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Submitted for publication 20 January 2003
Accepted for publication 7 October 2003

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Background. Stroke is the third most common cause of death in industrialized countries and a major cause of adult disability. However, the burden of caring for stroke survivors usually rests with family members who have neither chosen nor volunteered for the role of ‘carer’.

Aims. This paper reports on a study which aimed to describe the experience of caring for a stroke survivor one year after stroke in Scotland.

Study design. Semi-structured, taped interviews were conducted with 90 carers of stroke survivors one year after stroke and the data analysed using NUD*IST. The interviews were part of a larger study, which included the administration of a range of valid and reliable multidimensional instruments to both carers and stroke survivors. The interview prompt schedule had been developed and tested in a previous study.

Findings. Although a medical emergency, stroke was not always diagnosed or treated as such by either the public or general practitioners. Initially most carers found that they lacked the knowledge and skills to care for the stroke survivor at home and so they had to learn how to obtain the information and assistance required. Carers had to adapt to the changes that stroke effected in the stroke survivor and seek alternative ways of securing the resources they needed for managing their lives. They thought that they had not been prepared adequately for the caring role or assessed satisfactorily in terms of whether they could manage given their skill level, age and/or health status.

Conclusions. A public health campaign to educate and inform that stroke is a medical emergency is required if stroke disability is to be minimized. The use of
new technologies should be considered in facilitating carers’ learning how to care. There is a need to test alternative models of stroke follow-up in multicentre studies that are holistic and place the carer-stroke survivor at the centre of care.

Keywords: stroke, informal carers, patients, stroke survivors, nursing

Background

Stroke is the most important cause of morbidity and long-term disability in Europe and the third most common cause of mortality in industrialized countries (The Intercollegiate Working Party for Stroke 2000). In the United Kingdom (UK) annually there are 110 000 first strokes with a further 30 000 recurrent strokes (Bath & Lees 2000). In the United States of America (USA), stroke is the leading cause of adult disability with up to 50% of stroke survivors incurring partial or total dependence in daily living (AHCPR 2001). Current estimates suggest that 80% of UK stroke survivors (henceforth patients) are living in the community one year after stroke, with more than a third dependent on an informal carer (hereforth carer) (Cassidy & Gray 1999).

The burden of caring can cause serious disruption to carers’ lives (Bugge et al. 1999). Carers may be older and have pre-existing illnesses or functional limitations that limit their ability to cope with the physical aspects of caring (Han & Haley 1999). Over time, if the burden of care is excessive, the carer’s health may breakdown, with a subsequent loss of support for the ‘patient’ (Van den Heuvel et al. 2001). While there is extensive literature on caregiving (Dowswell et al. 2000a; Bugge et al. 1999; Department of Health 1999; Low et al. 1999; Scholte op Reimer et al. 1998), less is known about stroke carers’ experiences over time and the skills and knowledge they require to facilitate caregiving.

The study

The findings reported in this paper are part of a wider study that sought to determine the influence of a range of patient and carer variables on the health and well-being of informal stroke carers. This paper reports on the interviews conducted to explore the stroke carer experience at one year after stroke.

Aim

The aim of the study was to describe the experience of caring for a stroke survivor at one year after stroke.

Design

This was a two-year, descriptive study with retrospective and current data collected in 2000–2001. Each patient–carer ‘pair’ was visited at home once, one year poststroke. The one-year timeframe was selected because: (1) the functional ability of most patients has stabilized by 12 months; (2) most rehabilitation has ceased by one year; and (3) carers would have been in the caregiving role for some months.

Population and sample

Patient inclusion criteria were: a WHO (1990) diagnosis of stroke excluding subarachnoid haemorrhage; discharge from hospital 3–11 months previously; living in the community; and having an identified carer providing emotional, physical or social support. Patients were excluded if they were dependent on a carer prior to the index stroke; lived in a residential home; or had a terminal or psychiatric illness which in the researcher’s judgement made study participation inappropriate.

Carers were accessed via general practitioners (GPs) who provided their names and contact details in relation to patients meeting the entry criteria.

