats encourage the use of non-verbal and indirect communication. People can convey their opinion by simply placing an option symbol under the visual scale themselves, or by indicating (e.g. by using finger or eye pointing, or hand or facial gestures) the emotional symbol that best corresponds to how they feel about a subject. In addition, careful placement of an option symbol (e.g. between the happy face and the midpoint) can allow people to communicate detailed opinions that they may not be capable of making explicit verbally. Figure 28 (Panel A) clearly illustrates this point: the 'television/radio' option symbol is placed midway between the 'happy' and 'not sure' visual scale symbols to demonstrate that this moderate-stage participant did not enjoy the television as much as she used to, but did still quite like to listen to the radio. Another (early-stage) participant partially hid the 'religion' symbol under the 'unhappy' symbol to demonstrate the extent to which he deplored religion (Figure 28, Panel B).

Third, and crucially, Talking Mats allow people with dementia to take time to express themselves. Individuals with communication difficulties may take much longer to respond than those whose communication is unimpaired (Mace and Rabins, 1999), and this delay can often be interpreted as a lack of responsiveness by a conversation partner. 'One of the ways in which people with dementia are disempowered in communication is that of being continually outpaced, having others speak, move and act more quickly that they are able to understand or match' (Killick and Allan, 2001, pp. 60–1). In everyday conversation, waiting for a person with dementia to respond to a question or action (e.g. a smile) may feel like an inordinately long delay to their conversation partner. The conversation partner is likely to become uncomfortable and feel obliged to fill the silence (Jefferson, 1989; Roberts *et al.*, 2006) with their own interjection or action (e.g. moving away), thus denying the person with dementia the opportunity to express themselves. Talking Mats give both parties in a discussion an alternative focus that deflects their attention from the normal conventions of conversation, such as turn-taking (Sacks *et al.*, 1974). Consequently,

the conversation partner should not feel so uncomfortable with any silences that may develop and will be more likely to give the person with dementia time to respond. The resulting more relaxed interaction should encourage the person with dementia to express themselves more readily and freely (Mace and Rabins, 1999).

Figure 28 Completed 'Activities' Talking Mats of two participants

Finally, not only do Talking Mats give people with dementia time to express themselves, the communication framework also provides them with an opportunity to reconsider the opinions they have expressed. At the end of each topic, both conversation partners should take time to review the completed mat to confirm that the person with dementia is happy that the option symbols have been placed correctly under the visual scale. If the person with dementia feels the position of any option symbol does not accurately reflect their view, they can use this opportunity to move the symbol to another part of the visual scale. This confirmation phase can be particularly helpful when an interviewee has been unable to place the option symbols themselves; it allows the interviewer to confirm that he or she has correctly interpreted the intentions of the person with dementia.

Policy relevance

This project has clear implications for practitioners, commissioners and policy makers. Recent guidance aims to ensure that all older service users (including people with dementia) are involved in policy decision making and has strongly promoted the implementation of a more person-centred care approach (Scottish Executive, 2000b, 2005a; Department of Health, 2001, 2006a, 2006b). Specific guidance on dementia services (NICE/SCIE, 2006; Scottish Intercollegiate Guidelines Network, 2006) has confirmed the key principles of person-centred care. The NICE/SCIE and SIGN reports stress that the human value and unique identity of every person with dementia should be respected, and that these individuals should be involved in decision making about care and treatment options, and about key life transitions (e.g. moving from one's own home into a care facility). Moreover, people with dementia should remain in control of their own daily living arrangements for as long as possible. Health and social care staff must therefore be able to identify the specific needs and preferences of people with dementia, and individual care plans must address and record the views of the person with dementia.

