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Dementia care: insights, practicalities and change

Speech and language therapists are increasingly involved in the management of people with dementia, often working with carers rather than directly with the affected individual. But what do these carers think about what we have to say? Does it make any difference to the person with dementia? And what constitutes 'best practice'? Colin Barnes investigates.

In common with the growing number of speech and language therapists involved in the care of people with dementia, my role is based around the assessment of communication and memory or feeding and swallowing difficulties. It also entails running group or individual therapy programmes for people with dementia and / or their carers to maintain experience and skills of communication and memory.

At the first national meeting of speech and language therapists working in old age psychiatry in October 1997, 14 of the 17 people there reported offering some communication advice and training to carers. A review of the literature identifies a small number of studies in which carers have reported that communication advice and training is useful, though none of these studies have given specific reasons why.

To find out more - and to explore implications for our practice - I carried out a local study designed to consider the question "To what extent do carers of individuals with dementia benefit from communication advice and training?"

Initially, six individuals with mild to moderate dementia determined using the ABCD Assessment (Bayles and Tomoeda, 1993) were seen for a communication and memory assessment. I then contacted their carers and visited them at home within four weeks. For this study, the term 'carer' referred to immediate family members directly involved in caring on a day to day basis and included one husband, three wives and two daughters. During this visit carers were provided with;

1. the opportunity to talk about communication difficulties being experienced
2. an explanation of the communication and memory assessment results
3. a standard presentation on approaches to communication and confusion in dementia (Barnes, 1998)
4. demonstration of a range of approaches to communication
5. the opportunity to have carer : patient interaction observed and discussed
6. a written record of no more than three key recommendations
7. an agreed number of follow-up appointments or telephone contacts.

My approach to working with carers is based on a number of beliefs, though particularly I attempt to:

- I. Discuss the possible range of approaches to managing confusion and memory difficulties rather than prescribing carers one approach to cover all situations.
- II. Use visual material in the form of a colour presentation called Chatter Matters to help explain the difficult abstract concept of 'communication' and provide some structure to giving advice.
- III. Limit the number of recommendations made and subsequent pressure on the carer by setting a limit of no more than three key recommendations. Examples of these specific

recommendations are in figure 1.

Figure 1 Specific recommendations

1. Introduce using his hearing aid for two hours each day over lunch
2. Fill a small box with photographs and mementoes to act as subjects of conversation. Keep the box by his chair, placing it on the coffee table when friends visit.
3. When the family come for dinner, ask her to clean and peel the vegetables. Talk about her hard work during the meal.
4. Keep labels from food cartons. Put these together into a picture book to help her select which food she would like.

Range of options

The discussion with the carer is primarily about the ethics of approaches to communication and aims to equip them with an understanding of the pros and cons of a range of approaches that they can use across most situations. When a carer asks "What should I do when he says something that isn't correct?", I answer by discussing the range of options open to them (figure 2), from correcting the person (Reality Orientation) to ignoring their error and encouraging them to tell you more (Validation). In some situations, it may even be possible to talk with the relative about positively encouraging some confused ideas, an approach which is used selectively by the Special group in Oxford.

Figure 2 - Options example

Question from relative:

What should I say when my husband tells me he's off to work? His job was his life, but he's been retired for 10 years now!

Answer:

You have a choice:

1. *You can correct him ('Reality Orientation' - see Zanetti et al, 1995) but you should ask whether he is likely to remember what you have said - this will depend on his memory skills and how often the error occurs - and how it will make him and you feel.*
2. *You can listen to what he says neutrally without comment, ignore him or even distract him. But you should consider if he is likely to notice that you have ignored his first comment. You may want to introduce a well established subject of conversation or ask an alternative question ('Reminiscence' - see Bourgeois, 1991), for example "Do you remember the good old days when we used to..."*
3. *You can let him tell you more about what he has said, for example about work. Ask him more using 'where', 'when', 'what', 'how' questions like a reporter ('Validation Therapy' - see Feil, 1995). He is more likely to enjoy being listened to, but you should ask yourself whether he is likely to realise that he has made an error and that you have gone along with it.*
4. *You can positively reinforce the reality of what he has said using props. For example, if he says he is off to work, you can give him a briefcase and diary and wish him a good day at the office. This may seem deceptive, but you should ask yourself how it will make him feel or whether you are reinforcing something that is likely to lead to further complications. This*

may depend on the value he attributed to work and the previous nature of his job. ('Special' approach - see Garner and Godel, 1996).