A total of 605 stroke patients from two Scottish University teaching hospitals were identified; 149 met study criteria. From these, 90 patient–carer pairs agreed to participate (60.4% recruitment rate). Of the 59 who refused there were 15 patient refusals, nine carer refusals, three joint refusals and 32 who did not respond to the study invitation. There were no refusals or withdrawals once participants agreed to participate.

Data collection

We collected patient and carer demographic data. Reliable and valid outcome measures were administered to both, but only the Barthel ADL Index (Duncan et al. 2000) and Hodkinson Abbreviated Mental Test (Wade 1992) are reported here. An audiotaped, semi-structured interview was held with each carer. The same interviewer conducted all interviews, using a prompt schedule that had been developed and tested in a previous study (Table 1: Kerr &
Interviews were arranged at a date and time of carer choosing and lasted between one and two hours.

Ethical considerations

Ethics approval was obtained from the Local Research Ethics Committee. All participants received information sheets and provided written informed consent. All interviews were held in participants’ homes and audiotaped with their permission. Anonymity and confidentiality were protected in line with the Data Protection Act 1998. Usually interviews were conducted in the patient’s presence, but they seldom interrupted. Sometimes carers corroborated details with patients or sought agreement to the interpretation of an event.

Data analysis

Interviews were transcribed verbatim, checked for accuracy and entered into QSR NUD*IST [Non-numerical Unstructured Data Indexing Searching and Theorising]. Data were coded, compared and reduced to concepts and named categories (Eaves 2001). The reports generated were examined for linkages and organized into themes for data analysis and interpretation. A summary was produced for each theme that could be cross-referenced to participants’ data. In relation to each theme we asked the question ‘So what?’ in order to identify key issues. We compared all summaries to eliminate duplication and to ensure that all data relevant to that theme was being grouped together. Finally we discussed all thematic data to reach agreement.

Findings

The findings are presented thematically, moving from the initial stroke event to one year after stroke; they reflect the balance, emphasis and content of the prompt schedule. The carer’s perspective is reported but is occasionally echoed by a patient’s view because the patient interrupted an interview with a comment. Patient and carer profiles are presented, including patients’ disability and cognitive functioning levels (Tables 2 and 3). Throughout, situations that prompted the carer to adopt new behaviours are described. Respondents are identified by numbers.

The stroke event

When the onset of stroke was rapid, help was requested quickly. Those with previous experience of stroke sometimes ‘diagnosed’ this and phoned the GP or took the patient

<table>
<thead>
<tr>
<th>Table 1 Carer interview prompt schedule</th>
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<tbody>
<tr>
<td>1. Can you tell me something about [patient’s name] life before s/he had the stroke?</td>
</tr>
<tr>
<td>2. Can you tell me about your life before [patient’s name] had the stroke?</td>
</tr>
<tr>
<td>3. Please describe what happened when [patient’s name] had the stroke.</td>
</tr>
<tr>
<td>4. Tell me about the time that [patient’s name] spent in [acute care setting].</td>
</tr>
<tr>
<td>5. Tell me about the time that [patient’s name] spent in [rehabilitation unit]. <strong>Omit if discharged directly home</strong></td>
</tr>
<tr>
<td>6. Can you think back to the time when [patient’s name] was discharged/was about to be discharged home from [acute care setting/rehabilitation unit].</td>
</tr>
<tr>
<td>7. What about the early days and weeks at home – can you tell me what happened during that time?</td>
</tr>
<tr>
<td>8. It is now approximately a year since [patient’s name] had a stroke. Can you tell me what about what life has been like since the early weeks?</td>
</tr>
<tr>
<td>9. Can you describe a typical day?</td>
</tr>
<tr>
<td>10. Can we talk about how you see the future?</td>
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<tr>
<td>11. Summary (focus on needs).</td>
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<tr>
<th>Table 2 Patient profile</th>
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<tbody>
<tr>
<td>Age</td>
</tr>
<tr>
<td>Range: 33–90 years</td>
</tr>
<tr>
<td>Mean: 67.5 years</td>
</tr>
<tr>
<td>Males (n = 56)</td>
</tr>
<tr>
<td>Age range: 45–86 years</td>
</tr>
<tr>
<td>Mean: 68.0 years</td>
</tr>
<tr>
<td>Females (n = 34)</td>
</tr>
<tr>
<td>Age range: 33–90 years</td>
</tr>
<tr>
<td>Mean: 66.6 years</td>
</tr>
<tr>
<td>Number of patients married: 60</td>
</tr>
<tr>
<td>Number of patients widowed: 17</td>
</tr>
<tr>
<td>Barthel activities of daily living index (0–20)</td>
</tr>
<tr>
<td>Independent: 20 16 patients</td>
</tr>
<tr>
<td>Mild disability: 15–19 52 patients</td>
</tr>
<tr>
<td>Moderate disability: 10–14 15 patients</td>
</tr>
<tr>
<td>Severe disability: 0–9 7 patients</td>
</tr>
<tr>
<td>Hodkinson’s abbreviated mental test (1–10)</td>
</tr>
<tr>
<td>Normal: 8–10 70 patients</td>
</tr>
<tr>
<td>Abnormal: 16 patients</td>
</tr>
<tr>
<td>Unable to complete test: 4 patients</td>
</tr>
</tbody>
</table>
directly to an accident and emergency department (A & E). With insidious onset or a feeling that ‘something was wrong’ (R46), a waiting period elapsed to see if the situation resolved before calling the GP:

I went to work on Saturday and Sunday and he was still sleeping. So it was Sunday when I got concerned. (R23)

On contact, most GPs or emergency doctors made a home visit, usually within the hour. Some diagnosed stroke over the telephone, referring the patient directly to A & E. A few requested that the patient come into the surgery. Patients arrived at A & E via ambulance, taxi or were driven by a friend/relative, depending on availability and what was judged to be the quickest.

The hospital experience

For many, admission through A & E involved waiting 4–5 hours:

They [the ambulance crew] said it was very important that dad (father) was seen right away. My dad wasn’t. My dad was left in the corridor. (R45)

Carers described themselves as agitated and stressed by A & E, particularly regarding lack of information, for example, on why pain relief was not given for headache or tests being conducted or the whereabouts of the patient. As one carer said:

Once she disappeared behind those doors...She could have been anywhere, and nobody seemed to be able to tell me anything. (R12)

Patients with aphasia found A & E to be particularly distressing, in part due to communication difficulties, but also because aphasia was a new and terrifying experience. As one carer said:

He was actually sitting writing things out and he was breaking his heart crying because he couldn’t speak. (R52)

Once patients were admitted carers had to cope with their symptoms, including physical impairment, second strokes and failure to recognize family members. Carers found the implications of stroke difficult to assimilate:

You can’t take it in...You don’t know at that time, just how bad it is. (R53)

Expectation of recovery varied, with most carers fearing the worst – that is, death.

Visiting, while performed willingly, was tiring, stressful and restricted the visitor’s daily routine. Life had to be planned around visits, especially if the carer was employed, older, had mobility problems, was responsible for young children or dependent on public transport. As one carer put it in relation to hearing of her husband’s discharge:

I was really happy because I was exhausted going out everyday to the hospital. (R21)

Carers thought therapists, doctors and particularly nurses to be ‘too busy’:

It was a busy, busy place. So I’m glad he was there for just a short time. They were always so busy, busy, busy. (R22)

Carers were prepared to excuse a lack of attention on the basis of staff’s ‘business’. However, this made it difficult to approach staff who appeared so occupied. Carers preferred staff with an open, friendly manner who approached them, such as a stroke liaison nurse who sought out a carer, answered questions, provided a contact number. Generally carers thought medical and nursing staff to be insufficiently forthcoming in terms of information-giving:

Nobody really told me anything. They couldn’t tell me how bad he was even when he went to Hospital D. (R32)

Often carers relied on patients for feedback even if they were aphasic.