Accordingly, it has become increasingly important that every effort is made to ensure that people with dementia are able to express their views successfully, and the NICE (2006) and SIGN (2006) guidelines recommend that appropriate interventions should be used to ensure that communication difficulties do not become a barrier to accessing services, treatment or care. The demonstration that Talking Mats can allow people with dementia to communicate their opinions suggests that policy makers and commissioners should consider promoting the use of Talking Mats to help staff consult people with dementia more easily on a range of issues. The communication framework could be adapted to help care staff and service evaluators ask people with dementia what they think about various topics: from what they want recorded in

their own personal care plan and what they want to do on a day-to-day basis to what they think about the services on offer and where they would like to see improvements made (Care Commission, 2005).

However, in order to use Talking Mats to consult with people with dementia effectively, care staff and service evaluators need to be given adequate support. It is therefore important that organisations like the Care Commission and the Commission for Social Care Inspection take an active role in encouraging their staff to use the communication framework. These bodies have a responsibility to ensure that care staff and service evaluators are not only provided with the necessary equipment (mats and symbols), but are also given the practical assistance (training and information) necessary to allow them to become confident and fluent in using Talking Mats. By fostering the use of Talking Mats within care homes, social work departments, dementia service providers and other relevant organisations, policy makers and service commissioners can help secure better communication with people wherever they are in the journey of living with dementia.

Practical implications

Talking Mats are a low-tech and therefore highly accessible communication tool; they are also inexpensive and can be used in any setting. This project has shown that the framework is capable of providing carers and staff with an effective tool to allow many people with dementia to more easily communicate their needs and preferences. Furthermore, copies of the completed mats (obtained using a camera or a photocopier) can readily provide a permanent record of the views of a person with dementia. This record can subsequently be used to inform care planning and the development of services and support systems, as well as to ensure that the person with dementia remains in control of their own day-to-day living arrangements for as long as possible.

Importantly, most of the participants in this project appeared happy to use Talking Mats. This observation suggests that the framework is acceptable to people with dementia. Moreover, as Talking Mats are already used successfully with people with a range of needs (Murphy, 1998, 1999, 2000; Cameron and Murphy, 2000), their use will not be stigmatising for people who have not received a formal diagnosis of dementia. Nevertheless, it is vital to recognise that Talking Mats may not be suitable for everyone: some people with late-stage dementia may not be able to use the framework effectively, and others may become distracted as an interview progresses. However, the problem of distraction could be avoided by introducing more breaks in an interview.

The project has shown that Talking Mats do take longer than simply having a conversation with a person with dementia, especially when the confirmation phase is taken into account. This time factor might make Talking Mats less attractive to busy care staff. Nonetheless, it is important to realise that Talking Mats interviews do not necessarily have to be completed in a single sitting. One or more different topics can be easily discussed at subsequent sessions over an extended period of time. Moreover, the instant record provided by Talking Mats is potentially extremely time-saving: care staff no longer have to write up the views of the person with dementia, they can simply put a photocopy or photograph of the completed mats in that person's notes. Finally, when staff are using Talking Mats they are evidently 'doing something'. The fact that staff can be seen to be occupied may give them 'permission' to spend time simply chatting to people with dementia, getting to know them and interacting with them as individuals.

Although this project has looked specifically at using Talking Mats to ask people with dementia about their well-being, it must be stressed that the framework has the potential to be used to discuss any number of issues. The demonstration that many people with dementia can use Talking Mats effectively means that they should find the tool helpful in expressing their views about a wide range of topics. For example, Talking Mats may:

■ allow people with dementia to more readily choose what they want to do on a day-to-day basis

■ help people with dementia tell family carers and care staff how they feel (e.g. how bad their pain is)

■ help people in early (and perhaps moderate) dementia to make key decisions

■ help people with early or moderate dementia remember what they have said

■ provide a structure for conversation between a person with dementia and their friends/relatives during social visits

■ provide an instant record of what people with dementia have said to put in their notes (see above) or simply to show to their families.

