

CONSUMERS AND CARERS' EXPERIENCES OF THE ACUTE PHASE OF STROKE CARE

A report for the Clinical Systems Project, Monash
University Consortium

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Health Issues Centre is a non-government, health policy/research centre which recommends improvements to the health system from the perspective of consumers. Its overall aim is to help create a more equitable health care system that is more responsive to users, particularly those disadvantaged by current arrangements.

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INTRODUCTION

This report describes consumers and carers' experiences of acute stroke care as part of the Clinical Support Systems Project (CSSP), Monash University Consortium. The Monash University Consortium is one of four consortia (projects) participating in the overall Clinical Support Systems Project, an initiative of the Royal Australasian College of Physicians. Projects are sponsored by the Commonwealth Department of Health and Ageing, the Victorian Department of Human Services and the New South Wales Department of Health. The Clinical Support Systems Project seeks to integrate the methodologies of clinical practice improvement and evidence based medicine to facilitate best practice in clinical care (Royal Australasian College of Physicians, 2001:4).

The purpose of the Monash CSSP project is to investigate how to facilitate the uptake of clinical practice improvement and evidence-based research by clinicians in the management of acute stroke care. Consumer participation is an important aspect of the Monash CSSP project¹. This was recognised at the very beginning of the project when the Monash University Consortium submitted its tender proposal to the then Commonwealth Department of Health and Aged Care stating:

We propose to involve consumers in the design, evaluation and review of the project with the aim of developing a more consumer-focused model for health services (Monash University Consortium, 2000).

As a member of the Monash CSSP consortium, Health Issues Centre has sought to bring the perspective of consumers to the Monash CSSP project. To achieve this, Health Issues Centre has been involved in a number of activities throughout the project including:

- Member of Project Board;
- Member of project Working Groups;
- Established and facilitated a Consumer Reference Group;
- Participation in project review days;
- Literature Review on Consumer Issues in Stroke Care; and
- Focus group and individual interviews on consumers and carers' experiences of the acute phase of stroke care (this report).

LAYOUT OF THIS REPORT

This report is broken into four parts. **Part 1** is an executive summary that describes the key issues to emerge from this report and lists a number of recommendations for the Monash CSSP project. **Part 2** is a review of the literature examining consumer issues in stroke care². **Part 3** reports on the research methods used in this study. **Part 4** presents the results from focus group and individual interviews conducted by Health

¹ The Commonwealth Department of Health and Aged Care's Consumer Focus Collaboration (1998:iv) defines consumers as "those who use or are potential users of health services, including the family and carers of patients and clients. This includes those who may be directly or indirectly affected by health services".

² A full version of the literature review – *Literature Review on Consumer Participation in Health and the Key Consumer Issues in Stroke Care* – is available from Health Issues Centre.

Issues Centre with patients and carers and treated for stroke at Monash Medical Centre and West Gippsland Hospital.

ACKNOWLEDGEMENTS

Health Issues Centre extends its thanks to those patients and carers who participated in this research. They spoke openly and honestly about their experiences of stroke and in particular their experiences of hospital care. For this we are most grateful.

Health Issues Centre would also like to thank staff from Monash Medical Centre and West Gippsland Hospital who assisted us to recruit patients and carers for this study. Finally, Health Issues Centre would like to extend its thanks to Alex Butler who shared the role of facilitating the focus groups and conducting individual interviews for this report.

PART 1: EXECUTIVE SUMMARY

Focus group and individual interviews conducted by Health Issues Centre provide an important insight into consumers' experiences of stroke care at Monash Medical Centre and West Gippsland Hospital. Participants interviewed by Health Issues Centre included patients and carers. Patients were selected from a non-random sample of patients treated at Monash Medical Centre and West Gippsland Hospital for stroke who were discharged home from hospital. Patients discharged to residential care were not interviewed for this report.

Although there is a large body of medical research examining stroke, little research has been undertaken to understand patients and carers' experiences of the acute phase of stroke care. By undertaking a review of the literature and by conducting focus group and individual interviews this project seeks to contribute to the Monash CSSP's understanding of consumers' experiences of stroke care. As is made clear in Part 3 (see below), this report does not claim to be a definitive study of all consumers' experiences of stroke care. While the report will be particularly useful for Monash Medical Centre and West Gippsland Hospital, there may be some key learnings from the report that are useful to a wider audience interested in stroke care.

During our focus group and individual interviews we found that participants did not speak so much about their day-to-day experience of hospital care but were more inclined to discuss major events such as the onset of stroke, admission to hospital, good or bad things that occurred while in hospital and their discharge home.

When discussing the onset of stroke this project found that many participants felt a sense of shock when reflecting that they had suffered a stroke. This was particularly the case for participants who regarded themselves as fit and healthy. For these people stroke came as a complete surprise. For the majority of participants the onset of stroke occurred when they were going about their normal daily activities. People said they were doing nothing out of the ordinary, an issue that added to their sense of shock and surprise. This finding is consistent with previous research, as discussed in Part 2 of this report.

Many participants interviewed for this study described long and frustrating periods spent waiting in the emergency department for medical care, or once they received treatment in the emergency department to be admitted to the stroke ward. Despite the difficulties encountered in the emergency department most participants said they were largely satisfied with their overall hospital care. Participants spoke positively of the care they received on the stroke ward and praised the care provided by doctors, nurses and other allied health staff. Generally, participants felt the best care would be provided in a ward dedicated to stroke, particularly if that ward is staffed by a team with expertise in stroke care.

Although participants were satisfied with their overall care a number were critical that men and women were required to share the same hospital ward. Participants were almost unanimous in their view that men and women should be in separate wards as a measure to protect their privacy in hospital. It was perhaps this issue, more than any

other, that provoked the strongest response from participants interviewed for this study.

A review of the literature (see Part 2 below) indicates that many stroke survivors and their carers are unsure what stroke is and what its implications will be. A lack of information and poor communication about stroke is a major issue raised by consumers when they indicate they are dissatisfied with their care. The provision of verbal and written information about stroke – including information about its cause, prognosis and treatment options – was rated by participants in this study as being very important. Interview participants indicated that information about stroke was provided by the hospital on an ad-hoc basis. Some participants received a wide range of information about stroke whilst others received no information. From our interviews it appeared that neither Monash Medical Centre nor West Gippsland Hospital had a formal process to provide written information to stroke patients during their time in hospital³.

When consumers are informed about stroke and receive a clear explanation of tests and medical procedures they are able to participate in making decisions about their care. Previous research (as discussed in the literature review below) has shown that participating in the decision-making process can have a positive impact on a stroke survivor's rehabilitation, overall satisfaction with care and long-term recovery.

