

Chief Scientist Office

Form 4

Final report form	CSO reference number: CZG/2/100
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Project title: Consultation between General Practitioners and people with a communication disability	
Start date: 1 st September 2003	Finish date: 31 st August 2004

Grantholders:

Professor Ivana Markova FRSE, FBA	Professor of Psychology

1. Summary

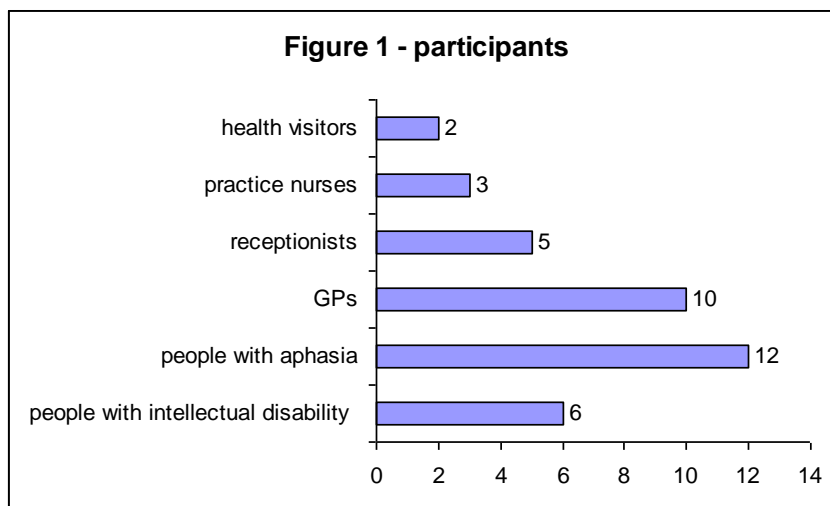
There is now recognition that communication disability (CD) causes a particular problem in primary care and that this issue has not yet been adequately addressed^{1,2,3,4}. Inadequate communication can prevent the client's access to proper assessment and can result in wrong diagnosis, inappropriate medication and poor health care services. This small study examined the perceptions and discrepancies, experienced both by general practice staff (GPstaff) and people with communication disabilities (PCD), in consultations about health issues.

2. Original aims

1. To obtain the views of PCD on how they consult with GPs
2. To obtain the views of GPs on consulting with PCD
3. To identify priorities of PCD and GPs and with reference to understanding the needs of patients
4. To identify appropriate research questions for further study

3. Methodology

Eight focus groups were held with a total of 38 participants. Figure 1 shows the role participants.



Four focus groups were held in GP practices. At the initial meeting to explain the project, GPs suggested including receptionists and nurses to provide a wider perspective. Two focus groups were held with people with intellectual disability who were members of *Quality Action*, a Stirling based advocacy group and two focus groups with people with aphasia from the local *Speakability* group. Eighteen participants with CD, including aphasia, dysarthria, dyspraxia and intellectual disability took place. All the participants had a comprehension level of 3 or more pieces of information in one sentence and understood the nature and the purpose of the study.

The format of the focus groups was to ask the participants to consider and discuss communication at each stage of the visit – before, during and after the actual consultation - and the same topic prompts were given to all groups (appendices 1 and 2). All discussions were audio recorded. In order to assist the participants with CD, picture symbols and *Talking Mats™*, a visual framework that uses symbols to help people with a communication difficulty understand and respond more effectively^{4,5}, were also used.

Analysis:

The tape recordings were transcribed verbatim, then read and listened to several times for familiarisation with the data. The data from each focus group were analysed using progressive thematic analysis⁶ to take into consideration not only what the participants said but also how they developed their arguments and negotiated issues in question.

4. Results

i) How do GPstaff consult with PCD and what enhances and what makes communication more difficult?

(Appendix 3 summarises the comments from the GPstaff)

There was a lack of awareness among GPstaff of the extent of the problem, both in terms of the range of CD that exist and the number of PCD presenting at surgeries. The main groups identified were patients who were either deaf or had profound learning disabilities. GPstaff did not appear to be aware of the more subtle yet substantial difficulties experienced by people with mild aphasia or intellectual disability.

You never think that there could be a problem with reading (participant 38)

Before consultation:

GP staff simply assumed that carers would make appointments.

It was acknowledged that the waiting room itself created problems for PCD such as lack of privacy and embarrassment at having to try to speak in front of other patients.

They're exposed, they come out and they stand there totally exposed (participant 32).

GP staff were initially unaware that finding the consulting room might be a problem for PCD. This led to discussion of the pros and cons of having a buzzer system to alert people to their turn versus the doctor coming out to meet them in the waiting room.

