Abstract—Stroke affects many aspects of the lives of stroke survivors and their family caregivers. Supporting long-term recovery and rehabilitation are necessary to help stroke survivors adapt to living with the effects of stroke and to help family members adapt to the caregiving role. During recovery and rehabilitation, many elements of the health care continuum are utilized, including emergency response, acute care, inpatient and outpatient rehabilitation, and community and long-term care. With the advent of thrombolytic therapy and the benefits of stroke units, stroke survival and outcomes are improving. As a result, the current emphasis of stroke system improvement is to implement stroke units throughout the developed world. To enhance the patient centeredness of stroke care delivery, an important next phase of stroke system improvement will center on the experiences of stroke survivors and their family caregivers as they move through diverse care environments. The objective of this article was to conduct a scoping review of the literature on stroke transitions to identify the current areas of research emphasis. This article highlights stroke survivors’ and family caregivers’ experiences with transitions across care environment and some potential strategies to improve those transitions. (Stroke. 2008;39:2637-2643.)

Key Words: stroke ■ system of care ■ continuity of care ■ transitions

Stroke very abruptly affects many aspects of the lives of patients and their family members. Stroke survivors commonly have difficulty performing even the simplest of everyday activities well into the first year after stroke. Depression is a common outcome that can affect stroke survivors’ abilities to resume everyday activities and long-term survival. Aphasia or communication difficulties make community reintegration challenging. Resumption of paid employment has received little attention, but this area deserves greater emphasis as strokes continue to occur in the younger population. Family members and friends who provide care and support to stroke survivors also experience poor health outcomes. To meet stroke survivors’ and family caregivers’ varying needs during their long-term recovery and rehabilitation, many elements of the health care continuum are utilized, including emergency, acute, rehabilitation, community, and long-term care. As we strive to improve stroke care delivery systems, there are many aspects of care that must be considered.

Stroke care has made considerable strides during the past decade. Available evidence suggests that early recognition of stroke symptoms, caring for stroke survivors in acute stroke units, using thrombolytic therapy (ie, clot-busting drugs like tissue plasminogen activator), and providing enhanced rehabilitation can decrease stroke-related morbidity and mortality. This evidence has been translated into numerous best-practice guidelines and clinical care pathways.

Changes in stroke care to incorporate current evidence are occurring around the world. Acute stroke units are the driving forces of stroke care system reforms in many countries. Accounts of stroke care services in countries such as Hungary, Poland, Scotland, France, and Norway reveal high stroke-related mortality and morbidity rates and the small percentage of patients who receive care in acute stroke units. This situation is leading governments to create or add to the existing number of stroke units available to service the population. The resulting policies often address in detail the required capabilities and resources present in the stroke units, and in so doing they demonstrate their defining characteristics of comprehensive and timely acute care. For example, Portugal’s stroke unit guidelines state that there must be 24-hour availability of computed tomography scans.
and laboratory facilities; echocardiography and noninvasive extracranial vessel investigation available within 12 hours; and a full-time multidisciplinary staff consisting of a neurologist, internist, physiatrist, stroke-trained nurses, ultrasound technicians, rehabilitation therapists, social services, and a secretary. Other countries such as Norway already feature stroke units as an established part of their health care system and have shown significant benefits in long-term survival and function as a result.22

The recognition that stroke units, thrombolytic therapy, and enhanced rehabilitation may significantly improve patient care and outcomes now affords the opportunity to focus on aspects of stroke care associated with stroke survivors’ and family caregivers’ experiences with the system, via, transitions across care environments. To date, this area of research has received little attention. Currently, it is common for elements of the stroke care system (eg, acute care, inpatient rehabilitation, community care) to be clearly demarcated in terms of definition, purpose, and accountability. They are often organized as distinct units that lack a common coordinating system.15 As a result, stroke survivors and family caregivers are often responsible for their movement across these diverse care environments.23 For many of them, these aspects of the health care system are new, and they have difficulty negotiating the transitions.