Furthermore, in the clinical setting, Talking Mats could be used by care staff or family carers prior to a visit from a general practitioner or community psychiatric nurse. Copies of the completed mats could then provide the GP or CPN with more information about how people with dementia feel about themselves in general and

about their health in particular. Similarly, Talking Mats could be used prior to the visit of a social worker to explore how a person with dementia feels about the care options and services that are available to them.

With increasing numbers of care home staff now being recruited from overseas, Talking Mats may also prove extremely useful in overcoming communication difficulties between people with dementia and staff members who are not native English speakers. Likewise, people with dementia who are not native English speakers may revert back to their native language as their condition progresses (Ekman, 1996). In these cases, Talking Mats may also help overcome any confusion over language.

Finally, it must be emphasised that communication is a two-way process. Consequently, staff must be given the time, skills and motivation to talk with people with dementia, to record their views and to feed these back into everyday living choices and care plans. Before staff can use Talking Mats effectively with people with dementia, they must undergo some basic training. More information about Talking Mats training programmes and packages can be found on the Talking Mats website www.talkingmats.com.

Recommendations

This section summarises the main messages that have emerged during the course of the research carried out in this project. These recommendations are subdivided into three areas: 'Using Talking Mats', 'The Communication Difficulties Scale' and 'Consent in research'.

Using Talking Mats

Specific advice

■ The option symbols should be as simple as possible with large text to make them clearly visible. Make sure the person with dementia can see the symbols before starting an interview and be prepared to enlarge them if necessary.

■ People with dementia may need help with placing the symbols on the mat. The interviewer should make use of verbal and/or non-verbal communication when considering the person's intent.

- Personalisation is extremely important when using Talking Mats with people with dementia: for example, be prepared to change the images used in the symbols if an individual with dementia misinterprets the picture.

- People with dementia may have different preferences with regard to the colour of Talking Mats symbols. Some people may choose high-contrast symbols: for example, using a yellow background (or a black image against a yellow background) may be helpful in increasing the ease with which someone can see the symbols.

General advice

- People with moderate- and late-stage dementia could use Talking Mats to express their day-to-day needs and preferences.

- People with early (and in some cases moderate) dementia could use Talking Mats when facing difficult decisions. The communication framework would allow them to order their thoughts and to weigh up the benefits and drawbacks of a particular course of action more easily.

- At all stages of dementia, Talking Mats may simply be enjoyed as a personally meaningful activity.

- Talking Mats can play an important role in improving the quality of care experienced by people with dementia by prolonging the period during which they can communicate their views about their well-being and daily lives.

The Communication Difficulties Scale

- The Communication Difficulties Scale is brief, straightforward and quick to complete, and may therefore provide a highly useful tool for the care staff, clinicians and practitioners involved in assessing the needs of people with dementia.

- A CDS score of less than 11 indicates that the person should be able to use Talking Mats successfully, but may be equally capable of conversing effectively.

- A CDS score of between 11 and 19.5 suggests that the person should be able to use Talking Mats effectively, and will likely be able to express their views better when using Talking Mats than when simply conversing.

- A CDS score of 20 or more suggests that although the person may not be able to use Talking Mats effectively, they may still be able to express their views better when using Talking Mats than when conversing.

Consent in research

- A three-stage consent procedure involving staff, relatives and participants and a policy of ongoing consent allow most people with dementia to be actively involved in giving informed consent to taking part in research.

- Although individuals with dementia should, wherever possible, be encouraged to give consent to video/DVD recordings, consent must also be obtained from a third party (ideally a family member) who would be more likely to recall the existence of the video at a later date.

- People with dementia and their families should be allowed to specify the duration of retention of any videotapes (or similar).

Future research

The current project addressed two principal research questions, namely:

1   Do Talking Mats help people with dementia communicate?

2   Are Talking Mats effective for all people with dementia, or do only those in the earlier stages of the illness benefit?

The main findings are that Talking Mats do help people with dementia communicate and that the benefits of using the low-technology communication framework are most evident in people in the moderate and later stages of the condition.