Participants interviewed for this research spoke of the large number of tests and other medical procedures they underwent during the acute phase of care. A number of participants said they expect hospital staff to provide a clear explanation of why and how tests are to be carried out. The experience of a number of participants interviewed for this study indicates this does not always occur and for some this was an upsetting experience. (For example, refer to the discussion of MRI in Part 4 of this report).

Carers play a vital role supporting stroke survivors during and after the acute phase of stroke. The role of the carer can be stressful and time consuming, particularly for people caring for stroke survivors with functional disabilities. It is for this reason that support services for carers is an important aspect of stroke care.

The provision of written information targeted specifically to carers was raised by participants in this study as one measure to support this group. A number of participants argued that the provision of information about stroke would assist carers to care for the stroke patient once discharged from hospital. Among other things, information would assist carers to understand the physical and emotional impact of stroke and to manage any unexpected medical events, such as the onset of a second stroke.

Patients and carers do not see stroke as something that ends once the patient is discharged from hospital. Rather, they live with stroke on a long-term basis. It is for this reason that coordinating hospital discharge to ensure appropriate rehabilitation

³ Since these interviews were completed Monash Medical Centre has commenced a process of providing written information to all stroke patients.

and community support services are available is an important responsibility of hospital care.

Overall, participants interviewed for this study spoke positively about the care they received in hospital. Although the Monash CSSP project is focused on the acute phase of stroke, participants said they regard stroke as a medical event with long-term physio-social implications. The provision of information to patients and carers; a clear explanation of tests and other medical procedures; encouraging patients to participate in making decisions about their care; and ensuring that community support services are arranged post-discharge are important factors that contributed to participants' perceptions of the care they received while in hospital.

RECOMMENDATIONS

The following recommendations are made to Monash Medical Centre and West Gippsland Hospital by Health Issues Centre in consultation with the Monash CSSP Consumer Reference Group. Recommendations are based on a review of the literature and results from focus group and individual interviews conducted for this report. As the results from focus groups and individual interviews are consistent with the literature, a number of recommendations may be applicable to Frankston Hospital and Cabrini Hospital who are also participating in the Monash CSSP project.

1. Arrival and admission to hospital

- Upon arrival, emergency department staff should inform patients how long they (patients) can expect to wait before they will receive medical treatment in the emergency department.
- That the Monash CSSP project convey the problems experienced by stroke patients in the emergency department to senior staff who manage the emergency department.⁴

2. The stroke ward

- That Monash Medical Centre and West Gippsland Hospital endeavour to provide separate wards for male and female patients receiving treatment for stroke.

3. Communication by hospital staff about tests and medical procedures

- That hospital staff responsible for conducting tests and other medical procedures explain to patients (and where appropriate their carers) the reason for tests and medical procedures and an explanation of how they are to be carried out.
- That hospital staff provide an opportunity for patients and carers to ask questions or seek clarification about any issues concerning tests and medical procedures.
- That interpreting services be offered to patients from a non-English speaking background to explain tests and medical procedures and answer questions posed by patients and carers about their care.

4. Information about stroke

- That hospital staff provide written and verbal information to patients and carers about stroke. Information should include the latest medical evidence about stroke;

⁴ The problems encountered by patients in the emergency department, as described in this report, were a particular issue at Monash Medical Centre.

how stroke care is provided in the hospital; discharge procedures; rehabilitation; and community support post-discharge.

- That each hospital's Stroke Unit Protocol make specific reference to providing information to patients and carers, including when information will be provided.

5. Discharge and community support

- That staff responsible for discharge provide information to patients about: secondary prevention; community support services; driving after a stroke; who to contact for further information; carer support; and stroke support groups in their local area.

PART 2 – LITERATURE REVIEW

CONSUMER ISSUES IN STROKE CARE

Despite a large body of evidence supporting the view that people who have experienced a stroke should be cared for in an organised inpatient stroke unit (Stroke Unit Trialists' Collaboration, 2001), there has been comparatively little research that seeks to understand the experiences of consumers in hospital when treated for stroke.

Research by Anderson (1992) and Pound et al (1998:494) found that for the majority of people stroke occurred when they are going about their daily routine, such as working, shopping, visiting friends or completing household tasks. Whilst the onset of stroke was experienced as threatening and frightening it was a condition that most people had some knowledge about.

In interviews with 173 stroke survivors and their carers, Anderson (1992:59) found that little is known about stroke survivors' daily experiences of hospital care, their attitudes to care in the hospital, and their short and long-term concerns and aspirations after suffering a stroke. To some extent Anderson argued this may reflect the hesitation of health professionals about how much they want to know about stroke survivors' experiences of stroke and their uncertainty of what they can do to improve the life of stroke survivors.

A major study recently completed by the National Stroke Foundation (2001:192) found that 91.5 per cent of stroke survivors and their carers were satisfied with their hospital care. Although only 22.9 per cent of those surveyed were satisfied with every aspect of their care, this figure rose to 46.5 per cent when a question referring to information about managing at home was excluded, indicating that people are not always satisfied with the information they receive about managing at home.

The same study found that although patients and carers were largely positive about the care they received in hospital, some concerns were raised regarding the hospital's role in coordinating post-discharge care including information about rehabilitation services, carer training and other community-based support services (National Stroke Foundation, 2001:203-204).

The National Stroke Foundation's study also highlighted the stress faced by carers of stroke survivors, particularly those caring for stroke survivors with functional disabilities. Carers concerns focused on their need for practical support to assist with activities of daily living; the need for emotional support; how follow-up services were organised; and communication with hospital staff, particularly regarding information about the patient's medical status. Generally, carers spoke positively of the level of care provided by the hospital, however, improvements in discharge planning and discharge services were suggested by carers as ways of improving hospital care (National Stroke Foundation, 2001:204-212).

In a series of interviews with stroke survivors about their experiences of hospital care, Pound et al. (1995) found that in most cases stroke survivors expressed positive views about their experiences of care. The majority of participants indicated they felt

personally valued and respected by hospital staff. Stroke survivors attributed their recovery to the clinical skills of health professionals and being looked after and treated with respect while in hospital. Participants also spoke of their appreciation of handing over responsibility to experts in clinical care in a time of crisis. Whilst the research by Pound et al. (1995) was largely positive, some participants spoke of their desire to receive more information about their condition during their time in hospital.