More recently, some initiatives have been undertaken to enhance stroke care across the entire care continuum. For example, the Ontario Stroke System endeavors to coordinate stroke survivor care across the continuum ranging from primary prevention to community and long-term care.24 It was developed in response to the growing aging population, the research supporting the benefits of thrombolytic therapy and acute stroke units, and the existing fragmented and inconsistent care across the province and care continuum for individuals who experience a stroke and their families.24 The purpose was to ensure that all Ontarians had access to appropriate, quality stroke care in a timely manner. To date, the Ontario Stroke System has seen improvements in indicators across the care continuum, including decreases in patient readmissions and increases in the number of stroke inpatients receiving consultation from a stroke specialist, being assessed by neuroimaging technologies such as magnetic resonance imaging or computed tomography, and receiving rehabilitation services.25

The Ontario Stroke System is a model of integrated service delivery. These models typically aim to enhance “quality of care and quality of life, consumer satisfaction, and system efficiency for patients with complex, long-term problems cutting across multiple services, providers, and settings.”26 A key element of these models is enhancement of the continuity of services across the care continuum. As a result, integration commonly occurs at many levels, including policy, finance, management, and clinical.27

With the advent of models of integrated service delivery to improve health care delivery, some have questioned the extent to which these models are meeting patients’ and family members’ needs.28 This research suggests their needs and experiences should be of central importance in system development and evaluation. Consistent with this idea, our article emphasizes stroke survivors’ and family caregivers’ experiences during their journey across the stroke care continuum. The objective of this article was to conduct a scoping review of the literature on stroke transitions to identify the current areas of research emphasis.

Methods

Design

We conducted a scoping review of the literature pertaining to stroke transitions.29 A scoping review is distinct from a systematic review in purpose and approach. Scoping reviews are often conducted early in a field of study to take a broad look at what research has been conducted to date on the specific topic. It can be viewed as preliminary to a systematic review because it identifies areas of research where systematic reviews may be performed in the future. Scoping reviews are used to highlight the range of research in a specific area and to identify gaps.29

Approach

We searched Medline, Psychinfo, and CINAHL databases with the following key words: “stroke,” “cerebrovascular accident,” “transitions,” “care linkages,” “continuity of care,” and “care continuum.” Because the review process in a scoping review is iterative, as we reviewed articles we searched additional terms, including “elderly,” “older adults,” “integrated service delivery,” “case management,” “discharge planning,” and “self-management.” We included articles written in English and published before July 2007.

Sample

The difficulties inherent in facilitating smooth transitions between stages of care across the continuum are not unique to stroke. Other health care contexts also involve multiple providers over an extended period of time. In particular, care for the frail elderly is a multidisciplinary long-term process, and there are well-integrated systems that have been created to answer this challenge (eg, PRISMA30). The structure of these systems, as well as the initiatives that they have for ensuring smooth transitions, may be useful in stroke systems of care as well. Thus, when stroke-specific literature was limited, we included research in other areas including the elderly.

Results

The research included in this review came mainly from North America, the United Kingdom, and Europe. Seventy-five articles were reviewed to identify the key research areas concerning transitions. Specifically, 2 broad areas of research that examined transitions across care environments were identified: (1) stroke survivors’ and family caregivers’ experiences with transitions across care environments and (2) strategies to enhance stroke survivors’ and family caregivers’ transitions across the care continuum. The following sections highlight the issues discussed under these 2 areas. In a review of models of integrated service delivery for older people, Reed et al31 examined integration strategies at 3 levels: (1) macro (societal), (2) mezzo (system), and (3) micro (individual). We used this framework to guide our review. Therefore, the strategies were organized into 3 levels: (1) societal, (2) system, and (3) individual.