During the 15-month course of the project, however, several other research questions have arisen. These questions could form the focus of future projects:

1   How effective are Talking Mats in helping people with early and moderate dementia make key decisions?

2   How effective are Talking Mats in helping people with other conditions make key decisions?

3   What are the facilitating factors/barriers to allowing staff carers and family members to use Talking Mats effectively with people with dementia?

4   Would becoming familiar with Talking Mats in earlier stages of dementia make the framework easier to use in the later stages of the condition?

Finally, a more extensive examination of the reliability and validity of the Communication Difficulties Scale should be conducted before it is made generally available to care staff, clinicians and practitioners.

Conclusions

> The goals of quality care giving should … be to prolong communication between patient and caregiver for as long as one can.
> (Carroll, 1989, p. 100)

The current research project has shown that Talking Mats can enhance the ability of people with moderate- and late-stage dementia to communicate their views. Accordingly, the low-technology communication framework appears to offer a valuable resource to people with dementia, family carers, care practitioners, service commissioners and all those who are interested in improving the quality of care delivered to people with dementia. Specifically, Talking Mats that have been designed to address precise topics, questions or issues could extend the period during which people with dementia can play an active role in making decisions about their lives.

Notes

Chapter 2

1   www.widgit.com/mayer-johnson/products/index.htm.

Chapter 4

1   Paired samples *t*-test, $t(30) = 7.38$, $p < 0.001$ (Bonferroni-corrected).

2   Paired samples *t*-test, $t(30) = 21.97$, $p < 0.000$ (Bonferroni-corrected).

3   Paired samples *t*-test, $t(30) = 15.37$, $p < 0.000$ (Bonferroni-corrected).

4   A mixed ANOVA produced a main effect of Stage Estimate [$F(2,26) = 4.27$, $p < 0.05$], and post hoc tests revealed a significant difference between the early and late groups, $p < 0.05$ (Bonferroni-corrected).

5   Wilcoxon signed-rank test, $z = 2.93$, $p < 0.01$ (Bonferroni-corrected).

6   Wilcoxon signed-rank test, $z = 2.85$, $p < 0.05$ (Bonferroni-corrected).

7   Wilcoxon signed-rank test, $z = 2.40$, $p = 0.051$ (Bonferroni-corrected).

8   Wilcoxon signed-rank test, $z = 2.70$, $p < 0.05$ (Bonferroni-corrected).

9   Wilcoxon signed-rank test, $z = 2.76$, $p < 0.05$ (Bonferroni-corrected).

10 Wilcoxon signed-rank test, $z = 2.43$, $p < 0.05$ (Bonferroni-corrected).

11 Structured Conversation – Wilcoxon signed-rank test, $z = 2.40$, $p = 0.051$ (Bonferroni-corrected); Unstructured Conversation – Wilcoxon signed-rank test, $z = 2.70$, $p < 0.05$ (Bonferroni-corrected).

