Qualitative Studies of Stroke
A Systematic Review

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Background and Purpose—Qualitative studies are increasingly used to investigate social processes and phenomena influencing health behaviors and service provision. We aimed to identify the scope of published qualitative studies of stroke, consider their relevance to development and delivery of services for people with stroke, and make recommendations for future work.

Methods—Literature review of published articles was identified by systematically searching online literature databases using keywords from the start of each database until 2002. Articles were reviewed by 2 authors, using a standardized matrix for data extraction. The 2003 European Stroke Initiative recommendations for stroke management were used to categorize the literature for consideration of its contribution to stroke research.

Results—We included 95 articles. Their empirical contribution includes an emphasis on recording the “human” experience of stroke; identification of needs as perceived by patients and their families, differences in priorities between patients and professionals, and barriers to best-quality care. We identified 12 papers that were specifically undertaken to develop or evaluate interventions.

Conclusions—Qualitative studies have addressed a wide range of issues related to the impact of stroke on individuals and caregivers, and to the organization and delivery of services. Significant problems remain in ensuring the delivery of best-quality stroke care, which such studies have the potential to address. Maximizing this potential requires greater collaboration between nonclinical and clinical scientists, service providers, and users to formulate research questions of interest as well as new research strategies, such as meta-analysis, to pool qualitative research findings and multisited investigations. (Stroke. 2004;35:1499-1505.)

Key Words: qualitative research ■ caregivers ■ delivery of health care ■ evaluation studies ■ quality of health care ■ stroke

The relevance of social science research for medical practice has long been recognized.1 Studies conducted using qualitative methods, which are drawn from the social sciences, are now commonly advocated and used in health and healthcare research.2 The aim of qualitative research is to understand social processes and behaviors (such as responses to disease or the organization of health services) in natural rather than experimental settings, and from the perspective of participants. Specific methods used include unstructured or semistructured interviews, focus group interviews, and ethnographic observation. These methods tend to generate textual rather than numerical data, and their analysis entails identifying meanings and developing concepts, but not measuring frequency. Studies using a variety of qualitative research methods have investigated social factors that influence the delivery and uptake of a wide range of health services.

Qualitative research is undertaken by researchers from a variety of disciplines, and reports may be published in journals not widely read outside the discipline concerned. The aim of this review is to identify the scope of qualitative investigations of stroke and stroke care conducted to date, to consider the relevance of such research to the development and delivery of services for people with stroke, and to highlight problems and opportunities for further work.

Methods

Search Strategy

Searches were conducted using the following electronic databases: PubMed, Social Sciences Citation Index, ASSIA, PsychInfo, and Arts & Humanities Citation Index. These are databases of literature emanating from a variety of disciplines including medicine, nursing, social care, psychology, sociology, and anthropology. The key words used were: stroke; cerebrovascular accident; qualitative.

We also drew on the literature in our own collections from our ongoing research into risk for stroke and stroke care. We searched the bibliographies of 3 existing reviews.3-5

Selection Criteria

Criteria to select material for inclusion in the review were as follows: studies of stroke or stroke care; English language; publication in a...
Data Extraction
Each paper selected for review was independently evaluated by 2 of the authors (all health service researchers in stroke). We constructed a matrix to record the following data for each reviewed paper: purpose of enquiry, method and participants, robustness of methodology, summary of findings, and summary of implication for practice.

Framework
To assist in the organization of identified material and consider the contribution of the studies to the assessment and development of interventions, we used the most recent European Stroke Initiative (EUSI) recommendations for stroke management.7 These recommendations, compiled with reference to published evidence and expert opinion, draw together the current best practices concerning care for people with stroke from onset to the longer term. This includes recommendations about early access to services, multidisciplinary stroke unit care, rehabilitation, secondary prevention, and longer term medical and social services. These recommendations have the advantage of being international, and include both short-term and longer term care provision.

Findings
We identified 113 papers. We excluded 18 papers that were exclusively theoretical or methodological, not specific to stroke, or where reviewers agreed that the study did not meet our evaluation criteria. In all, 95 papers were included in the final review.