Stroke Survivors’ and Family Caregivers’ Experiences With Transitions Across Care Environments

Qualitative research has begun to shed light on stroke survivors’ and family caregivers’ experiences across the stroke care continuum. During the period immediately after
discharge into the community, family caregivers often report that they were not supplied with the necessary training to enable a successful transition to the home environment.\textsuperscript{23} Caregivers are infrequently trained to assist the patient in activities such as bathing, administering medication, performing rehabilitation, or helping a patient up after a fall.\textsuperscript{32} Only rarely is advice given regarding the psychological and emotional impact of a stroke and how to assist the patient in managing these complex feelings.\textsuperscript{25}

Information and assistance in accessing health care services once the patient has been discharged into the community are also difficult to obtain.\textsuperscript{23} Patients and caregivers report not routinely being provided with information on how to access the next step in the sequence of care.\textsuperscript{23} They are then left to locate the necessary services, schedule appropriate appointments, arrange for their payment, and provide medical history by themselves.\textsuperscript{23} Financial aid can also be difficult to obtain if they do not receive information regarding the existence of funds and how to access them.\textsuperscript{23}

Stroke survivors and their family caregivers can also experience difficulties with the timing of care and service delivery. Some community services can take too long to arrive, complicating the transition from acute care to rehabilitation to community. For example, some stroke survivors and their family caregivers report delays in the receipt of financial aid for home modifications, such as special toilet seats and bath aids.\textsuperscript{32} In other instances, progression through the care continuum is perceived to happen too quickly, before the caregiver can prepare the home, modify his/her job or reduce work hours, sell their home to move in with the stroke patient, etc.\textsuperscript{23}

Another contributor to fragmentation lies in the fact that the onus is on a patient to initiate follow-up visits and progress evaluations, especially once discharged from the acute setting.\textsuperscript{33} That is, many health care systems operate with the philosophy of “pushing” patients between institutions (and leaving them to ensure that they actually get there), as opposed to “pulling” patients in (actively ensuring that the subsequent necessary visits occur through follow-up mechanisms).\textsuperscript{34} This results in the patient and/or family caregiver initiating most contacts with the health care system, especially after the transition to community care. There are reports of no follow-up visits from occupational therapists or physiotherapists during the crucial early months back at home and no follow-up visits scheduled with or initiated by the patient’s general practitioner.\textsuperscript{32} This may be due to the lack of a central mechanism for tracking patients’ care and condition across time and care environments as well as the limited availability of health care professionals to provide care in the community.\textsuperscript{35} Health care professionals are also affected by the lack of information: the medical records that each of them holds about the patients they have treated are not shared across care environments. The result is that they must obtain medical information from the patient and readminister tests when new patients arrive in their system of care.

In summary, stroke survivors and family caregivers highlight 3 areas that, if addressed, may enhance their experiences with transitions across care environments. First, there is no consistent approach to educate and train stroke survivors and caregivers to manage in the community. Second, transitions are often difficult because stroke survivors and caregivers often do not know about the services available to them. In the cases where they do, the services may not arrive when patients and caregivers would like to receive them. Last, the health care systems’ paradigm of “pushing” patients out of acute care hospitals leaves them to navigate through arrangements for the remainder of their care by themselves.

### Strategies to Enhance Stroke Survivors’ and Their Family Caregivers Transitions Across the Care Continuum

The strategies are divided into society, system, and individual levels to ease comprehension and to reflect the organizational structure of any health care body.\textsuperscript{15,31} Society level initiatives are put forth by the national or provincial government and have broad and general consequences for an entire population. They encompass more than merely a health care or stroke care system; eg, the allocation of extra funds for hospitals may come at the expense of other social programs. A system level change affects the relationships between or within the care environments of a stroke care system. For example, system level changes can include the creation of stroke units in acute care hospitals and agreements between community-based and larger hospitals for provision of acute stroke care. Last, individual level ideas are those that focus on 1 individual at a time and are thus the smallest in scope. For example, case management for other patients, such as the frail elderly, entails a case manager working with 1 patient at a time to organize aspects of care, such as hospital visits, rehabilitation appointments, and social services.\textsuperscript{36}

### Society Level Strategies

Societal decisions may be discussed and implemented at a level far removed from that of the stroke survivor’s day-to-day experiences. Policies that affect multiple institutions within society, such as the choice to spend a country’s financial and human resources on community long-term care, can be of great benefit to stroke survivors.