12 Wilcoxon signed-rank test, $z = 2.71$, $p < 0.05$ (Bonferroni-corrected).

13 Wilcoxon signed-rank test, $z = 2.67$, $p < 0.05$ (Bonferroni-corrected).

14 Wilcoxon signed-rank test, z = 2.40, p = 0.051 (Bonferroni-corrected).

15 Wilcoxon signed-rank test, z = 1.54, p > 0.3 (Bonferroni-corrected).

16 Wilcoxon signed-rank test, z = 2.32, p < 0.06 (Bonferroni-corrected).

17 Wilcoxon signed-rank test, z = 2.70, p < 0.05 (Bonferroni-corrected).

18 Wilcoxon signed-rank test, z = 2.65, p < 0.05 (Bonferroni-corrected).

19 Wilcoxon signed-rank test, z = 2.70, p < 0.05 (Bonferroni-corrected).

20 Wilcoxon signed-rank test, z = 2.70, p < 0.05 (Bonferroni-corrected).

21 Friedman's ANOVA, χ^2 (2) = 7.58, p < 0.05.

22 Wilcoxon signed-rank test, z = 2.94, p < 0.01 (Bonferroni-corrected).

23 Wilcoxon signed-rank test, z = 2.76, p < 0.05 (Bonferroni-corrected).

24 Wilcoxon signed-rank test, z = 2.80, p < 0.05 (Bonferroni-corrected).

25 Wilcoxon signed-rank test, z = 2.29, p = 0.066 (Bonferroni-corrected).

Chapter 5

1   Wilcoxon signed-rank test, z = 3.54, p<0.001 (Bonferroni-corrected).

2   Wilcoxon signed-rank test, z = 23.12, p<0.01 (Bonferroni-corrected).

3   Wilcoxon signed-rank test, z = 3.38, p<0.01 (Bonferroni-corrected).

4   Wilcoxon signed-rank test, z = 2.40, p=0,051 (Bonferroni-corrected).

5   A mixed ANOVA produced a main effect of Interview Type [F(1,27) = 13.01, p = 0.001].

Chapter 6

1   An independent ANOVA produced a main effect of Stage Estimate [$F(2,30) =$ 17.17, $p < 0.001$], and post hoc tests revealed a significant difference between the early and late groups, $p < 0.001$ (Bonferroni-corrected).

2   Wilcoxon signed-rank test, $z = 3.18$, $p < 0.01$ (Bonferroni-corrected).

3   Wilcoxon signed-rank test, $z = 3.11$, $p < 0.01$ (Bonferroni-corrected).

4   Wilcoxon signed-rank test, $z = 2.55$, $p < 0.05$ (Bonferroni-corrected).

5   Wilcoxon signed-rank test, $z = 2.31$, $p = 0.063$ (Bonferroni-corrected).

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Appendix: Topics for discussion, consent procedure documents and questionnaires

Topics and options used in interviews

Topic	Activities	People	Environment	Self
Options	clubs/groups	friends	safety	support
	television/radio	shopkeepers	keeping warm	pain
	games/puzzles	family	noise	mood
	chatting	carers/home-help	garden/outside	appearance/looks
	music	time alone	where you live	memory
	religion	doctor/nurse/therapist	meals	teeth
	trips	minister/priest	comfort	eyesight
	going for a walk	neighbours/residents		hearing
	reading			clothes
				memories
				health
				medication

Family Information Sheet

A tool to help people with dementia have their say?

The deterioration of communication between people with dementia and their relatives and carers is one of the saddest and most painful aspects of the illness. Communication problems may include reduced vocabulary, word-finding difficulty, losing track of the topic and distractibility. As the illness progresses, the person becomes harder to reach and it is increasingly difficult to ensure that their views are included, and that decisions are made with their involvement. Nevertheless, it is important to enable people with dementia to be more actively involved in expressing their views about aspects of their life, such as their relationships, their surroundings and the activities available to them, in order to improve their quality of life.