The need for quality information about stroke is supported by van Gijn and Dennis (1998:26) who argue one of the major causes of dissatisfaction among stroke survivors and their carers relates to poor communication, including a lack of information about the cause, management and prognosis of stroke. When information is given, it is often presented in a way that is difficult to understand. As Hill (1996:8) has previously found, many stroke survivors and their carers are unsure of what stroke means or what its implications are. In the Australian context, stroke is often confused with heart attack.

When asked about the type of information they require, research indicates that survivors of stroke have very clear ideas. As Anderson (1992:223) found:

Patients and carers are anxious for knowledge in quite explicit areas: causation of the stroke and risk of recurrence; prognosis and rate of recovery; mental health and social isolation; services available and what they can do to help themselves.

Research by Health Issues Centre and the Centre for Clinical Effectiveness for the Department of Human Services (2001a:34-38) found that consumers and carers want information about the warning signs, symptoms and risk factors of stroke to help them make informed decisions about their care. Consumers also felt there was little opportunity to be involved in the decision-making process in hospital, even when treatment choices were limited. Consumers, who in many cases were admitted through emergency, said they felt compelled to follow their doctor's suggestions without the opportunity for consultation.

The summary findings from the report for the Department of Human Services found:

- public education about stroke as an emergency is important;
- access to information while in hospital is important to consumers;
- consumers would like the opportunity to be involved in decision-making about their care;
- consumers want detailed information about treatment options made available to them;
- consumers want the latest treatment options to be covered in information provided in pamphlets;
- the emotional trauma and life-altering impact of stroke on consumers and carers needs to be addressed; and
- information brochures or pamphlets should include advice to help consumers recognise the early warning signs of stroke (Department of Human Services, 2001a:34).

In a protocol for a Cochrane Review, Forster et al (2001) cite a recommendation by the King's Fund in 1998 for the provision of accurate information and advice about

stroke to consumers and carers as a key component of stroke care. The review argues that consumers have a poor understanding of stroke, its consequences, and the type of support available. The review points out that inadequate information may have important consequences for secondary prevention and consumer's long-term psychosocial outcomes.

One solution to improve the quality of information given to stroke survivors and their carers is for a member of the stroke team to sit down with the stroke survivor and carer to discuss what has occurred and answer any questions (van Gijn and Dennis, 1998:26). This is supported by Cochrane Protocol (Mant et al., 2001) which proposes that information, emotional and social support and practical advice may be best provided by a 'stroke liaison person' who would liaise with consumers, carers and the other community/rehabilitation services.

The United Kingdom's *National Clinical Guidelines for Stroke* describe stroke as a family illness. Like any other illness family members and carers require information and support throughout the crisis. The guidelines list the following recommendations:

- from the outset the family should be given information, involved in decision-making and planning and provided with support;
- stroke services should be alerted to the stress on carers;
- families should receive information on the nature of stroke and its manifestations. They should also be given information about local and national support and information services; and
- family support workers should be available to help family members manage stress (Royal College of Physicians, 2000:27).

Research has shown that encouraging stroke survivors to participate in their rehabilitation can have a positive impact on their rehabilitation outcomes. An important role for health providers in this process is to support stroke survivors to identify and set short and long-term rehabilitation goals (Holmqvist and von Koch, 2001). This is supported by Maclean et al. (2000) who described the positive impact of information (provided by stroke unit staff to stroke survivors) on the motivation of stroke survivors to actively participate in their rehabilitation. Consumers interviewed for the study by Maclean et al. (2000) described how information provided by stroke unit staff influenced their attitudes towards rehabilitation. Understanding the goals of rehabilitation and receiving support from staff (particularly stroke unit nurses) was an important aspect of rehabilitation. The study found that consumers with low motivation were often those who did not understand their rehabilitation plan and reported anxiety that stemmed from a lack of information.

PART 3 – RESEARCH METHODS

QUALITATIVE RESEARCH

Qualitative research methods were used by Health Issues Centre to gather information from participants about their experiences of stroke care. In a study such as the Monash CSSP project, qualitative research methods (in this case focus groups and individual interviews) are particularly useful in understanding participant's attitudes, beliefs and preferences to health care. The advantage of qualitative research methods is their ability to ask research questions that are not able to be asked using quantitative research methods (Green and Britten, 1998:1230). As Pope and Mays (1995) have emphasised, qualitative research "helps us understand social phenomena in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences, and views of all the participants".

Health Issues Centre conducted focus group and individual interviews with consumers (patients and carers) who had been treated for stroke in 2001 at Monash Medical Centre and West Gippsland Hospital. Monash Medical Centre and West Gippsland Hospital are two of four hospitals participating in the Monash CSSP project. The other two hospitals are Cabrini Hospital and Frankston Hospital. Interviews were conducted by Greg Ford and Alex Butler from Health Issues Centre.

Powel and Single (1996:499) define a focus group as:

... a group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research.

A focus group involves a discussion on a particular topic among a group of people, guided by a facilitator. Data is collected through open-ended non-directive interview questions. Focus groups usually include five to ten participants who are selected because they have certain characteristics in common with the topic of discussion. Focus groups produce qualitative data that provides insights into the attitudes, perceptions and opinions of respondents (Krueger, 1994:6-19).

Focus groups allow researchers to draw on respondent's feelings, attitudes, beliefs and interpretations of their experiences in a way that cannot be achieved using other research methods such as observation or questionnaires. Those attitudes, feelings and beliefs are more likely to be revealed in a greater level of detail in a group setting where there is ongoing interaction between participants. The interaction and discussion between participants is seen by social researchers as a major advantage of focus groups. Focus groups are a research method that allows participants to discuss issues in depth. They are not for decision-making or problem solving. Managing and guiding this discussion is one of the central tasks of the facilitator (Gibbs, 1997; Consumer Focus Collaboration, 2000).

Participants who wished to be interviewed, but not in a group setting, were given the option of an individual interview. In-depth individual interviews are usually semi-structured face-to-face interviews. They involve a two-way exchange of information that allows the researcher to explore issues in-depth, providing opportunities for the

interviewee to explain the topic of discussion from their own perspective. The in-depth individual interview seeks to elicit respondent's interpretation of the subject being discussed (Consumer Focus Collaboration, 2000:36; Powell and Single, 1996:502).

ETHICS

Ethics approval was sought and received from the four hospitals participating in the Monash CSSP project. Due to delays in receiving ethics approval from Frankston and Cabrini Hospitals, Health Issues Centre was unable to interview consumers from these two hospitals for this report.

As a result, this paper reports on results from focus group and individual interviews with patients and carers from Monash Medical Centre and West Gippsland Hospital.