The financial policy surrounding the allocation of health care resources is discussed as an important strategy for improving transitions of care for stroke survivors because of its influence on the quality and quantity of health care available. Some stroke survivors can become “bed blockers” when they are ready for discharge, but there are no rehabilitation or long-term care beds available, thereby delaying their discharge from the more expensive acute care beds.\textsuperscript{16} In addition, variability in the availability of human resources across care environments also influences the continuity of care. For example, in some areas, there can be delays in the continuation of rehabilitation therapy after patients have been discharged home due to the limited availability of trained professionals in the community.\textsuperscript{37} It is important that any effort to improve the continuity of care across the continuum for stroke survivors be accompanied by a financial commitment of the necessary resources.

The allocation of finances can also be leveraged to create new relationships of accountability and responsibility between care institutions.\textsuperscript{38} Currently, for example, organiza-
tions receive financial compensation for care that they provide within their own care environment. There are rarely financial incentives in place to reward concern with care provided or received after discharge. Financial policies rewarding acute care physicians for successful discharges with a minimum of complications would provide incentive for greater collaboration with rehabilitative and community care institutions.

**System Level Strategies**

Initiatives with a system-wide scope are those that encompass single institutions in the health care system (ie, an acute care hospital) or the relationships between institutions (ie, the level of integration between rehabilitation centers and community care). System level strategies fall into the categories of multidisciplinary cooperation, the storage of data, and measuring the quality of service delivery.

The establishment of interdisciplinary relationships in acute care settings has facilitated communication and cooperation between health care providers, reducing the number of redundancies in care and improving health outcomes. There is the potential to achieve these same benefits across the care continuum. Therefore, strengthening the links between different care environments and providers in the rehabilitation and community settings may benefit stroke survivors residing in the community. Evidence for the success of such initiatives has already been shown with postmyocardial infarction patients, who experience better health outcomes when they are referred to multidisciplinary rehabilitation programs.

Establishing interdisciplinary relationships in the community poses different challenges than in acute care because the various health care providers (eg, family physicians and home care providers) may no longer be geographically close to each other. One strategy that has been proposed to address this is the concept of “virtual coordination,” whereby physical assets and funding are not shared but yet there are interorganizational alliances and joint committees. Through regular multidisciplinary meetings among the various postdischarge care providers, patient progress would be reviewed and collective decisions made with respect to future directions for treatment. This could improve the patient experience and reduce friction in the transitions back and forth between care providers.

Integrated care pathways are another example of multidisciplinary care used to organize many aspects of treatment and rehabilitation. They are standard plans of care based on best evidence that prescribe certain treatments at certain times for stroke survivors and seek to achieve specific goals. By necessity, care pathways are multidisciplinary because these goals span multiple domains of health and function. In a Cochrane Review, the effects of stroke care pathways included a reduction of certain complications (eg, urinary tract infections), a decreased likelihood of readmission, and an increase in the number of diagnostic tests (eg, brain scans) being performed. However, reductions in the likelihood of independent patient function and quality of life after discharge were also noted. More research is needed to determine the characteristics of integrated care pathways that could benefit stroke survivors and their family caregivers.

Individualized care plans are similar to integrated care pathways but are applied in the community. They are evidence-based, long-term prescriptions for the type and timing of care that a patient should receive after discharge. They could be used to structure the multidisciplinary meetings among community care providers. In one example of utilizing care planning for frequent users of the Emergency Department, individualized care plans have been shown to significantly reduce the total number of return visits.