The idea of introducing a range of approaches is based on my experience that many carers naturally feel obliged to correct their relative irrespective of whether it is in their relative's best interests. A tendency to orientate may be associated with common perceptions of caring as a job of 'making better' or 'rehabilitating'. Another tendency amongst carers may be the idea of respecting an individual's rights. Unfortunately, though, this can mean carers asking patients to answer questions which are beyond their understanding, leading to decisions which are not in their best interests.

The presentation *Chatter Matters* is also used to illustrate the equal importance of content and quality in conversation. I explain that too great a focus on the content of conversation may lead to a reduction in quality and ultimately cause the person with dementia to lose interest and withdraw.

Other popular topics of discussion include:

- How to involve their relative in conversation
- Which things to correct and ignore
- What to say when they return from the day centre
- Asking questions
- How to make major decisions between them
- What kind of activities they could be doing
- Coping with repetition.

Real attitudes

Research suggests that, when asked, carers will invariably comment politely and positively about a service they have received, especially if they are being asked by the service provider (Knight et al, 1993). To identify the carers' real attitudes to my visit, I employed an independent interviewer (another mental health professional) to visit each carer four weeks later. Other researchers argue that interview responses alone are not sufficient to measure carer burden and, therefore, following Knight et al's (1993) recommendation, the carers in this study were also asked to complete a Subjective Measure of Carer Burden Scale (Montgomery et al, 1985). This scale was completed twice, at the beginning of both the speech and language therapy and interviewer visits. It consists of thirteen statements designed to reflect the extent of burden the carer may be feeling, for example 'I feel that my relative doesn't appreciate what I do for him/her'. The carer is asked to rate their agreement with the statement from rarely or never to most of the time.

Along with a second independent researcher, I analysed the anonymous results from the interviews, typed verbatim onto transcripts, and the Carer Burden Scale. The results from the study can be broken down into three areas:

1. The Subjective Measure of Carer Burden Scale

The results from this measure were disappointing. On average, all carers reported an increase in burden between visits and following contact with the speech and language therapist. However, decreased burden was indicated in two questions, which suggested that the majority felt less nervous and depressed and interpreted their relative as being less demanding.

The scale was introduced to give an additional quantitative element to the study though the results did not illustrate the trend expected. The answers to the quantitative questions clearly showed that the carers found the visit very helpful. It therefore seems unlikely that the carers should have experienced an increase in burden. Closer examination of the results also suggests that some difficulties may have been experienced in interpreting the questions in the measure and that additional differences were created by having two testers. Whilst I would tend to conclude that no real significant increase in burden was experienced, we should never dismiss the real possibility that our intervention can add to a carer's burden.

2. Quantitative (Yes/No) responses from the interview

Unfortunately, one carer was unable to complete the interview fully as the patient had insisted on remaining in the room and objected to being talked about, therefore only the results for the other five carers are given.

Interview Questions with Average Score/Response

1. Was the visit helpful? **2.8** *
2. Was an explanation of the assessment results helpful? **3**
3. Was it helpful to simply talk about your communication difficulties? **3**
4. Was it helpful to be given information on communication? **2.8** *
5. Did the visit influence your thinking? All said **Yes**
6. Have there been any changes in your attitude and approach? All said **Yes**
7. Were you able to carry out the recommendations made? All said **Yes**

Carers were asked to give responses using a three point scale where:
1=not helpful, 2= helpful and 3= very helpful.