During consultation:

The GP groups expressed the frustration they felt during the actual consultation and complained of patients forgetting appointment times, poor understanding on both sides and lack of time. However there was limited awareness of the reasons behind these difficulties.

A lot of hassle and anxiety ... a lot of frustration, because trying to get the message across if they can't get their formation right or they forget what they want to say when they come in... (participant 21)

One GP felt that patients need to take more responsibility for their own communication.

After consultation:

GP staff made no comments about the problems patients might have in explaining the doctor's advice once they had gone home. When pressed further, they thought it might help to give something in writing or to have the district nurse make a follow up visit.

When prompted to propose solutions to the problems, the main suggestion was 'to rely on carers', not only to make appointments, but also to speak for the patient and to carry out any instructions following the consultation. All groups commented that they would use carers to overcome CD. They appeared surprised when it was suggested that patients might have a different view from their carer but one nurse commented:

Not everybody wants somebody to come in with them (participant 34).

Other suggestions were made such as getting to know the patient better, making a double appointment to give them more time and watching the patient for non verbal clues.

In summary GP staff often struggle to communicate with people with communication disabilities, particularly if they do not know them well, and tend rely on carers. Previous knowledge of the person was considered the best way to enhance communication.

ii) What are general practitioners' views on more effective involvement of speech and language therapists?

Their initial comments were to suggest interpreters for people for whom English is a second language and social workers for the deaf. They had few comment about SLT and pointed out that often the need for help was immediate and that it was hard to get help from SLTs. One GP said:

I don't know that there's enough of you quite frankly ... (participant 21)

One nurse said she was aware that people got SLT in hospital but felt it was not followed up quickly enough in the community.

It's just obviously there is not enough Speech Therapists to follow these patients up so they sort of sit in limbo for so long (participant 38).

In summary, GP staff made very little comment about SLTs, except that there were not enough of them, and were not clear about their role.

iii) Would specialist training in understanding communication disability be of value? If so, what should such training involve?

None of the GP staff said they had received any training in relation to CD and when the possibility of training was introduced, reactions were mixed. They all felt that time was the main obstacle to training and that because they might not use it regularly they would forget it. When specific training based on the findings from the study was suggested, there was clear interest and several participants stayed at the end of the focus groups to ask more about training and offered to pilot materials. Some suggested using visual material such as pictures, models and communication books but stressed that they did not have time to learn about communication aids.

In summary GP staff agreed that they would benefit from specific training in disability provided it was practical and simple to implement.

iv) How do general practitioners determine the capacity of people with communication disability to make decisions about their lives?

There was general disquiet concerning this. Some GPs commented that it was fairly straightforward where the person had a marked difficulty that left the doctor in no doubt, but admitted there is a problem with people with less obvious disability:

Well the border line ones, if you want an honest opinion, would just get ignored. I don't mean they get ignored as patients ... I think they get ignored as far as the Act goes. (participant 22).

In summary GPs appeared unsure how to determine capacity for people with CD who are on the borderline of making their own decisions and were concerned at the additional onus put on them by the ACT.

v) What criteria do they use to make such decisions?

GPs concluded they would mainly rely on carers, ask yes/no questions or guess. When asked if a simple communication tool to help people express their views would be helpful one GP replied:

Yes I think something like that would be very helpful but I wouldn't see it as my job to be administering it. (participant 36)

GPs in this study did not appear to have any systematic criteria for determining a patient's capacity to make decisions.

vi) How do people with communication disability express their health concerns in consultation with general practitioners? What enhances understanding and what makes it more difficult?

As the views of the participants with aphasia concurred and overlapped with those with intellectual disability, their comments have been combined and summarised in Appendix 4. There were considerably more comments from the PCD than from the GP staff.

Before consultation:

All 4 groups described problems when using the phone to make their appointment. Some had difficulty dialling the number; some could not cope with the speed of the receptionist's speech; some had difficulty understanding time e.g. they would confuse quarter **past** ten and quarter **to** ten; some were unable to write down the date and time of the appointment given and all said that auto attended calls with voice menus were particularly hard to use. For everyone it was important to get an appointment with a doctor who knew and understood them but this was often difficult.

They all found the waiting room stressful for a variety of reasons. Some found it noisy:

Sometimes the phones start to get to you ...ringing was something that gave me great problems...I call it the starling effect... it's just like starlings in your head. (participant 10)

Others were anxious about the lack of privacy in the waiting room and feeling that people were watching them as they struggled to speak to the receptionist. Some worried that they might not find the correct room because they could not read the number or name on the doctor's door. Several described feelings of panic before they even saw the doctor.