An improved system for storing patient information has been proposed to improve the ability of multiple health care providers in the community to coordinate stroke care. Traditional paper-based storage systems make sharing information difficult and can reinforce the isolation between care environments. Suggestions have been made to reform the entire health care system by developing and utilizing a centralized electronic patient record system that could be accessed by health care professionals from multiple care environments. In stroke, this would improve the transition process for the patient because it would no longer be necessary to repeat tests or provide an illness history for each institution. The prescription of conflicting drugs or treatment regimens could be reduced.

The third category of system level strategies to improve stroke survivors’ and family caregivers’ transition across care environments is measuring quality of service delivery. Any tangible attempt to enhance transitions should be accompanied by a strategy for assessing its effectiveness. This means that performance measures should be established, and system administrators and individual care institutions should be accountable to them. The measures will allow identification of interventions that improve transitions, which could then be duplicated.

A tool for such evaluation has already been documented (eg, the report by Spath). It measures the features of a health care system that are related to a patient’s transition experience, including questions such as whether every patient care setting used up-to-date admission and discharge criteria, whether care planning was collaborative (including the patients and their families), and whether there was a well-defined mechanism for reviewing patients’ progress along a plan of care. Evaluation tools that measure outcomes such as these are important to solving any of the problems with fragmentation of care discussed earlier, because they will reveal whether the situation is improving.

**Individual Level Strategies**

The last group of strategies for improving stroke survivors’ and family caregivers’ transitions between environments is found at the individual level. Systems of care for other health conditions, such as the frail elderly, can be used as a model for the organization and delivery of stroke care at the individual level. Specifically, case management, discharge planning, and self-management are concepts that can be applied to stroke.

Case management, as proposed by models of integrated service delivery, and discharge planning share the same general aim of choreographing a patient’s transition between care environments to ensure continuity and facilitate progress...
in recovery. They differ, however, in scope. Case management has been used in the care of the elderly and is delivered by a dedicated case manager (such as a nurse or a community care worker) who oversees all of a patient’s care as they cross multiple care environments. In doing so, case managers hold a comprehensive and long-term perspective. They are often assigned to their clients during acute care and will track them through the subsequent stages of discharge and enrollment into community services, such as nursing homes and home care. Existing research suggests potential benefits of case management. For example, significant improvements in cost savings, physical function, and cognitive status have been observed when case management is used within a system of integrated social and medical care. It is likely that case management and integrated care are mutually beneficial, which further underscores the necessity of enhancing transitions by increasing multidisciplinary collaboration.

Case managers could be used in stroke care just as they have been used with the elderly. As explained earlier in this article, many stroke survivors and their caregivers are unaware of the community services available to them and how to access those services. A case manager could provide leadership in devising a comprehensive care plan for the stroke survivor and would be ultimately accountable for its execution. Specifically, this could include following up with patients after referral to ensure that they arrived at their next destination. This approach has been shown to improve compliance with referrals and reduce rehospitalizations and deaths in high-risk patients, such as those recovering from coronary artery bypass graft or cardiac valve replacement.

The process of discharge planning, although it applies only to single instances of transition between 2 care environments, aspires to the same goals and uses many of the same techniques as case management. These interventions usually include predischarge instructions for the patient, procurement of necessary medical equipment or social resources before discharge, and referrals to subsequent care environments accompanied by follow-up to ensure that they have been accessed. Many of the arguments for discharge planning are economic—its proposed benefits include shorter hospital stays and fewer unplanned readmissions—but it also has the potential to facilitate smoother transitions for patients into postdischarge environments. As such, we encourage further research into the utility and optimization of discharge planning in stroke settings.

Self-management is another potential strategy for facilitating transitions across care environments. The central premise of self-management techniques is to empower patients to manage their own health conditions, including symptoms, treatment, physical and social consequences, and lifestyle changes. Self-management techniques have demonstrated improvements in illness management. More recently, researchers have extended the concept of self-management to assist elderly patients and their family caregivers to manage transitions between care environments. Specifically, they are taught to manage their medications, follow-up care, and treatment history and to identify symptoms in need of further care. In a randomized, controlled trial, researchers observed significantly lower rates of rehospitalization and hospital costs when compared with a control group not receiving self-management training. This approach may also facilitate stroke survivors’ and family caregivers’ transitions across care environments.