The level of daily physiotherapy was perceived as inadequate, and little mention was made of carer or family involvement in physiotherapy sessions, whether as an observer or to receive tuition in moving and handling. Therapy was unavailable during weekends or after 17:00 hours, again limiting carer involvement. Most occupational therapy (OT) involved dressing and kitchen practice, but again with little carer involvement. A few carers made a conscious effort to learn nursing skills and

<table>
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<th>Table 3 Carer profile</th>
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<tbody>
<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td>Range: 19–84 years</td>
</tr>
<tr>
<td>Mean: 57.8 years</td>
</tr>
<tr>
<td><strong>Males</strong> (n = 25)</td>
</tr>
<tr>
<td>Age range: 19–84 years</td>
</tr>
<tr>
<td>Mean: 53.7 years</td>
</tr>
<tr>
<td><strong>Females</strong> (n = 65)</td>
</tr>
<tr>
<td>Age range: 26–78 years</td>
</tr>
<tr>
<td>Mean: 59.4 years</td>
</tr>
<tr>
<td><strong>Number of carers married:</strong> 64</td>
</tr>
<tr>
<td><strong>Number of carers widowed:</strong> 1</td>
</tr>
<tr>
<td><strong>Number of hours caring per week</strong></td>
</tr>
<tr>
<td>Range: 4–168 hours</td>
</tr>
<tr>
<td>Mean: 104 hours</td>
</tr>
</tbody>
</table>

L.N. Smith et al.

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physiotherapy exercises by observing and listening to the professionals at work on the wards.

After discharge: at home and unprepared

Usually prior to discharge, an OT and physiotherapist or nurse made a home assessment visit. Structural alterations (showers, stair lifts) required funding applications, and waiting lists, often a year long, and ‘border’ disputes between agencies, created problems. Immediately after discharge, several carers found themselves having to deliver ‘hands on’ care without any skills training. They appeared to worry less if they had previous care skills or knowledge about what to expect after a stroke.

Carers expected immediate and automatic GP follow-up for at least one year after discharge. In practice, very few carers reported GP follow-up, yet most patients continued to feel medically vulnerable. Carers felt ‘abandoned’ and were disappointed by the lack of GP aftercare. As one patient interjected during interview,

Even your own doctor doesn’t come to you! You’ve got to send for her. (R12)

Lack of follow-up meant that carers had to be persistent and learn how to get information and/or the services and financial assistance required. They felt they had enough to cope with, without these additional burdens.

Most patients had a least one stroke follow-up hospital appointment, but they often had co-existent medical conditions requiring outpatient attendance. Carers found multiple appointments, transport, reduced patient levels of mobility and some patients’ unwillingness to leave the house difficult to manage. Carers wanted more prolonged contact with a Stroke Liaison Nurse but the caseload was often too large to provide the extended service expected. For example, one carer felt that she did not need,

somebody coming out and in but I felt that the community stroke sister should have at least lifted the telephone and said, Is there anything you need advice about?. (R53)

At one year, therapists had little contact with patients unless their condition had deteriorated.

The financial benefits system was perceived as complex and inequitable, and carers with company pensions and/or who were homeowners felt discriminated against. As one reported:

I've got a works pension and thanks to my works pension, it has left us £1 over the limit [for financial assistance]. So that's me penalised...It makes you wonder if it's worthwhile working all your days and going into a pension scheme. (R34)

Almost all patients in this study had applied for Disability Living Allowance. The process from application to the almost inevitable appeal was described as lengthy and ‘degrading’. One interviewee said,

The one time I went to the appeals panel, I would never, never go back again!. (R49)

Often the services of a third party, usually a social worker or a Citizens Advice Bureau representative, were required to ensure that applicants eventually received the benefits to which they were entitled.

For patients living alone, the Home Help Service was reported as supportive. However, carers living with patients found that this did not always meet their needs because the range of tasks was too restricted or the time available with each client too limited or too expensive. One carer noted:

The Home Help Service [is] fairly inadequate in terms of lack of continuity and they don’t spend a great amount of time. It’s very dependent upon the individual. (R19)

Lack of continuity in Home Help personnel impaired the development of trust and security.

Improvements in environmental access were beneficial to carers and patients (e.g. ramps, wider doorways), as were new technologies (e.g. personal computers, mobiles, Internet) to facilitate communication. For the few carers who accessed voluntary agencies, these proved to be important sources for information and equipment in the immediate postdischarge phase.

The foregoing illustrates that most carers had to learn how to access and obtain community support after discharge. Some received an excellent service and received the information and support required, and in a timely fashion:

I must admit the help was pretty good in the hospital and the aftercare has been not bad. (R46)

For the majority, however, this was not the case.