PARTICIPANT RECRUITMENT

Interview participants were recruited by Health Issues Centre from patient lists provided by Monash Medical Centre and West Gippsland Hospital. Patients on these lists were those well enough to be discharged home from hospital. Health Issues Centre did not interview patients who were discharged to residential care.

Recruiting participants was a two-staged process. Firstly, by using hospital patient lists Health Issues Centre wrote an introductory letter to patients explaining the Monash CSSP project, Health Issues Centre's role in the project and the purpose of the focus groups and individual interviews. Secondly, Health Issues Centre followed this letter with a phone call to ask people if they would be interested in participating in a focus group or individual interview.

Health Issues Centre conducted four focus groups and four individual interviews. Interviews were held in August and September 2001. In total, 23 participants were interviewed (19 patients and four carers). Of the 19 patients, 11 were male and eight were female. Five people were from a non-English speaking background. The age range of participants (excluding carers) was from 45 to 85 years of age. Those who agreed to participate in a focus groups or individual interview were paid \$30. Taxi vouchers were provided to people who required transport assistance to attend focus groups. Individual interviews lasted up to one hour while focus groups lasted up to an hour and a half.

QUESTIONS

The focus of the Monash CSSP project is the best management of the acute phase of stroke care. With this in mind, Health Issues Centre was interested in understanding participants' experiences of this phase of care. Interviews explored the following themes:

- Participants' experiences of the onset of stroke;
- Arrival and admission to hospital, including a discussion of the stroke ward;
- Participants' experiences of the explanation of tests and other medical procedures provided by hospital staff;
- Whether information about stroke provided by the hospital was adequate; and
- Discharge and support services.

ANALYSING DATA

Health Issues Centre received permission from interview participants to tape interviews. Following the interviews, tapes were then transcribed and it was from these transcripts that Health Issues Centre was able to analyse the data.

According to Yin (1984, cited in Krueger, 1994:140) the task of analysing research data consists of:

...examining, categorizing, tabulating, or otherwise recombining the evidence, to address the initial propositions of the study (Yin, 1984 cited in Krueger, 1994:140).

The first step in analysing the data was to conduct a content analysis by reading through the transcripts and coding the data by looking for common trends and concepts (including phrases, sentences or exchanges between participants) that arose during the discussions relevant to the particular questions asked by the interviewer. (Lewis, 1995:4; Stewart and Shamdasani, 1990:104-105; Powell and Single, 1996:502).

The second step was to analyse the data using open coding, a method based on grounded theory (Strauss, 1987:28-32, 59-64). Issues were raised by interview participants that did not fit pre-defined categories were analysed using open coding. Barbour (2001:1116) argues that by using this method "... coding categories reflect the content of the data collected rather than the questions on the interview schedule or focus group topic guide ..."

Before the final version of this report was completed, Health Issues Centre sent an earlier draft to those who participated in the study for their review and comment. This was to ensure that the final report was a true and accurate reflection of what participants had said in our focus groups and individual interviews.

LIMITATIONS TO THE RESEARCH

When reading this report it is important to keep in mind that it is an account of the experiences of those people who participated in focus groups and individual interviews conducted by Health Issues Centre. The study was limited to group and individual interviews with patients and carers from Monash Medical Centre and West Gippsland hospitals. Patients and carers from Cabrini Hospital and Frankston Hospital were not included in this research.

This research does not purport to be a definitive study of all consumers' experiences of stroke care. Participants recruited for this research were from a sample of patients who were well enough to be discharged home from hospital. The research did not include patients discharged to residential care. It is unclear whether this group discharged to residential care (who may have suffered a more severe stroke and who may have spent a longer period in hospital) may have a different perspective of their hospital care. This could be a focus of future research.

Despite its limitations this research raises a number of issues that are consistent with previous research examining consumers' experiences of acute stroke care (see literature review above) allowing Health Issues Centre to draw conclusions and make recommendations for the Monash CSSP project.

PART 4 – RESULTS

THE ONSET OF STROKE

Almost all consumers who participated in focus groups or who were interviewed individually expressed surprise and shock when recounting their experience of suffering a stroke and subsequent admission to hospital. The majority of participants indicated they were doing nothing ‘out of the ordinary’ when the onset of stroke occurred. With the value of hindsight some participants were able to recognise what may have been warning signs indicating that something was wrong. In most cases though, the onset of stroke was a complete surprise to participants interviewed for this study.

As two participants recalled:

It amazed me. I regarded myself as pretty fit ... I couldn't believe it.

I thought I had a stroke because a friend of mine had something similar ... (It) gave me an awful shock.

As well as being surprised, a number of participants were fearful of what was happening to them. According to one participant:

Well I went to bed alright. I got stabbing pains. I thought I was going to die.

The first reaction to the onset of stroke varied significantly among participants. Some acted quickly and contacted their general practitioner, family members or friends, while others thought the onset of stroke may simply be a bad headache or tiredness that would improve with rest.

As one participant said:

I didn't know I was having a stroke. I was amazed ... previously I was very, very tired. I just put it down to age and I just worked harder, all that type of thing. Then one night I was doing the garden, only for an hour or so and I felt very queer. Very, very odd. So I went inside and my wife was asking me a question and I couldn't answer her. I knew what she was saying, I knew perfectly. I wasn't even worried but I just couldn't answer. She thought I was fooling around. Then after a while she rang her daughter, the daughter came over and she said, 'Dad's having a stroke'. I was saying 'that's mad, what are they talking about'?

The experience of not knowing what was wrong was also recalled by another participant who said:

... the whole night I was quite restless, I was waking up, should I get out of bed or not. I got up the next day, I still wasn't feeling right. I went to see a local doctor who gave me some medication. I went home but continued to become worse and worse. It was after that I decided to go to the hospital.

One participant who regarded himself as being relatively fit and healthy expressed surprise that he had suffered a stroke:

So I got my stroke, I never thought it existed. On the layman's point of view I thought the person who has a stroke has a very bad heart, very sick and all the rest of it and I didn't have anything like that.

Despite realising something was wrong, seeking immediate assistance was not always people's first reaction. The influence of family members to encourage participants to seek medical treatment was vital in some instances:

I knew a stroke came because I kept dropping my bag. I picked it up and three times it dropped. Then my family went mad, 'you're going to hospital'. I said 'no I'm not going. I know I've had a stroke I don't want to go'. They made me go.

Another participant knew very quickly that something was wrong:

I knew I had a stroke. I was just out of the shower. I put the towel over my shoulder to dry my shoulder off. I pulled it that way. The towel, I couldn't pull it back that way because my arm wouldn't move. It was like that for a couple of minutes. I was paralysed all one side.