Acute Care
EUSI recommendations identify the increasing recognition of stroke as an acute emergency, and call for education of the general public to allow them to recognize symptoms more quickly and to seek treatment urgently (Table I, available online at http://stroke.ahajournals.org). A focus group study conducted in Australia sought to explore needs for information about stroke to inform the development of a public campaign to educate people about stroke.8 Awareness was found to be similar between stroke survivors and members of the general public, although the characteristics of participants in the latter group were not clear from the study. A key finding was that stroke was not easy to recognize because the associated symptoms vary widely. Qualitative studies have reported individuals’ descriptions of the onset of stroke10–12 with different responses to first symptoms, including waiting to interpret their implications13,14 and being told by others to seek help.15

Since the publication of the meta-analysis showing the benefits of organized stroke care, stroke unit care has become the gold standard.16 An early study from Canada describes the prevailing pessimistic attitude toward stroke management in an acute-care hospital with professionals’ views that “nothing can be done” at odds with patients’ expectations.17 The author’s call for reconfiguration of services to meet the needs of stroke patients is being realized, but the findings of the problems associated with the management of expectations remain relevant.

Although the term “stroke unit” covers a range of different types of care, it is agreed that organized stroke care should be provided by clinicians with expertise in stroke and from a cross section of disciplines, including medicine, nursing, rehabilitation therapies, psychology, and social work. Qualitative studies focused on process and organization would lend themselves to investigating unanswered questions about which aspects of stroke unit care contribute to improved outcomes and how they do so. We identified few studies that specifically investigated such questions, although some have focused on what nurses contribute to patient rehabilitation, with suggestions that nurses are central to goal setting and rehabilita-

Rehabilitation Therapies
According to EUSI recommendations, rehabilitation of patients with deficits should begin once they are clinically stable and following multidisciplinary assessment (Table II, available online at http://stroke.ahajournals.org). Rehabilitation therapies are described as taking place in dedicated stroke rehabilitation wards, rehabilitation hospitals, and in outpatient clinics. It is recommended that rehabilitation in the acute period should not last longer than 6 to 12 weeks, but, also, that active rehabilitation should be administered for as long as an improvement in function is observed.18

A number of issues related to the delivery of rehabilitation therapies have been investigated in qualitative studies. Some have investigated broadly what rehabilitation means for patients and professionals. An early sociological study investigated how people with stroke disability adapt in light of societal expectations and norms, arguing that rehabilitation seeks to teach patients to redefine stroke as an inconvenience that can be overcome through new techniques.19 Findings from a UK study indicated that physiotherapy was valued because it was felt to lead directly to functional recovery,20 while a US study identified a failure to meet individual needs or to facilitate the transition to life at home.21 Only one study, conducted in Hong Kong, aimed specifically to allow patients to identify their own rehabilitation needs. These were reported as psychosocial, social, and spiritual as well as physical dimensions of need.22 One study reported patients’ accounts of the difficulties they face eating, and the fear and shame this and their changed physical and social appearance created for them.23 Patients assessed as needing adaptive aids were found to be sometimes reluctant to use such devices because they reinforced the sense of loss associated with stroke impairment.24 Thus, their unwillingness to use devices was an attempt to avoid stigma rather than noncompliance.

Contrasting perceptions of rehabilitation therapies from patient and professional perspectives have also been investigated. In a series of papers from a study conducted in the 1980s, Becker and Kaufman identified sociocultural factors influencing the delivery of rehabili-
Other problems related to the delivery of rehabilitation include identifying appropriate ways of measuring progress and quality, role overlap between physiotherapists and occupational therapists, and questions related to the participation of patients in rehabilitation therapies. Shepherd (1994) reported that patients’ misapprehensions about the role of rehabilitation—thought to be convalescent care—was hindering their participation in therapy. Encouraging nurses to educate patients was found to improve their participation. One study focused on goal setting in the rehabilitation process, suggesting that therapists need to improve the participation of patients in setting goals. A study of whether therapists encourage patients’ high expectations of recovery, reported that although professionals err on the side of caution, patients anticipated high levels of recovery up to 3 months after stroke. It was suggested that communication between therapists and patients needed to be improved.