During consultation:

They were aware that difficulties with communication damaged their relationship with their GP:

I just don't understand him and he doesn't understand me and it gets you off to a bad start (participant 12).

The groups talked about their concern that doctors do not always understand the nature of communication difficulties such as aphasia and the subtle problems faced by patients such as understanding complex language structures and reading difficulties.

When discussing the actual consultation with the doctor there was obvious agitation amongst the participants. They described difficulty remembering what to say, not being understood, feeling the doctor did not believe them, being rushed and not following what the doctor said because he spoke too fast and used words they did not understand. Although some acknowledged that they needed help from their carer, most of them wanted independence and privacy and objected to the doctor speaking to the carer and not to them, particularly when they felt the carer had a different agenda from them. One man, who used a Lightwriter™ communication aid competently, told the group:

The doctor never asks me a question because it takes too long and instead always speaks to my brother (participant 16).

For those whose carer went with them they preferred the carer to be 'a second pair of ears' rather than take over the consultation.

Apprehension of different doctors and lack of trust emerged as issues for concern and one woman spoke specifically about her fear of doctors since the media coverage of the Harold Shipman case.

After consultation:

The purpose of any visit to a doctor is that the patient's problem should be understood and that there should be a positive outcome. This did not always seem to be the case. Participants worried that they could not understand what advice they had been given and were unable to explain what the doctor had said once they went back home:

They tell you so much that by the time you get home, you really cannot remember it, as you should. (participant 13)

Not all comments were negative and several participants described positive experiences, most noticeably when they saw a familiar receptionist or doctor who they felt understood their CD and gave them enough time.

A number of positive suggestions were made about how things could be better. They all preferred the doctor to come out of his/her room to 'collect' them and some suggested that pictures as well as written signs around the surgery would help those with reading problems. One woman took the responsibility to explain to her doctor what aphasia meant. Prepared lists of problems both to aid their memory and to help explain their illness helped. Some booked a double appointment so that they would not feel rushed. They all felt it would help if

the doctor spoke slowly and clearly and gave them something in pictorial and/or written form to explain and to take home to their carers.

In summary the PCD had strong views about the difficulties they experienced in consulting with their GPs but had a number of positive suggestions. They all thought there should be better training about CD for GPstaff.

5. Discussion

The aims of this study were first to obtain the views of GP staff and people with communication difficulty on consulting with each other and second to identify priorities of with reference to understanding the needs of clients and to identify research questions for further study.

It was extremely difficult to get GP practices to agree to be involved and initial letters to 30 practices produced no replies. The final 4 groups were enlisted following numerous phone calls and personal contact. Comments from GPstaff were not always forthcoming and several prompts from the researcher were met with silence. However, as the interviews progressed GPstaff appeared to become more cognisant of the issues concerned and became involved in the discussions lasted approximately an hour. The focus groups created tension and debate⁷ with new knowledge being gained and participants developing an increasing awareness of the problems of CD. Staff recognised the significance of poor communication in terms of access to health services and conceded that the extent of the problem was perhaps greater than they had previously believed:

They agreed that the experience of visiting a GP includes much more than just the actual time spent in the consulting room. The initial preparation made by the patient can have a significant impact on the consultation; the manner in which the patient is dealt with by the receptionist is crucial; the waiting room itself can affect the patient's experience and the implementation of advice once back home is compromised by poor communication. They also acknowledged that it was not enough to simply rely on carers and that patients' health might be compromised if their views were not taken into account. Some suggested that improving communication skills could benefit all patients.

The participants with CD responded enthusiastically to the focus group discussions and found the group setting helped them compare and develop their views, especially as they felt strongly about the particular difficulties they had encountered. Talking Mats™ helped explain the issues to be considered and allowed them to share their views more easily.(Appendix 5) They had numerous comments about the difficulties they had encountered and felt strongly that poor communication with their doctors could have had adverse effects on their health.

Speech and language therapy:

GPstaff made very little comment about SLTs, despite their role as the main professionals with skills in CD, and pointed out that the speech and language therapy profession is seriously understaffed.

However SLTs may have several roles to play in helping to improve the communication between PCD and GPstaff. Firstly, they may be able to help their patients prepare for going to see their GP by providing them with strategies and visual materials^{9, 10}. Secondly, they are the professionals best placed to assist doctors in determining the capacity of people with a CD to making decisions about medical treatment¹¹. Thirdly, they could provide training and information directly to GP staff in order to equip them with strategies to deal with individual patients.