Observing how stroke can impact on others was a frightening experience for some participants. Recounting the experience of observing another patient in hospital, one person said:

The next morning when the neurologist came to do the rounds, he came to his bed first and they greeted him and he said 'lift your right arm'. He says 'yeah'. He said 'lift your arm'. He says 'yeah'. He said 'what's your name'? (He said) 'I don't know'. That terrified me. That was the most terrifying experience.

ARRIVAL AND ADMISSION TO HOSPITAL

Although the Monash CSSP is not a study of hospital emergency departments, the issue of long waiting periods in emergency was consistently raised in our discussions with interview participants as being a problematic aspect of their care. This was particularly an issue for patients attending the emergency department at Monash Medical Centre. At a time of anxiety and uncertainty, participants' concern about what was going to happen to them was highlighted by the long periods waiting in a (sometimes) crowded emergency department. On some occasions people waited for long periods on a hospital trolley before being admitted to the stroke ward⁵.

Participants' experiences of the emergency department was described along the following lines:

I think we've all got hideous stories of (the) emergency ward. The first (stroke) my neurologist organised (hospital admission) but it still had to wait from like 9.00 o'clock that night ... I didn't go to the ward 'till about 2.00am, but they put me on Heparin straight away. But the next time (second stroke) I was paralysed on my left side. I went in the ambulance and I was there at like again, 9.00 or 10.00 o'clock that night and I didn't go upstairs to a room 'till after lunch the next day. That was horrible. Because you don't know what's going to happen to yourself. You are all paralysed and you can't do anything. It was so noisy, of course you

⁵ The description by interview participants of long waiting periods in the emergency department is not isolated to this project. Research published by the Department of Human Services (2000b) indicates that demand for emergency treatment in Melbourne's major metropolitan public hospitals has increased by 22.6 per cent during the period from 1996-2000. This corresponds with a national and international trend of increased demand by patients for public hospital emergency care.

can imagine. All the different pieces of equipment going on, people with dementia walking past (asking) 'where am I'? It was hideous.

The emergency ward was overcrowded as usual ... (I) spent nearly a whole night on a little narrow stretcher because there was no beds.

Long waiting periods in the emergency department was a universal theme to emerge in our discussions as pointed out by a number of participants:

I arrived (at the hospital) around about 10.00am. Emergency was very crowded, a lot of sick people. I was one of the lucky ones. But it was around 4.30 in the afternoon before anything occurred, in my particular case I was taken for various examinations which went from about 9.00pm.

I waited for ages there. They said 'you'll have to wait your turn because there's a lot of people'. I waited and I went in and they fixed me up and I waited for a long time before I went upstairs because they were busy. They never came to me because they had emergencies, people in accidents came in.

Of course, not everyone had a bad experience of the emergency department. Some people waited for only a short time before they received treatment as indicated by comments from two participants:

(My daughter) took me down to emergency. Fortunately, there wasn't a lot of people waiting, just four or five people there. But the triage nurse just got my records and said OK and about five minutes later, ten minutes later, and people were starting to come because it was the end of the morning, and the sports injuries were starting to come in. They said, 'right you, you, you and you', and there was about four of us shepherded through to the emergency at once. So I was through emergency within about 15 minutes or arriving. They were brilliant.

I don't have any complaints. I guess maybe it was just fortunate on the day ... Everybody was very helpful and concerned. I'd had a hell of a fright so I didn't know what was going on.

The stroke ward⁶

Participants made a clear distinction in their assessment of care in the emergency department and their care once admitted to the stroke ward. Despite the difficulties of waiting in the emergency department, participants were positive in their appraisal of the stroke ward. Participants spoke highly of the care provided by doctors, nurses and other allied health staff.

Various views of the stroke ward included:

... the next day I was put on a stroke ward which totally blew me away because I thought, 'I don't think I've had a stroke'. Well we still don't know (but) you'll get the best care there ... They were brilliant ... They were really kind, the staff were brilliant.

... once I got up to the ward, you had their undivided attention. Especially when you first came.

Participants praised the role of staff when discussing their care on the stroke ward. Members of one focus group argued that patients are aware of, and take into account

⁶ This also refers to West Gippsland Hospital where stroke patients are admitted to the hospital's general ward.

the demanding and stressful work environment faced by hospital staff when they assess their overall experience of hospital care:

Because it is pretty scary isn't it when you are having these things happen to you and you don't know what to expect. Or if you are going to get worse while you are there. So I was very appreciative of the staff and their care. The neurologists were brilliant, they were all very nice and treated me with every respect and courtesy. So I really haven't got anything to say but the highest praise for them.

The care provided by nursing staff was a highly valued aspect of care.

The nursing staff were very good when they come and check you thoroughly. Pretty regularly which is good.

... I'd like to thank the nurses. I thought they were wonderful. When you got up there I thought the nurses were very sympathetic. Yeah, they'd always come by and have a chat or when I was having blood tests every six hours. If it was three in the morning, that's OK it's every six hours. Would you like a cup of tea while you're awake ... They were really good. They were wonderful.

The role of the social worker was also recognised by a number of participants. As one person said:

Well the social worker ... he was most helpful. He came to my ward, introduced himself and he spoke at length. (He asked) if I needed any help to cut the lawns and stuff like this, and who's looking after me. So he was very thorough.

Despite the generally positive attitude towards members of staff, the barrier (real or perceived) between medical specialists and their patients was a point of discussion in one group. As one person indicated:

It was hard speaking to a professor or specialist, its difficult to speak to him and explain to him exactly how I was feeling.

Mixed wards

Despite their overall praise for the stroke ward and the stroke ward staff, participants were critical there was not separate wards for men and women, an issue raised in almost all groups. The criticism of mixed wards is best expressed by the thoughts of interview participants themselves:

I hated sharing a ward with three men. It's a shame they can't say 'look there's two women there, two men there, why can't we just swap the beds over'. I thought that was, I didn't like that.

The only thing I hated about the hospitals is the mixed wards.

Lack of privacy.

Especially when you are trying to manoeuvre into the bathroom door with your drip.

I'd rather be segregated. For no other reason that it's a bit more dignified.

Yes, I think men should be separate.

COMMUNICATION BY HOSPITAL STAFF ABOUT TESTS AND PROCEDURES

The ability of hospital and medical staff to communicate to patients and carers information about tests and procedures was raised as an important issue in our discussions. Participants indicated a desire to be kept informed with the latest information and developments relating to their care.