A UK study considered how the concept of motivation influences the delivery of therapy. Patients classified as having high motivation were found to understand and share professionals’ aims and methods. Consequently they were more likely to understand the nature and purpose of their rehabilitation, compared with those identified as having “low motivation.” From interviews with rehabilitation professionals, it emerged that motivation, which is attributed to patient demeanor, compliance, and cultural and social influences, is frequently used to assess patients and their continued participation in rehabilitation. It was suggested that categorization of patients according to their perceived levels of motivation may lead to false labeling of patients. To avoid this, greater sensitivity to patients’ beliefs, manner, and educational level was advocated.

 Novel methods of delivering rehabilitation therapies have been investigated in qualitative studies. A study of early discharge to home-based rehabilitation described the content of early discharge rehabilitation at home and identified differences between stroke therapy at home and in hospital. Home-based rehabilitation encouraged a partnership between the patient and therapist, and provided the opportunity to discuss rehabilitation issues and give advice and teaching in the family setting. Early discharge had a positive impact on rehabilitation, encouraging patients to practice activities on their own and devise their own solutions to problems. The therapy was more relevant to the patients’ needs in their own environment.

An evaluation of a pilot intervention providing home and community rehabilitation, and coordinating existing health and social services, identified mismatches between professional and patient goals as well as defects in the organization of existing services leading to setbacks in patient recovery. A descriptive study of a late rehabilitation service (1 year poststroke) focused on patients’ and carers’ understanding of the purpose and benefits of longer term rehabilitation. Apart from some functional improvements, late therapy was viewed as providing stimulus, continuity of care, and, for carers, respite. However, hopes for resumption of previous roles were not met.

Life After the Acute Event

EUSI recommendations for best practice in care after the acute event are not extensive, but they do call for patients with “chronic symptomatic stroke” to be supported in the social environment with access to a family physician, outpatient rehabilitation services, secondary prevention, and support in psychosocial functioning (Table III, available online at http://stroke.ahajournals.org).

Despite the less than optimal implementation of secondary prevention strategies, few qualitative studies have investigated this issue in relation to stroke, although there is a large body of literature investigating relevant questions of communication between professionals and patients and use of medication more generally. A pilot study investigated patients’ and clinicians’ perceptions of risk, information needs, and decision-making preferences in diagnosis and treatment of carotid stenosis. Patients’ decision-making about carotid endarterectomy was influenced by their notions of risk, trust in professionals, and intuition, but only to a lesser extent by trial evidence.

There is a sizeable body of qualitative research that seeks to document the longer term impact of stroke on patients, indicating needs that should be considered when planning and delivering longer term services for people with stroke.

The impact of stroke on survivors has repeatedly been described as “loss” in the qualitative literature, with the significance of reduced functional ability being explained in terms of loss of activities, abilities, personal characteristics and independence, emotional and social loss, and a loss or change in the individual’s own identity. Patients have also been reported to experience uncertainty about the expected trajectory of recovery and possible implications. Similar findings have been reported in relation to aphasia and eating disabilities following stroke. Other studies have focused on the specific problems of loss of ability to drive and the problems of returning to the work force, particularly for younger people. Studies that sought to investigate the experience of stroke with reference to the concept of quality of life have reported that survivors relate this to the effects of stroke on their own sense of well-being and to existential aspects of suffering and loss.

Another focus has been the ways in which patients respond to the changes brought about by stroke. For example, it has been reported that survivors regard following professional advice, making their own care decisions, and staying positive and motivated as important. Survivors have also been found to develop their own strategies to combat disabilities, including tackling tasks more slowly and initiating learning and exercise, developing strategies to maintain or reestablish a sense of continuity after the disruptive life event that stroke represents, and drawing on spiritual practices.

Nevertheless the process of adjustment after stroke has been described as difficult and slow, with plateaus in recovery presenting survivors with unexpected obstacles. It was argued in a study that previous experience of illness and hardship helps some people accept the difficulties of life after stroke in an unproblematic way, an interpretation that was subsequently questioned. Attempts to draw on patients’ accounts to delineate phases of the stroke trajectory have been made, with the argument that services as currently configured do not adequately reflect survivors’ experience of trying to adjust to the effects of stroke. Studies reporting patients’ concepts of recovery have also found a mismatch between their views and those of professionals. While professionals measure recovery in terms of regaining function, for patients this can mean return to prestroke life. It has also been suggested that recovery is redefined by patients in the promotion to their own social context and in terms of achieving their own goals. Thus, current methods of assessing progress after stroke have been criticized for failing to take into account patients’ ideas about what recovery means to them.