Talking Mats and improving communication
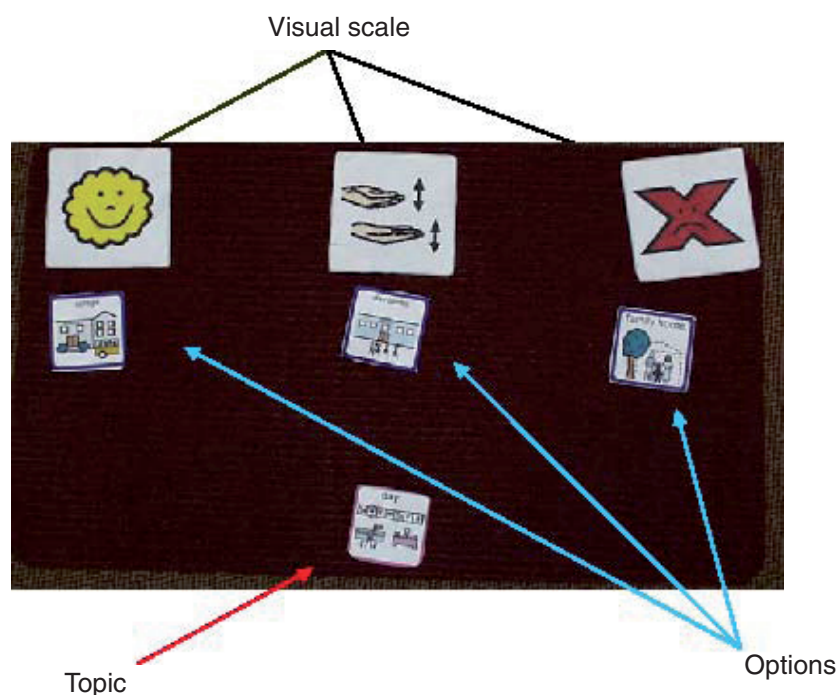
1 *Topics* that are relevant to the problem explored (e.g. pictures symbolising where you want to live, who you want to spend time with, what you want to do during the day, and so on).

2 *Options* relating specifically to each topic (for example, whether you wish to have your own home, or to live in a group home or in a family home, and so on).

3 *Visual scale* in order to allow participants to indicate their general feelings about each topic and option (for example, whether they are happy, unsure or unhappy).

There are several factors which could improve communication for people with dementia. These factors include the use of carefully chosen pictures, making use of both verbal and non-verbal communication, giving people opportunities to talk in indirect ways, and providing resources to help family and paid carers communicate with people with dementia. Talking Mats is an innovative communication tool that makes use of all of the above. Since it was developed in 1998 by Joan Murphy, a research speech and language therapist, Talking Mats has been used with many people with a wide range of communication difficulties to help them express their thoughts and feelings.

Although a previous work has indicated that Talking Mats might be useful to help people with dementia express their opinions, a study specifically designed to address this important issue has never been carried out. Therefore a major UK charity, the Joseph Rowntree Foundation, has agreed to fund the project that we are hoping that your relative might become involved in.

We are aiming to recruit 30 people, at different stages of dementia, to take part in the research. We will meet with each participant (and a relative or carer) on three occasions at a place where they feel comfortable. During the first visit we will explain the project to them, introduce them to Talking Mats, and ask them if they would be happy to take part. On the second and third visits we will ask the participants about their well-being (i.e. what they feel about the things they do, about the people they know, about the place they spend their time, and about themselves). One of these occasions will just be a normal face-to-face conversation; the other will be a conversation using Talking Mats. Both chats will be videotaped so that we can later assess how Talking Mats helps communication in people with dementia.

We very much hope that your relative will be able to help in the study. Previous work suggests that most people with dementia enjoy the experience of using Talking Mats. We would be delighted to answer any questions or queries that you might have about the project. Please feel free to contact us:
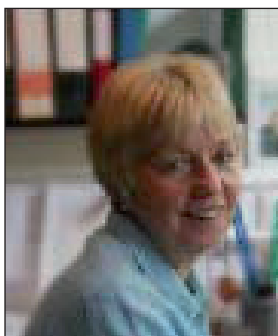
AAC Research Unit
University of Stirling
Stirling FK9 4LA
Telephone: 01786 467645

Joan Murphy: jm9@stir.ac.uk
Cindy Gray: lmg1@stir.ac.uk

Participant Information Sheet

Talking Mats and Well-Being Information Sheet

I am carrying out a study to find out about the well-being of people with memory problems.

The study is looking at:

- what people feel about their lives

- how to help them share these views with other people.

I would like you to help me.

If you agree to help me, I will use Talking Mats to help you tell me what you feel.

This is a picture of someone using Talking Mats.