*One person gave a score of 2 instead of 3. This appears linked to their comments that some of what was said was common sense.

3. Qualitative (reasons why - to what extent) responses from the interview

The comments made by each of the carers (five people) were sorted into ten categories agreed by the two researchers, then key themes were identified using a method of content analysis. Although the quantitative responses in the study clearly indicate that this sample of carers found their contact with a speech and language therapist useful, the qualitative data from the study is able to provide some possible reasons. The five most significant themes are described with resulting suggested learning points giving direction for best practice:

i. Comments and insights into the caring role

Surprisingly, over thirty comments about being a carer were volunteered though none of the interview questions had asked for these. Of these comments, twenty-one were negative including being tired, not sleeping, being alone with no-one to talk to, only conversing when the patient wants to and having to compromise.

Learning Point: Be careful not to over-empathise. Although we may spend much of our working life with people with dementia our experience is emotionally very different from the family carer.

ii. Practicalities of the visit and speech and language therapist approach

The majority of carers preferred having the meetings in their own homes. They reported appreciating having time to talk, having realistic recommendations and simply being encouraged. Difficulties arose when carers failed to understand the purpose of the visit - that is, that it was for them as much as their relative.

Learning Point: Be clear about the purpose of our visits and offer the carer a range of options to ensure their interest and attention.

Carers also varied in their ability to understand the idea of 'communication'. Two appeared to misunderstand what is meant by this term. It was also clear that carers were more able to apply and remember recommendations that involved specific activities than more general changes in approach such as "Try talking in less complex sentences".

Learning Point: Allow for varied understanding of 'communication' and consider using very specific, preferably activity based, recommendations.

iii. Changes in Belief, Attitude and Understanding

In keeping with the aims of the visit, three out of six carers reported a change in belief that it was now more acceptable to go along with confused ideas or errors. All six reported an increase in knowledge and two reported more tolerance in attitude.

Learning Point: The speech and language therapist has a valid role in helping some carers to broaden their beliefs and knowledge about ethically acceptable approaches to communication in dementia.

iv. Changes in approach

From five carers, twenty mainly activity based changes were reported. These included relaxation and talking to their relative and others about household tasks they can be given to do, such as washing, peeling, polishing and folding. The carers also reported difficulties in introducing another eight changes. For example, one carer found talking books didn't help and another was unable to follow the suggestion of returning from trips with a memento such as a menu because they don't go out much.

However, the carer who reported the greatest success in introducing changes also reported looking for alternative approaches after four weeks. They appeared to be looking for more variety, although their relative was unlikely to appreciate this.

Learning Point: We may need to prepare carers to cope with repetition. It is likely that some of the most successful changes made will be those that happen at least once a day.

v. Changes in carer and patient well-being

All comments in this section were related to communication activities and none to changes in communication style. The main benefit reported by carers was the value of being listened to and being encouraged. However, two carers found it difficult to see how the carer contact could help the patient.

Learning Point: Carers by definition provide the majority of care for their relatives. If they find gratification in what they do, it would seem likely that they will be able to care for longer. The carers appeared to appreciate encouragement about the job of caring they are doing and may benefit from contact with a 'knowledgeable professional'.

Worthwhile

Consideration of the results of the study suggests that communication advice and training for carers of people with dementia is worthwhile because it provides for more understanding of the patient's difficulties and needs, more success in communication and interaction, less difficulty being realistic about the future, encouragement about the job of caring they are doing, confidence to employ a broader range of approaches and an opportunity to talk about the difficulties they are experiencing.

This study considered the value of working with dementia carers on communication in more detail than any other known published study. Even so a number of limitations, including the relatively small sample size, call for future research. This could address at least three further questions;

- Which and what proportion of carers benefit?
- How long do the benefits last?
- What is the potential for and interest in further contact with a speech and language therapist?

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Reflections:

- **Do I try to encourage change without increasing feelings of burden?**
- **Do I genuinely attempt to alter my practice based on what the users of my service think?**
- **Do I enable people to see they always have more than one option?**