Carers’ Experiences and Needs

Although only briefly mentioned in guidelines, numerous studies have investigated how informal caregivers of people with stroke are...
affected (Table IV, available online at http://stroke.ahajournals.org). We identified 11 qualitative studies that specifically focus on carers, reporting their experiences and needs for support. Caregiving often takes place within a context of family relationships, and, so, is bound up in expectations about kinship ties and obligation.87–89 Although it has been reported to have positive benefits,89 caregiving also creates a range of problems. Carers feel ill prepared for their role and have concerns about their own competence.90–92 Caregiving can result in lifestyle changes89,93 as well as physical, emotional, and financial problems.90,94–96 It was also reported that carers feel isolated,91 and that family relationships can suffer.96 Carers develop their own strategies including trying to increase their competence,91 creating their own solutions for patient’s functional loss, constructing their own sense of what recovery means,97 and using their own spiritual beliefs and practices.87

The specific needs for support identified by carers include information about the long-term implications of stroke and the availability of community services.90,92,94,98 Reported solutions suggested by carers include access to advisers, opportunity for regular reassessments of the patient, improved access to day care and respite care, carer support groups, and access to emergency calls for support.94 Simon and Kumar (2002) reported that caregivers felt that they were not adequately consulted and considered by professionals.98

Community Services

Studies investigating the impact of stroke for patients and carers commonly draw out implications for service delivery, but relatively few studies have focused specifically on community services themselves (Table V, available online at http://stroke.ahajournals.org). One study investigated patients’ and carers’ problems after stroke to inform the development of a community stroke support service.99 Stroke patients’ problems were diverse, complex, and changed over time; initially practical, and, later, psychological. Two papers reported findings from qualitative studies undertaken as part of evaluations of novel interventions.100,101 An interview study of patients’ and carers’ views of a specialist nurse support intervention, which was also evaluated by randomized controlled trial, found—in contrast to the trial’s generally negative results—that the intervention was valued for the “less tangible” aspects of nursing care it provided: concern, attention, empathy, and interest, combined with emotional and practical support. A qualitative evaluation of a pilot intervention to support stroke survivors in the community, reported that existing problems in the interface between health and social care were such that the intervention was unable to prevent stroke survivors falling between the gaps of service provision.57,58 A similar picture of poorly coordinated services has been reported elsewhere,56,102 with particular gaps identified in the provision of personal care services for people in the community,103 and the limited contribution that district nurses report they can make to care for people with stroke.104

Needs for information in the longer term have also been reported by many authors, with dissatisfaction expressed about the amount of information provided, the style of delivery, and the timing.a A UK study specifically investigated patients’ and carers’ experiences of obtaining information after stroke.105 Respondents were dissatisfied with what had been provided and wanted individualized information related to clinical questions, practical issues, and issues related to services and resources.

Discussion

This review aimed to identify the scope of stroke studies undertaken within a qualitative social science framework, to consider the contribution and limitations of the work in relation to questions of stroke service organization and delivery, and to propose future directions. We did not aim to conduct a meta-analysis, methodologies for which are now being developed to synthesize qualitative research findings related to specific questions.106

What is the Contribution of These Studies?

The range of studies identified was wide, but we consider their empirical contribution to include an emphasis on recording the human experience of stroke; identification of needs as perceived by patients and their families; identification of differences in priorities between patients and professionals; and identification of barriers to best-quality care. These issues are fundamental to the successful delivery of clinical and social services to people with stroke. While many studies were simply descriptive accounts, others were closely linked to the development and evaluation of interventions.