Discussion

This scoping literature review identified the key experiences of stroke survivors and family caregivers with transitions across care environments. First, there is no consistent approach to educate and train stroke survivors and caregivers to manage in the community. Second, transitions are often difficult because stroke survivors and caregivers often do not know about the services available to them. In the cases where they do, the services may not arrive when patients and caregivers would like to receive them. Last, the health care systems’ paradigm of “pushing” patients out of acute care hospitals leaves them to navigate through arrangements for the remainder of their care by themselves.

There is a need to enhance and standardize the provision of education, training, and information provided to stroke survivors and their family caregivers to ease their transitions across care environments and ultimately, back to the community. This suggests that more research is needed to develop and evaluate educational and support programs for stroke survivors and family caregivers and to enhance the uptake of effective programs by the health care system. It is also important to consider the fact that certain services and aids need to be available immediately, whereas others are more appropriate after the patient/caregiver dyad has had time to adjust and respond to a new situation. A heightened awareness of such concerns and the best ways to respond to them can help improve the health outcomes of stroke survivors.

The review also introduced 3 broad categories of strategies to address the problems experienced by stroke survivors and family caregivers with transitions across diverse care environments. At the societal level, additional financial resources or a reallocation of existing resources could be made to enhance the provision, availability, and coordination of services for stroke survivors. At the system level, the need for increased multidisciplinary collaboration and the accompanying requirement of a centralized electronic patient information system are potential strategies. Last, at the individual level, case management and/or discharge planning would improve patients’ ability to access needed services in the community, and survivors and family caregivers could be trained to self-manage their transitions across care environments.

Both case management and discharge planning address many of the fragmentation problems related to finding and accessing care in the community. Many stroke care organizations are using discharge planning. A natural extension of this would be the full case management approach proposed in models of integrated service delivery. Potential benefits to stroke survivors and family caregivers include relieving them of the stress of arranging services for themselves; obtaining and accessing services whose existence they otherwise may not have even been aware of, such as financial aid and psychological counseling; and ensuring that patients were provided with necessary follow-up care from the appropriate...
acute care physicians, even after they had been discharged into the community.

Because this is a new area of research, we used a scoping review to paint a broad picture of some key issues. There are some strengths and limitations associated with conducting a scoping review of the literature. Because a scoping review is not a fully “systematic” review, we cannot be confident that all relevant studies were identified by our search strategies. Because the number of studies in this area is still relatively small, we included all relevant studies and did not evaluate their methodological quality. In addition, this scoping study did not provide an in-depth review of any of the areas discussed. Therefore, as this field of research expands, future systematic reviews would be appropriate. Overall, this review identified some broad research areas relevant to the study of stroke transitions across care environments. This information can be used as a starting point for future research in this area.

Conclusions

Advances in technology and the use of best evidence in stroke systems of care mean that we are responding to this devasting event with greater effectiveness than ever before. As progress continues, we propose that the area of focus should expand from the acute care environment into the rehabilitation and community settings in recognition of the multidimensional consequences of stroke. Within these settings, it is crucial to ensure that patients’ transitions between care environments are safe and efficient. We have identified strategies at the society, system, and individual levels that may aid this process. Further research is needed to more comprehensively understand the experiences and needs of stroke survivors and their family caregivers as they move across care environments. In addition, strategies discussed in this article should be evaluated to determine their efficacy in the stroke population. Research in the area of stroke transitions across care environments can serve as a model for other chronic illness groups that are of sudden onset and require acute and rehabilitation care before returning to community living (e.g., traumatic brain injury, hip fracture in the elderly).

Disclosures

None.

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Optimizing Stroke Systems of Care by Enhancing Transitions Across Care Environments
Jill I. Cameron, Chris Tsoi and Amanda Marsella

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