I will not share your views with anyone unless you want me to.
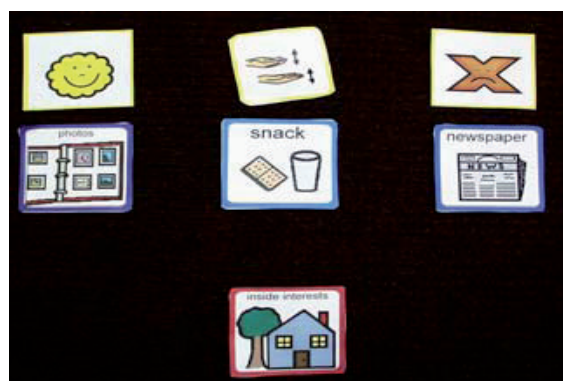
You will get a copy of your Talking Mat to keep.

If you agree to help, I will meet you today and on two other occasions.

I will always see you at a place that is comfortable and familiar to you.

When I come back to see you, I will ask you about your well-being.

I will video these chats; one chat will use Talking Mats, the other will just be like a normal conversation.

If you change your mind at any time you can tell me to stop.

You can contact me at:

AAC Research Unit
University of Stirling
Stirling FK9 4LA
Telephone: 01786 467645

Cindy Gray: lmg1@stir.ac.uk

Cindy Gray

Participant Consent Form

	Have you read the information sheet, or had it explained to you?	**YES NO**
	Have you had time to ask questions and talk about the study?	**YES NO**
	Are you happy with the answers you have been given?	**YES NO**
	Do you understand that it is your choice to take part in the study?	**YES NO**
	Do you understand that I will use video as part of the study?	**YES NO**
	Do you understand that you can stop at any time? (You do not have to say why you want to stop.)	**YES NO**
	Are you happy to take part in the study?	**YES NO**
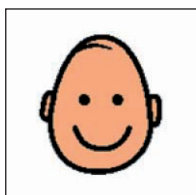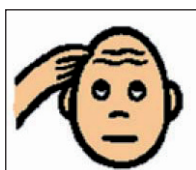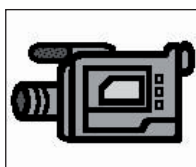
Name ....

Signature .... Date ....

Observer Consent Support Form

NAME ....

Relationship to participant ....

Any comments on the communication observed:

I observed the project being explained to...
and feel that they would be happy to take part in the project.

Signature ....Date....................................

Video Consent Form

I agree to video and photographs being recorded on the understanding that the material will be retained securely and only be used for the current study and for the following:

	YES	NO
Educational purposes within Stirling University	☐	☐
Educational purposes outwith Stirling University	☐	☐
Professional publications	☐	☐
Press/media publications	☐	☐
Exhibitions/displays/presentations	☐	☐
Future research	☐	☐

TIMESCALE ....

I understand that my full identity will not be revealed.

SIGNATURE OF PARTICIPANT .... Date ....

SIGNATURE OF CARER .... Date ....

RELATIONSHIP TO PARTICIPANT ....

Participant Background Questionnaire

Please circle one option for EACH question to provide some background information about the person who is taking part in the Talking Mats and Memory Research Project.

ACTIVITIES	1) Is the person religious?	Yes	No	Don't Know	
	2) Do they go on trips?	Often	Sometimes	Never	Don't Know
	3) Do they go for walks?	Often	Sometimes	Never	Don't Know
	4) Do they participate in clubs or group activities?	Often	Sometimes	Never	Don't Know
	5) Do they like music?	Yes	No	Don't Know	
	6) Do they play games or puzzles?	Yes (which)	No	Don't Know	
	7) Do they read? (please specify)	Books	Magazines	Newspapers No	Don't Know
	8) Do they enjoy chatting?	Often	Sometimes	Never	Don't Know
	9) Do they enjoy the television and/or radio?	Television	Radio	Neither	Don't Know
	10) Do they go outdoors/in the garden?	Often	Sometimes	Never	Don't Know
	11) Do they eat most meals?	Alone	With others	Both	Don't Know