Limitations of the Studies

Most of the studies were small-scale and one-off interviews. This may not be inherently problematic, since qualitative research aims for in-depth knowledge rather than breadth. However, as noted elsewhere,106 the localized nature of many qualitative studies means that their potential to influence wider clinical practice remains limited. With some notable exceptions, the one-off open-ended interview was the predominant method used. This is often a pragmatic choice in terms of convenience and feasibility, but interview-based studies should acknowledge that actual practices may differ from what was reported.107

Much attention has been paid to questions of validity in qualitative health research, with diverse proposals to ensure that published research is of satisfactory quality.107,108 We used a minimum set of criteria to assess methodological robustness. Nevertheless, we considered the quality of papers to be variable, particularly in terms of the applicability of findings to familiar questions of service development and delivery.

Opportunities

Mapping the research identified to the care pathway, we found reasonable coverage across the range of issues highlighted by clinical experts. However, there are several areas where qualitative investigations might be illuminating. Firstly, there are examples of published reviews of qualitative studies,3–5 but given the mass of published studies, there are now opportunities for meta-analyses of findings relevant to stroke service delivery.

New qualitative studies could also investigate specific issues that could be useful, including the processes leading to delays in presentation and admission following stroke; research to develop novel methods of providing longer term care to meet problems identified by patients and families; and research focused on improving secondary prevention strategies. There are also opportunities for qualitative researchers to contribute to the development and evaluation of new methods of service delivery. We identified 12 studies specifically undertaken to develop or evaluate novel approaches to rehabilitation,49,54,55,59 to interventions in nurse training,13,36 and to the provision of community support services.56–58,99–101

The UK Medical Research Council has recently called for

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*aReferences 12, 38, 50, 52, 68, 90, 93, 95, 99, 100.
greater utilization of qualitative research in the context of randomized controlled trials of complex interventions, for example in the development of an intervention, as well as studies that help to explain the social processes at work in the delivery and uptake of an intervention.

Another recent development is the call for greater participation of health service users in the development and conduct of research. There was little evidence of qualitative researchers involving those they study, other than as subjects of their investigation, although one study explicitly called for this. Many of the studies reviewed here reported differences between patients’ and professionals’ concepts and concerns, suggesting that stroke service users could contribute to the formulation of new research questions.

Social science research has the potential to reconceptualize old problems in new ways by questioning the nature of familiar categories. Such an approach might be useful, for example, to investigate why patients and carers consistently find the quantity and content of information provided to them inadequate. A starting point here might be to ask what constitutes information for those who provide it and for those to whom it is targeted.

Within the field of social anthropology there are calls for multisited ethnography, partly in recognition of the increasingly globalized nature of human cultures. The globalized nature of biomedicine—where increasingly, for example, clinical trials are multinational, and clinical guidelines are developed by international committees—also suggests that there are opportunities for multisited qualitative studies. We acknowledge that this suggestion has resource funding implications. However, such an approach might also provide the opportunity to apply such methods in areas where few or no such studies appear to have been undertaken (ie, in Eastern European and developing countries) but where there is evidence that stroke mortality has not declined, and where effective primary prevention strategies are required.

Greater attention should also be paid to the question of which specific method to use. Increasingly, questions of how clinical decisions are made are becoming important as new technologies are developed and increased emphasis is placed on patient participation. Yet unanswered questions about equitable access to care remain. It is unlikely that an interview-based study will best answer all research questions in this area, which lends itself rather to an ethnographic, observational approach.

Qualitative health researchers should more explicitly incorporate the theoretical insights from their own discipline to assist in the production of research that is valid and epistemologically sound. This does not necessarily mean using empirical data to demonstrate the value of a particular theoretical position. Rather, as illustrated in the work of Kaufman and Becker, who raised questions about the distribution of health resources and concepts of aging in relation to the provision on rehabilitation therapies to older patients, this is a matter of using the insights of one’s own discipline to interpret empirical data.

In the United Kingdom at least, stroke medicine has been characterized as a neglected clinical specialty. Yet stroke research in basic science, pharmacological developments, and innovative methods of delivering care appears to be flourishing. Nevertheless, significant problems remain in ensuring the delivery of best-quality care. For example, it has been reported that there continue to be delays in seeking and accessing acute care, some aspects of care are not equitably provided, information is inadequately provided to patients and caregivers, and, as many studies reviewed here argue, satisfactory longer term care is lacking. Finding solutions to such problems require improved understanding of the social processes that give rise to them. This can be best achieved through well-designed, conducted, and disseminated qualitative investigations.

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References

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