In our discussions, participants indicated they underwent a number of different tests and procedures during their time in hospital. As one participant explained:

They did various tests with needles up my arms and down my side and in my face to see what I could feel different to the other side. Holding hands, how much pressure I could use with my hands, if I could walk, and everything proved OK. I had a stroke, I've still got the effects of it. But they did everything to me they possibly could.

It was reassuring for most people that the latest medical and diagnostic equipment was available in hospital. As one person said:

I feel blessed I'm as well as I am and that all these facilities were available for me to have all these tests.

Despite this, long waiting times for tests was also frustrating for some people. One participant who was admitted to hospital on two separate occasions waited over the weekend before any tests were conducted explained:

Another thing it was over the weekend. It seemed like Saturday and Sunday they don't work to get a scan or X-rays. Twice, always the same. Saturday, Sunday nobody there. So I had to wait always to Monday ... That frightens you because you're lying there.

During our interviews we found that the type of information about tests and medical procedures and how this information was communicated to people varied significantly. People had a range of responses when the discussion turned to how well tests and procedures were explained by staff. We found that older people were less inclined to ask questions about their diagnosis and treatment options, while younger people expected to be kept informed about what was going on. As an older person said:

If they wanted me to know things, they'd tell me.

This view was shared by other participants who said:

I accepted the fact that I'd had a stroke and I just laid back and let them do what they had to do. I didn't ask too many questions. I asked a few (questions) for my wife and that and family. But other than that I just relaxed. I knew I'd find out eventually.

They never went into big detail but they just went on with their job ... I knew what I had, but they never went into big detail. They just did it and I cooperated. I was in a bit of shock. Because I just couldn't believe that it had happened and it had. So therefore I just let myself go and they were excellent. They had the ultrasound and they put me through the big tunnel and all this type of stuff, you know. I just accepted that, that was OK. But I still couldn't talk. That was a lot for me too. Not being able to talk for three days.

Responses by those who expected that tests and procedures would be explained to them varied from those who felt they were given an adequate explanation of what was happening...

They did all the tests, particularly the CT scans ... plus I got a lot of information. Because I was able to comprehend and my cognitive ability wasn't affected, I was able to understand it pretty much straight away.

The doctors were very good. There was a doctor and a registrar and they explained (what was happening). They were very good in their explanation.

... to those who felt things were not explained enough:

Nobody had the time to tell me until a social worker came to see me about the eighth day and he was able to spend a bit of time with me and explain what some these medical terms were. Maybe a lot of people don't particularly care but I am an inquisitive sort of individual and I want to know what's the matter with me.

I didn't know what was going on with me. The only thing was when they told me I had to go for the CT scan I didn't know why I was there. I was really surprised, because I had no symptoms at all.

Even when things were explained some people felt frustrated that they could not adequately respond due to their condition.

Two doctors came to see me and ran a number of tests and the doctor told me I'd had a stroke. Couldn't understand exactly what that was at the time. I could actually understand them and hear them, but I couldn't actually reply like I'm talking now. I couldn't use my mouth to reply.

MRI

The importance of adequately explaining to patients (and/or their carers) why tests and procedures were necessary and how they were to be undertaken was highlighted when one group discussed what proved to be an upsetting experience for a number of people – having an MRI scan. A number of participants in this group described that their fear of having an MRI was made worse because they were not told the reason why the MRI was taking place nor how the procedure would be conducted.

While the MRI machine itself looked frightening...

That rattly old machine they should replace it because its frightening. You can imagine children having to go through it. I know what's going on but still very, very confined.

... participant's apprehension about the MRI was exacerbated by a poor explanation of how the procedure would take place:

... he booked me in for an MRI which I fought against because I didn't really want to do it ... It was really daunting. I'm claustrophobic and I didn't like it. I had a hard time coping with that. I'm very proud of myself I handled it. But I wasn't very impressed with the operator. The first time he was caring and understanding but the second time I think he thought because I'd done it once I should manage again ... When I came out (the second time) I was a wreck. But this guy wasn't in the least interested. I just had to handle myself and get back to the ward and calm myself down and do my own deep breathing and relaxation ... I found it disconcerting that the technician, because I'd done it once he thought you're fine. I wasn't. I really wanted to kick him. I'm not fine, I'm terrified.

The person who operates those machines, they should give more information about what to expect and reassurance. Because it's the most frightening thing. I thought I'm going to get a scan done, just from neck upwards. I think I got a full body scan. I was ages in there. He should have told me at least.

INFORMATION ABOUT STROKE

Participants reported that the type and amount of information people received about stroke varied considerably. In most cases participants argued they require a clear verbal explanation of what has happened to them and what is likely to occur in the future. As one participant observed:

It is up to the doctors, mainly the specialist to actually explain things ... Maybe other specialists do, but the specialist I had didn't do that. Maybe other specialists do sit there and explain everything, or maybe bring an interpreter to explain everything. But maybe this doctor assumed that because the brain had been affected that maybe I wouldn't understand, so that's why he didn't explain it. But it's up to the doctors or the staff to actually explain all of that.

The amount of written information given to participants also varied significantly. Some participants received no written material while others received a range of information including stroke pamphlets. (Some people even brought pamphlets to the discussion groups to show others.) A participant who received a lot of information commented:

I thought the service was really good. I got lots of information, booklets. Not only for me but also for the family so that they would understand and help, which I thought was really good. The social worker ... he was wonderful. He was really good ... Yeah he was marvellous. There is so much written information for you and your family members. Your mood swings, your depression all of a sudden because you worry about something. There's a lot of information out there.

Another participant commented that he received information about what was likely to happen from the very beginning of his care when he was being transported to hospital in the ambulance:

I found them very good. Because the ambulance basically told me, I knew what it was anyway. But the ambulance confirmed it. They were very good. 'This is what you've got, this is what we're going to do. You'll be admitted. You'll be there for X number of days', I think they said five ... there were two or three doctors in emergency, they were very good, communicated everything.

Pamphlets explaining stroke were viewed positively by those who received them:

There's another one (pamphlet) they give you, 'Living with Stroke'. One complements the other very, very interesting.

I was given some pamphlets ... which explained stroke and the social worker gave me a few pamphlets on what could be done for stroke victims.

At Monash Medical there's a thing there with pamphlets in it, in about 10 languages, every one but English.

The issue of how information was provided to people whose first language is not English was raised in a number of groups. The importance of using interpreters

(particularly when staff are discussing complex issues or explaining test results for example) was highlighted by one participant who said:

The doctor could have told the interpreter all the information and then the interpreter could have explained that (to me). In this type of case it should be explained. So I could help myself more if I knew the right information.