Changing relationships

Carers, before the stroke occurred, were typical of the general population in that they had experience of work, children, redundancy, early retirement and voluntary work. Their social lives varied from ‘none’ to ‘extremely active’. Their responses to stroke were, therefore, individualized and depended in part on their own well-being and that of the patient, previous social life, family, other life-changing events such as terminal illness, as well as age and stroke severity.
Carers found patients less able to cope with crowds, sudden movement and noise. Some patients suffered a loss of confidence, which resulted in being housebound or feeling unable to go out alone. For many, stroke survival meant enduring gross breeches of personal sensitivity on a daily basis, particularly in relation to toileting and personal hygiene, even one year after stroke. One carer described her husband’s reaction:

I knew it was embarrassing for him. He was getting upset and crying…This is terrible! This is terrible! (R42)

while a male carer was distressed by his wife’s nakedness as such intimate contact had not been part of their married lives.

Depression and lack of motivation caused friction between carer and patient, and carers found it wearying to motivate patients constantly. Patients’ apathy, unwillingness to participate and non-communication provoked frustration in carers, who often attributed the unwillingness to be physically or socially active to ‘laziness’ (R31). Emotional lability was widely reported as a new behaviour and was difficult for both to cope with. However, the most commonly reported behaviour changes in patients were frustration and a quickness to anger which carers often attributed to loss of activity or role in the family/workplace; or lower levels of recovery than anticipated. Also, many carers could not comprehend patients’ ‘excessive’ need for sleep.

Patients’ prestroke leisure and work activities usually required a combination of good hearing, eyesight, motor skills, concentration and short-term memory, but often these were affected adversely by stroke. Carers reported that many patients’ only occupation one year after stroke was ‘just sitting there all day’ (R47) watching TV, either because they were physically dependent or because they lacked the motivation to be active. Patients with aphasia found the condition frustrating, despite carers reporting that with time their own understanding of gesture and facial expression improved and they developed intuitive levels of understanding.

**Adjusting to the carer role**

Patients wanted to go home from hospital as soon as possible; and carers wanted them home. Only a few reported worrying about the practical implications and their ability to cope.

I was very worried. How was I going to cope? How was he going to cope? (R52)

Most interviewees were of an age where co-morbidity sometimes affected their ability to care. Some were aware of their own ageing or deteriorating health and expressed concern about the future. They reported that they were not asked systematically if they could manage a house, cook, shop, assume financial responsibility, etc. In fact, many lacked some or all of these skills. They felt their role as carer was taken for granted, regardless of age, health or personal circumstances:

Nobody asked if I could cope, how we’d manage. (R32)

Carers often adapted by establishing a routine and by accepting support from statutory/voluntary agencies and/or family/social networks (e.g. doing ‘the big shopping’, heavy domestic chores, ‘chauffeuring’, sitting with the patient); and also by having specific times when they were not responsible for the patient. Breaks from physical caring were enjoyed, but for a few it was the ‘out of sight, out of mind’ (R37) that afforded respite so that to some extent carers could abrogate responsibility for the patients’ well-being, albeit temporarily, to another agency. Several felt that their quality time occurred when patients were in bed, but often they were too tired to use this time effectively. ‘Free time’ during the day was used to ease the pressure of the rest of the day by doing shopping and household chores rather than relaxing.

At one year after stroke, carers had learned not to plan for the future as they now saw life as unpredictable. They learned to ‘take life one day at a time’ (R1). Many had to adjust to life at a slower pace, but missed the stimulus of social interaction and opportunities to pursue their own interests. Carers perceived their world to be narrower:

Just sitting here, I’m away [from the patient]. And it’s wee (small) things…they add up all the time. There is restriction in my [life], a lot of restrictions. (R30)

Also some carers’ interests and social lives were restricted as a consequence of their own deteriorating health status.