PEOPLE	1) Does the person see any medical professionals?	Doctor	Nurse	Therapist (please specify)	Don't Know
	2) Do they see friends?	Often	Sometimes	Never	Don't Know
	3) Do they see a minister or priest?	Often	Sometimes	Never	Don't Know
	4) Do they go shopping?	Often	Sometimes	Never	Don't Know

SELF	1) Does the person suffer from pain?	Often	Sometimes	Never	Don't Know
	2) Do they have problems with their teeth?	Often	Sometimes	Never	Don't Know
	3) Do they have problems with their eyesight?	Often	Sometimes	Never	Don't Know
	4) Do they have problems with their hearing?	Often	Sometimes	Never	Don't Know
	5) How is their health in general?	Good	Fair	Poor	Don't Know
	6) Do they suffer from mood swings?	Often	Sometimes	Never	Don't Know

Please make sure you have answered EVERY question.

Communication Difficulties Questionnaire

For each of the following 13 statements, could you please circle one OPTION *that best describes the person you are thinking about.*

If you feel none of the options give an accurate picture of the person, you can put your circle midway between two options (e.g. SOMETIMES OFTEN*). Please provide an answer for* EVERY *statement.*

1) They have difficulty coming up with words
NEVER   SOMETIMES   OFTEN   ALWAYS   SAYS TOO LITTLE FOR ME TO JUDGE
2) They are likely to repeat things that they have just said
NEVER   SOMETIMES   OFTEN   ALWAYS   SAYS TOO LITTLE FOR ME TO JUDGE
3) They are likely to repeat things that other people have said
NEVER   SOMETIMES   OFTEN   ALWAYS   SAYS TOO LITTLE FOR ME TO JUDGE
4) They tend to digress / to go off on a tangent
NEVER   SOMETIMES   OFTEN   ALWAYS   SAYS TOO LITTLE FOR ME TO JUDGE
5) They use filler words (e.g. "thing", "whatsit") instead of content words (e.g. "pen", "cooker")
NEVER   SOMETIMES   OFTEN   ALWAYS   SAYS TOO LITTLE FOR ME TO JUDGE
6) They can understand simple language
NEVER   SOMETIMES   OFTEN   ALWAYS   SAYS TOO LITTLE FOR ME TO JUDGE
7) They can understand abstract/complex language (e.g. "Rome wasn't built in a day")
NEVER   SOMETIMES   OFTEN   ALWAYS   SAYS TOO LITTLE FOR ME TO JUDGE
8) They have problems understanding even single words
NEVER   SOMETIMES   OFTEN   ALWAYS   SAYS TOO LITTLE FOR ME TO JUDGE
9) They lose track of what they are saying
NEVER   SOMETIMES   OFTEN   ALWAYS   SAYS TOO LITTLE FOR ME TO JUDGE
10) They are easy to understand
NEVER   SOMETIMES   OFTEN   ALWAYS   SAYS TOO LITTLE FOR ME TO JUDGE
11) Their use of pronouns (e.g. "he", "she", "they") is poor
NEVER   SOMETIMES   OFTEN   ALWAYS   SAYS TOO LITTLE FOR ME TO JUDGE
12) Their speech makes little sense because they use the wrong words or sounds
NEVER   SOMETIMES   OFTEN   ALWAYS   SAYS TOO LITTLE FOR ME TO JUDGE
13) They use non-verbal ways (e.g. nodding, smiling, agitation, striking-out) to communicate
NEVER   SOMETIMES   OFTEN   ALWAYS   SAYS TOO LITTLE FOR ME TO JUDGE

PLEASE MAKE SURE YOU HAVE ANSWERED ALL 13 QUESTIONS

Please add any further comments you would like to make:

Thank you very much for taking the time to complete the questionnaire(s)