When a Greek speaking participant was asked if information written in Greek would have been helpful he replied:

Maybe I would not have been able to actually read and understand it at the time, because I wasn't well enough, but I would have liked to have had something provided in Greek.

Information for carers

Carers play an important role supporting stroke survivors during and after the acute phase of care. Information for carers about the medical and psycho-social impact of stroke is vital in supporting patient's care. As one carer who participated in the interviews explained:

I have to look after my Mum and need the information to make the right decision.

When visiting hospital carers are able to clarify issues and ask questions on the patient's behalf. This is particularly important for patients whose first language is not English, but whose children are fluent in English:

The children of course they speak English quite well. They were able to (ask) questions.

As well as verbal information, written information that carer can take home and read at a time that suits them was highly valued by a number of participants:

My family would appreciate anything like that because its alright me saying 'you need to understand' or 'I can't help what's happening to me' or 'I can't help this behaviour or spasm or whatever'. I think my family would rather have something, sit and quietly read it and talk about it and then plan how they're going to help and assist. I think most families would be much the same.

I agree with you. I think it's two-pronged really. Not only will they inform themselves what's going on, its also in preparation so that they understand what's going on ... they're prepared in case the worse case scenario happens.

I think it was important for the family to get written information like those booklets that I've got. So they can see the mood swings and thinking why you are depressed. It's such a whole different lifestyle for me now.

DISCHARGE AND SUPPORT SERVICES

Despite their overall positive assessment of hospital care most participants expressed a strong desire to be discharged from hospital and to return home as quickly as possible:

Yeah I don't want to stay in hospital, only sick people (stay) there.

I was out the door before they could say 'Jack Robinson'. I don't want to stay in hospital if I don't have to.

Despite their eagerness to be discharged, people also expressed an apprehension about returning home with some participants indicating they were fearful of suffering another stroke:

... when I got home after the first one you're on tenterhooks all the time. You don't know if you're going to wake up in the morning. You don't know when you're going to get paralysed again because it just hits you like that. You've got no warning at all. That's the scariest part to live with.

Going home was a bit daunting, you just think geezers is this going to happen in the next few days again, but it didn't.

I had more fear of going home. Because when I had the stroke I got mad because I'm very independent. I don't rely on no one doing nothing for me. I don't like that. The worst part was (when) my husband ... went back to work, that was like a door slamming in my face. All by myself. If I have a stroke what's going to happen and I just went hysterical.

Participants' perception of how their discharge was arranged varied considerably:

I don't remember if I received any prior notice or whether they just came and saw me on the day and said you can go home. It was very quick.

They just told me I was going home. I had to wait for transport. I couldn't drive so I had to get in contact with my son and that, and I waited for two or three hours. He came and left his work. No problems there, so I just waited. I felt bored just lying in bed, nothing wrong with me, just doing exercises with my hands. A lot of people were worse off than me. I was just glad to get home.

Some people received prior notice they were to be discharged and were able to prepare for their return home:

Well they started talking to me about it a couple of days before because they had to find out whether they were going to do this thing on my neck or what. When I went home I went home in a taxi with my sister and they told me not to go out on public transport for two weeks. If I went for a walk, just to go local.

When they came and told me that was really happening and I'd be going home and there'd be follow up and everything like that. I went to see the doctor and he explained to me how it was very important that I follow the instructions very carefully.

I was notified about 9.00 o'clock on Wednesday morning. It took until 4.00 o'clock to get sorted, medication etc. I live on my own so I was able to arrange a neighbour to thankfully come and pick me up.

The importance of family members and other friends to provide support post-discharge was highlighted by one participant:

... they made sure I had somebody. My daughter stayed for a few days. My neighbours are very good. Some did my shopping (for me).

Community support

Linking people into community support services such as those run by the Stroke Association of Victoria⁷ was highlighted by participants as an important aspect of ongoing care. According to one participant this was particularly important for people living on their own:

Because a lot of old people they've lost their partner, they're on their own, they really are in a desperate situation. They've got no one to talk to.

Another participant said:

It's important to know that there are places you can ring to get help, 'can I please have someone to drive me to a doctor's appointment'? Or to go down to do my shopping. Or something like that. Or even if you are on your own and you want company, for somebody to come and visit you once a week. Just help, have a cup of tea and a chat. Things like that I think the hospitals need, the social workers need to focus a little bit on that side of things. To see if the patient is interested and wants it and where it is in that area that they can get onto it.

This point was emphasised by two other participants who said:

So if there is a support organisation out there, the hospitals (should) know of them all. They can say to the patient 'well this one is in your area and if you need transport, if you need help with shopping, whatever, ring them and they may be able to help you'.

Or pop in and see how you are coping. If you are coping, good, if you are not she can see what you need, talk about it, because some people are very frightened on their own after it. I found out I got tired, I couldn't do much in half an hour, I was just weak.

One participant likened such support to that provided by maternal and child health nurses:

Like when you have a baby. When you have a baby the welfare health centre women helps you. She'll come straight to your home. They know you've given birth and she's there to help you ... That's what you need, something like that.

Referring patients to organisations who are able to provide specialised support was also recognised to be an important aspect of care beyond the acute phase. As one vision-impaired person said:

I had the Blind Society because of my vision problem. They were very good. They sent somebody into the hospital. They interviewed me, took statements and so on. As soon as I got out they took someone to our place and they arranged tests, more tests. Which I found they were very good. I didn't expect that but they looked after me. That was the only thing that I needed.

Information about driving

The importance of the hospital providing information and advice about activities that are/are not recommended post-discharge was highlighted in our interviews. One point that was raised on a number of occasions related to whether people are able to drive after a stroke:

⁷ The Stoke Association of Victoria is a voluntary non-profit organisation that provides information about stroke, advocacy, counselling, recreational outings and mutual support for stroke survivors, families and carers.

They never mentioned the driving. I just got home and about four or five days I started doing little trips. Just to drop the kids off. But no one actually said you're not supposed to drive. It wasn't until I went to the Hampton Rehab. Hospital just to be assessed. After I got there the second time, I was saying 'I'll drive there', and they said 'you shouldn't drive'.

One participant who received clear instructions about driving said:

(The social worker was) very strict when I told him I might drive my car. He said 'no don't do that. Might take somebody else out'. He was most helpful I must say that.

The importance of alternative arrangements for people who weren't allowed to drive was also highlighted in our discussions:

One thing I missed for about three months you're not allowed to drive around. That was terrible. I asked for assistance if somebody can provide transport. To my amazement I was told there's no such system going.