Carers found that they had to shoulder either more or total responsibility for patients and running the household. They believed that the support required to lead their lives was not there – and if it was, it was extremely difficult to locate and mobilize. As one reported,

No one tells you anything. How are you to know what’s out there, what’s available if people don’t…tell you? Everything’s a fight. Nothing’s easy and there are waiting lists for everything…It’s a struggle and they expect too much of you. (R32)

Becoming a carer meant learning to leave the patient alone. Initially carers were reluctant to do this for fear of another stroke, or that the patient might injure themselves. However, one year later many carers were prepared to leave the person
alone, although this might be restricted to one or two hours. As one carer stated,

I worried myself sick every time I was away…But eventually I had to say to myself ‘No, this is not any good’ and get on with it. (R27)

Some, however, would not ever leave the patient alone and some patients never wished to be left alone.

Fear of recurrence of stroke remained a concern. Carers called the GP more readily, and worried about seizures, medications, and further strokes. However, some did not believe there would be a recurrence. They set an arbitrary date, sometimes 6 months, sometimes a year, after which they believed it was safe to assume that there would be no further stroke.

One year after stroke, most carers continued to report disturbed sleep because

• patients required assistance to go to the lavatory;
• they listened when patients got up until they were safely back in bed;
• they were unable to ‘switch off’ (relax their attention);
• the physical effects of stroke, e.g. inability to turn in bed unassisted, made sleeping difficult.

Caring was relentless. Many were ‘on call’ 24 hours a day, 7 days a week, and felt they lacked alternatives and the ability to be spontaneous. For some the future looked bleak and unpromising:

He doesn’t want anybody else…All he wants is me! All the time. All he wants is me! (R52)

Altered roles within relationships were a major issue for carers. For some, this involved reversal of former domestic male/female roles; for others, there was an assumption of additional responsibilities, e.g. financial. For others, there was a transformation of roles – most commonly that of ‘husband and wife’ to ‘patient and carer’. Some carers hoped they would return, at a time unspecified, to their previous life, but others abandoned all hope of this.

In the presence of persistent cognitive and behavioural problems, which were inescapable sources of stress, a few carers felt they were living with a stranger. Not only were these patients unable to fulfil their previous roles, but now carers had to assume responsibility for every aspect of their mutual lives. Furthermore patients no longer provided support or relief from life’s daily irritations. There was a sense that cognitive impairment was an ‘invisible’ disability for which health professionals and social workers failed to provide adequate support.

For many carers the physical burden of caring eased over time, either because of an improvement in patients’ abilities or by successfully learning coping mechanisms: ‘We’ve settled into a routine and P’s health is much better than it was a year ago’ (R14). There also was evidence that one year after stroke some carers gradually were returning to activities outside the home, although these were more curtailed than formerly.

Gaining information

Most carers felt they had received insufficient information; that the content was unsatisfactory; and that it was not provided at the right time. They wanted information about stroke, the physical/emotional effects, risk factors, recurrence, medication, treatment options, aids, services, benefits and respite care:

It is the first time I have ever experienced anything like this [his wife’s stroke]. It’s like going up against a brick wall. You’ve just got to try and work things out yourselves. (R34)

Finding information was hard work, time-consuming, frustrating. Telephone calls were not returned, people were not given progress reports, and they were passed from person to person or department to department. Often information was found by chance, and nothing was easy. As one carer said:

I feel sorry for people that are on their own that take a stroke, because without family to fight for them to get something they are really left on their own. (R47)

Several carers felt let down by ‘the system’ that they had paid into throughout their working lives. They believed that if it were not for them taking on the carer role, the patient would be in a nursing home or receiving expensive home care:

You’ve got to be getting nothing to get a carer allowance. And yet you’re helping. I felt like saying to them up there [Benefits Agency], ‘I tell you what – you cut my money, I withdraw my labour, and you’ll have to get a nurse in here twice a day. (R30)

Discussion

Although this had not been intended, most interviews were conducted in the presence of patients. The extent to which this altered the content and management of the interviews cannot be known. However, all interviews were conducted by the same researcher in order to give a level of internal consistency, and data interpretation was subject to research team review.

In this study, there was little evidence that carers, as members of the general public, were aware of the signs and symptoms of stroke, a finding in line with other UK and
Swedish studies (Wester et al. 1999, Yoon & Byles 2000). Worryingly, not all GPs appeared to treat stroke as a medical emergency, as some patients were asked to come into the surgery as opposed to being referred directly to A & E. Since they were concerned about a recurrence, carers learned the signs and symptoms of stroke and came to understand through experience that it should be treated as an emergency. Public education programmes (Dressman & Hunter 2000) that include an understanding that a ‘brain attack’ (The Brain Attack Coalition 2000), like a heart attack, requires immediate assistance, have been introduced in the USA and are producing heightened public awareness (Goldstein et al. 2001). Therefore, a UK public health campaign [including television ‘soap’ story-lines, etc.] to introduce the concept of ‘brain attack’ might be effective in reducing stroke-related disability.