Training:

The lack of staff experience of how to deal with people with communication difficulty was obvious from the comments. Many did not understand the nature and implications of CD and appeared to use a reactive rather than a proactive approach with few strategies in place apart from relying on carers.

It was suggested that patients should take more responsibility for their communication and indeed some of the participants in this study had taken it upon themselves to 'train' their GPs about aphasia and had actively informed their doctors of their specific communication problems. All GPstaff acknowledged that they would benefit from training in CD but there was always the proviso that they did not have enough time for any in-depth training.

Specific training on communication is now being introduced in some medical schools but this still tends to focus on patients for whom English is a second language rather than people with a specific CD such as aphasia. As well as tackling this problem in medical schools, workshops could be provided by SLTs in GP practices to raise awareness and provide simple practical resources.

Determining Capacity:

The Adults with Incapacity (Scotland) Act ⁸ emphasises the importance of determining a person's capability to understand and communicate decisions. There was considerable discussion about the acceptability of relying on carers. Although this may be the only solution for people who clearly do not have the capacity to make decisions themselves, it is not acceptable for the majority of PCD who can and want to make their own decisions. Although the Act states that it is the doctor who should determine capacity, the GPs in this study felt that for those people who were borderline and/or who had difficulty communicating, determining their capacity to make decisions about medical treatment was not easy or even their job. From this study it appears that doctors have neither the time nor the skills to judge capacity where the patient has a CD.

6. Conclusions

Where patients find GP consultations stressful or unsatisfactory they lower their expectations, attend less and feel generally disaffected. This results in ineffective health care.

This small study has compared the perspectives of GPstaff and PCD on the same issues relating to GP consultation and has identified a number of difficulties that occur. The main priorities for GPstaff were the need for relevant and timely training and simple resources. For PCD the problems appeared to be the same irrespective of the type of CD. Their main priorities for better communication were continuity of staff, trust, better GPstaff communication skills and a reduction in reliance on carers.

7. Importance to NHS and possible implementation

- PCD are entitled to the same health services as anyone and should not be discriminated against because of their disability. This study has identified some of the problems facing GPstaff and has suggested some solutions.
- Doctors' judgements about patients' communication has major implications for the Adults with Incapacity Act.
- Speech and language therapists could be key professionals in providing support and training to PCD and GPstaff. The researcher is involved with other organisations to develop and pilot materials and training that could be used in GP practices.
- A priority should be training medical students about CD. The researcher is involved with staff at the Glasgow School of Medicine in producing training materials for medical students based on the findings from this project.

- One GP practice suggested that the findings from this study should be used to inform the planning of a new practice in Stirling. They commented that while it is now recognised that people with physical disability must be considered in new planning there is a danger that PCD are ignored.

8. Future research

This study has identified the need for:

- A larger study to provide additional information about the training and resources required.
- Piloting of resources to identify the most effective way to influence patients and GP staff.
- Research into how capacity of people with communication difficulty to make decisions should be determined and by whom.
- Research into the ways in which Speech and Language Therapists could provide training and resources
- Research into how NHS buildings should be designed to facilitate good communication.

9. Dissemination

- As a result of the findings the researcher has developed training materials (Appendices 6 and 7) and has offered feedback and training to all the participants. At the time of writing this has been taken up by *Speakability* and *Quality Action* groups and by 2 GP practices who have offered to pilot them. The researcher has contacted the CREATE coordinator in Forth Valley with a view to providing training to other GP practices.
- A paper has been presented at the ISAAC conference in Brazil in October 2004. Following this, researchers in Australia have asked to pilot the training materials developed from this project with GP practices in Sydney. Joan Murphy has also received several email requests for further information about this study.
- Workshops are planned for speech and language therapy staff.
- Presentations will be made at other relevant conferences.
- A paper based on the findings is in preparation.

10. Research workers

The study was carried out by Joan Murphy who obtained the relevant ethical permissions, collected the data, analysed it and wrote the report. An administrative assistant transcribed the interviews.

3600 words

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11. Financial statement

To be provided by Finance Department, University of Stirling University

12. Executive summary

The study has examined and compared the perceptions of GP staff and people with communication disability concerning GP consultation. It has identified some of the problems that occur and has made suggestions for improving communication. Data were obtained from 4 focus groups of GP staff and 4 focus groups of people with communication disabilities. The main priorities for people with communication difficulty were continuity of staff, better GP staff communication skills and less reliance on carers. The main priorities for GP staff were the need for relevant training and simple resources. Suggestions for implementation of findings and further research have been made. Although it was difficult to recruit GP practices all the original aims were achieved and the study was completed on time.