CONCLUSION

... since I had the stroke, I've found that I miss words ... A simple theme I can't think to say, a table (for example). For four or five minutes my wife will say stop and think about it. I'd think about it. This is the thing that's still leaving me, the fact that I'm having a little bit of trouble occasionally, not frequently, to think what I'm talking about. Once upon a time I'd just say it. I get people's names mixed up. But then again I put that down to age too ... I'm not sure if it's the age or the stroke, but I make a very big effort of trying to remember people's names ... Trying to think of the name of something I've known all my life. So that's what's happened to me.

Focus group and individual interviews conducted by Health Issues Centre provide a valuable insight into patients and carers' experiences of acute stroke care at Monash Medical Centre and West Gippsland Hospital. Our interviews highlighted a number of issues relating to how people experience stroke care. These included:

- the shock associated with the onset of stroke;
- long waiting times in the emergency department;
- a positive view of care once admitted to the stroke ward;
- the importance of information and explanation of tests and procedures
- the importance of information (verbal and written) about stroke; and
- the need for ongoing support post-discharge.

Despite some critical comments concerning various aspects of care, Health Issues Centre found that overall, interview participants made a positive assessment of their care. To a large extent, issues raised by participants in our discussions are similar to previous research examining consumers' experiences of stroke care. Although previous studies do not examine the problems encountered by consumers in hospital emergency departments that were highlighted in this study, issues such as information about stroke, the importance of an explanation of medical tests and procedures and the longer-term emotional impact of stroke are consistent with previously published research.

REFERENCES

- Anderson, R. (1992) *The Aftermath of Stroke*, Cambridge University Press, Cambridge.
- Barbour, R. (2001) 'Checklists for improving rigour in qualitative research: a case of the tail wagging the dog?', *BMJ*, Vol. 322:1115-1117.
- Consumer Focus Collaboration (1998) *Strategic Plan: 1997/98-2000/01: Strengthening the focus on consumers in health service planning, delivery, monitoring and evaluation in Australia*, Consumer Focus Collaboration.
- Consumer Focus Collaboration (2000) *Improving health services through consumer participation: a resource guide for organisations*, Produced by the Department of Public Health, Flinders University, and the South Australian Community Health Research Unit, Commonwealth Department of Health and Aged Care.
- Department of Human Services (2001a) *Communicating With Consumers Series Volume 2: Stroke, Chest Pain and Cholecystectomy*, Prepared for the Victorian Department of Human Services by the Centre for Clinical Effectiveness and Health Issues Centre, Melbourne.
- Department of Human Services (2001b) *Meeting Demand For Emergency Services: Better Management Of Emergency Patients*, Patient Management Taskforce Paper No. 2, Patient Management Taskforce, Melbourne.
- Forster, A., Young, J., Smith, J., Knapp, P., House, A. and Wright, J. (2001) *Information Provision For Stroke Patients and Their Caregivers (Protocol for a Cochrane Review)*, In: The Cochrane Library, Issue 2.
- Gibbs, A. (1997) 'Focus groups', *Social Research Update*, University of Surrey, www.soc.surrey.ac.uk/sru/SRU19.html accessed on 28 September 2001.
- Green, J. and Britten, N. (1998) 'Qualitative research and evidence based medicine', *BMJ*, 316:1230-1232.
- Hill, S. (1996) *Literature Review on Consumer Issues in the Prevention of Stroke*, Report to the National Health and Medical Research Council Working Party to develop clinical practice guidelines for stroke prevention.
- Holmqvist, L. and von Koch, L. (2001) 'Environmental factors in stroke rehabilitation', *BMJ*, 322:1501-1502.
- Krueger, R. (1994) *Focus Groups: A Practical Guide for Applied Research*, Second Edition, SAGE Publications, Thousand Oaks.
- Lewis, M. (1995) *Focus Group Interviews in Qualitative Research: A Review of the Literature*, www.cchs.usyd.edu.au/arrow/reader/rlewis.htm accessed on 29 November 2001.

- Maclean, N., Pound, P., Wolfe, C. and Rudd, A. (2000) 'Qualitative analysis of stroke patients' motivation for rehabilitation', *BMJ*, 321:1051-1054.
- Mant, J., Langhorne, P., Dennis, M. and Winner, S. (2001) *Stroke Liaison Workers for Stroke Patients and Carers (Protocol for a Cochrane Review)*, In: The Cochrane Library.
- Monash University Consortium (2000), *Model to Implement Best Clinical Care: Applied to the Management of Acute Stroke*, Clinical Support Systems Project Tender Document, Submitted to The Royal Australasian College of Physicians and the Commonwealth Department of Health and Aged Care.
- National Stroke Foundation (2001) *Stroke Care Outcomes: Providing Effective Services*, (Draft), An Evaluation of Victorian Stroke Services, Final Report of the Health Services Unit, National Stroke Foundation.
- Pope, C. and Mays, N. (1995) 'Qualitative Research: Researching the parts other methods cannot reach; an introduction to qualitative methods in health and health services research', *BMJ*, 311:42-45.
- Pound, P., Bury, M., Gompertz, P. and Ebrahim, S. (1995) 'Stroke patient's views on their admission to hospital', *BMJ*, 311:18-22.
- Pound, P., Gompertz, P. and Ebrahim, S. (1998) 'Illness in the context of older age: the case of stroke', *Sociology of Health and Illness*, Vol. 20, No. 4:489-506.
- Powell, R. and Single. H. (1996) 'Methodological matters-V: Focus groups', *International Journal of Quality in Health Care*, Vol. 8, No. 5:499-504.
- Royal Australasian College of Physicians (2001), *Evaluation Report on the Clinical Support Systems Program*, Prepared by KPMG Consulting.
- Royal College of Physicians (2000) *National Clinical Guidelines for Stroke*, Prepared by the Intercollegiate Working Party for Stroke, Clinical Effectiveness and Evaluation Unit.
- Stewart, D. and Shamdasani, P. (1990) *Focus Groups: Theory and Practice*, Applied Social Research Methods Series, Volume 20, SAGE Publications, California.
- Strauss, A. (1987) *Qualitative Analysis For Social Scientists*, Cambridge University Press, Cambridge.
- Stroke Unit Trialists' Collaboration (2001) 'Organised inpatient (stroke unit) care for stroke' (Cochrane Review), In *The Cochrane Library*, Issue 2, Oxford: Update Software.
- van Gjin, J. and Dennis, M. (1998) 'Issues and answers in stroke care', *Lancet*, Vol. 352 (suppl. 11):23-27.