In hospital, carers received little skills training despite needing and/or ‘seeking’ this (Brereton & Nolan 2000, Brereton 2002). The availability of both carers and patients to health professionals at visiting times therefore represented missed opportunities for structured skill training.

While there was no question that ward-based health professionals carried out rehabilitation activities, what was questionable was the understanding of what constituted rehabilitation within a ward context. Carers needed specific family-centred teaching conducted prior to hospital discharge, and to be included in and regarded as essential to the rehabilitation process. Like new family carers (Brereton 1997, 2002), those in this study also felt they had not been educated for their role of ‘carer’. While different discharge models have been proposed (Brereton 1997, Wiles et al. 1998), it remains unclear whether a predischARGE assessment, contextualized to the carer’s and patient’s health status and age, can produce an individualized care package which will enhance carer well-being and stroke survivor care.

Our carers, like those described elsewhere in the UK (Rodgers et al. 1999), experienced deficits and barriers to the acquisition of information. They had disparate information needs that required varied presentation formats and that changed over time. They needed access to resources which could be consulted for information, referral, ‘how to do’ and which did not send them from ‘pillar to post’, devalue them or add to an already heavy burden. The lack of a central stroke information resource, available and accessible 24 hours a day, meant that information-seeking was complex, burdensome and more difficult than necessary.

These carers were concerned about their increasing age, personal health status and continued ability to care in the future. Given the difficulties associated with outpatient attendance, and that outpatient departments are generally clinic-centred [as opposed to patient-centred], the lack of automatic GP follow-up assumed great importance. This, combined with the assumption that they would manage, meant that carers felt unsupported and unprepared. Previous UK and USA studies have demonstrated that caregivers value afterstroke support and/or stroke liaison workers, but their long-term impact on carer or patient well-being has yet to be established (Dennis et al. 1997, Dowswell et al. 2000b; Lincoln et al. 2003). Of the few UK trials reported, most focus on the introduction of a specialist stroke worker within a medical paradigm, allowing little opportunity for development and flexibility in the interpretation of the follow-up role (Dennis et al. 1997). Others are small-scale and/or descriptive in design (Dowswell et al. 1997; Dowswell et al. 2000a), or have highly prescriptive protocols (Forster & Young 1996), again limiting flexibility of approach.

Implications for nursing practice

Support after stroke must recognize carer individuality and aim to provide a service based on responding to individual concerns and needs which delivers value for money in relation to specific outcomes. A nurse-led, stroke follow-up service, based in primary care settings, might offer a way forward but has yet to be tested. Nurse-led services in the UK have expanded greatly over the past decade (BMA Online 2000) in response to changes in the working practices of junior doctors and consultants. Evidence has accumulated that nurse-led initiatives can provide effective, efficient and clinically-sound alternatives to more traditional care delivery systems (BMA Online 2000), and that patients and relatives respond positively to nurse-led services (Horrocks et al. 2000). Evaluation studies are needed in which multi-disciplinary teams permit expert stroke nurses to function creatively and apply holistic, family-centred care principles, while maintaining study rigour in terms of measurable outcomes.

Conclusions

Stroke aftercare is, in many respects, dependent on the carer and stroke survivor: they have the responsibility for their lives. However, in order to manage and exercise control, carers need to learn how to care and this requires that they have access to good quality stroke-specific information and education. However, alternative and innovative communication strategies [e.g. Internet-based] to facilitate and
enhance carer and stroke survivor quality of life should be explored. Stroke follow-up requires new approaches and the testing of other care models, including nurse-led initiatives, if quality of life is to maximized and further disability limited.

Acknowledgements

We would like to thank Chest, Heart and Stroke Scotland, who funded the study, and the carers and patients who gave of their time and allowed us some insight into their lives.

References


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